Strategic and governance issues for NHMRC

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Summary

1. The Australian health-care system and the Australian public are well-served by NHMRC

2. Nevertheless, additional gains for the public, for the health sector, for researchers and for industry should be achievable through modest changes to arrangements that would help NHMRC to better discharge its mandates of health advice and health research.

3. Most participants in NHMRC Council and committee processes can be seen to have a vested interest, whether as researchers, academics, or representatives of government health agencies or consumer organisations. The irony is that although all these parties would claim to represent the public interest, the cultural differences between them have led to many lost opportunities.

4. Council and/or senior committees should be reconstituted to include representation from the private health sector and from industry, as well as senior strategic thinkers and professional leaders from outside the health industry. This should allow discussion of strategic issues affecting health research and health translation and national health priorities to be less fettered by the inclination of researchers and government representatives to protect their own culture.

5. Benefits from such new arrangements would include:

    a. An expectation of franker communication and improved cooperation between the different interest groups;

    b. A broader forum for evidence-based discussion of the community interests in health, providing opportunities for leadership on potentially “difficult” issues such as the use of publicly-funded patient data for research, patenting of genes, or the circumstances under which health care should be rationed or provided by allied health practitioners;

    c. Inter-sectoral health research and translation initiatives that might otherwise have been impossible (eg because they might be seen to threaten the entrenched practice of a professional group or a health agency);

    d. NHMRC assuming an even higher profile in providing an alternative stream of evidence-based advice for the public and for health ministers.

Assumptions

1. Australia is well-served by the quality of its health care system and its health research, reflecting favourably on our education system and our health and research training.

2. Health research benefits the Australian public directly through the new knowledge that is gained by research in Australia. Research-trained experts in Australia are also better able to provide indirect benefit by interpreting and applying the specialist knowledge generated by overseas research.

3. Nevertheless, it is unclear whether Australians are deriving optimal benefit from the public expenditure on health services and health research.

4. For many years, Australia has been able to capitalise on its comparative advantages:
    a. A tradition of scientific rigour and leadership, with outstanding achievements in core disciplines such as immunology, virology and endocrinology;
    b. A cooperative research ethos which has enabled Australian interdisciplinary research on problems that would be more difficult to solve in many other countries;
    c. The public health orientation of its health-care system, supported by strong academic departments in medicine, health sciences and basic disciplines, which has enabled advances in clinical and translational research.

5. Unfortunately, Australian research is also at risk from the diseconomies of scale that are inevitable in a developed nation with modest resources:
    a. With the rise of digital technologies and automated molecular and genetic analysis, Australian science cannot easily afford to compete with larger countries in the generation of the largest bodies of data;
    b. As a middle-sized country, with limited entrepreneurial experience and limited access to venture capital, it has been difficult for Australia to derive commercial benefit from the original discoveries of its scientists.

Perceived problems with the Australian system

6. Australia cannot easily afford to develop and support the highest quality research in all disciplinary areas. Indeed, in order to be competitive by international standards, most programs of research have had to achieve a critical mass. Inevitably this means that many talented young researchers with good ideas and skills are likely to miss out on funding through the NHMRC system, because of the limitation of overall funding, and because of the tendency for funds to flow to established researchers with excellent track records in established disciplines[1]. NHMRC has sought to develop essential disciplines through special initiatives and capacity building schemes over a number of years, with considerable success.

[1] The Matthew effect: "For unto every one that hath shall be given, and he shall have abundance: but from him that hath not shall be taken away even that which he hath" (XXV:29).

7. It is difficult, in a relatively small country such as Australia, to provide high quality peer review for all applications. This problem is more evident in the Cinderella disciplines that have yet to attract substantial funding, making it even more difficult for new researchers to get established.

8. For many years, health service providers and public health researchers have tended to be critical of the large proportion of NHMRC funding that flows to laboratory or 'biomedical' research. They still lament the apparent lack of funds for the translation of research results in practice, and for the prevention of disease, even though NHMRC has taken steps, over a long period, to redress the apparent imbalance.

9. A number of different interests also influence the effectiveness and efficiency of NHMRC-funded research:

   a. Most NHMRC-funded researchers naturally view the research landscape through the prism of their discipline and their own projects. They apply their drive, curiosity and talent to solving the research and questions that are of greatest interest to them. The nation derives a great benefit from the fact that the intellectual rewards keep them in research, despite the uncertainty of funding and the modest salaries they receive.

   b. Nevertheless, there is a view, outside the research community, that researchers themselves have too great an influence, through the peer review system and NHMRC committee structures, on the research agenda. The historically dominant research disciplines can thus be portrayed as having undue influence, and researchers can, perhaps unfairly, be characterised as working to build their academic reputations at public expense, rather than as serving the health needs of the community[2] or the nation.

   c. The NHMRC responsibility to provide health advice to health agencies and to the public has been greatly advanced in recent years[3]. The commitment to translational research has also been strengthened, as it is widely believed that Australia can achieve important health gains by applying the wealth of knowledge that is already available but poorly applied. Such "how to" (translational) research projects, and other kinds of evaluation projects, usually require the active cooperation of health service providers in public &/or private sectors. Unfortunately, perhaps because of privacy or "ownership" concerns or because of the potential for translational or evaluation research to reveal gaps, inefficiencies or the lack of effectiveness in the services being currently provided, there can be a natural reluctance on the part of service providers to cooperate with expert researchers, and to allow access to any

[2] In past years, that claim was frequently made by Aboriginal people as subjects of research; in recent years, through the efforts of NHMRC and others to involve Aboriginal people themselves in setting research priorities, and as researchers and assessors of research proposals, there has been greater acceptance of research in Aboriginal communities.

[3] For example, during the BSE/variant CJD crisis in the UK, NHMRC established a special expert committee to mobilise Australian expertise and provide the best available advice.

necessary facilities and data. Although government health services are well represented on the Council of NHMRC through the Chief Health Officers of the states and territories, and through the Commonwealth CMO, there would be value in providing a forum for the more formal representation of the private health sector and for contributions from leaders and strategic thinkers from outside the health industry. Principles and processes also need to be developed to facilitate cooperation and greater involvement by both public and private health sectors with NHMRC-funded research.

d. The primary ethical responsibility of NHMRC is to protect patients and research subjects from harm or exploitation by researchers, and to ensure that personal privacy is respected, and that any information disclosed is treated on a confidential basis. There is also an ethical responsibility to inform the public about health risks that can be avoided or ameliorated. Is there also an implied responsibility to provide public advice about services that are deficient, and to be an advocate for measures that would uncover new risks or facilitate health improvement? For example, there is now a vast amount of digitised data on the health of Australians, generated at great public expense, which is almost entirely wasted as a resource for research to help protect the public. With the cooperation of governments and private providers, and leadership from trusted public figures to reassure the public, these data could be linked and mined in the public interest without any threat to privacy.

Recommendations

10. NHMRC should continue to promote and support research and health translation in areas where Australia is seen to have a competitive advantage, including:

    a. Traditional areas of research excellence such as immunology, endocrinology, cell and molecular biology, virology, infectious diseases and public health;

    b. Areas of research that benefit from the Australian ethos of cooperation, such as multi-centre clinical trials, and in studies of the genetics of disease susceptibility;

    c. Research that builds on Australia's strengths in mathematics, statistics and physical sciences; these disciplines are of increasing salience in an era when health research is making major advances through bioinformatics, the analysis of large data-sets and the study of complex systems;

    d. Research capitalising on the universal nature of our publicly funded health system, and an improved interface between the government agencies, the private sector, and the research community, eg:

        i. Routine use of de-identified patient data to identify new risks to public health and to monitor the effectiveness and efficiency of interventions and the incidence of adverse events;

ii. Research in health evaluation and translation projects, regardless of whether it might question the assumptions, traditional practices and interests of health services providers or government agencies;

11. NHMRC should be supported in its continuing efforts to promote translational research that will lead to the discovery and adoption of the most cost-effective treatments and health interventions, and to the phasing out of interventions that may be long-accepted, but not supported by evidence[4]. This will require expertise already available through the Cochrane Collaboration and clinical trial and health evaluation units, as well as skill-sets in social and behavioural science that have not been traditionally associated with NHMRC. There will also be a need for a continuing dialogue with the public, with health providers and with governments to emphasise the importance of robust evidence, to change the knowledge base and expectations of patients, families and providers, and over the longer term to consider how community needs can be more effectively met through appropriate changes to the health workforce and to funding arrangements.

12. Greater involvement of NHMRC with the private health sector and with industry, with appropriate safeguards to protect confidential information, could help with translational research, provide new perspectives and ideas, and also provide access to expertise and funds for the commercial development of Australian discoveries.

John Mathews has been associated with NHMRC as a researcher and member of committees since 1968. He also worked with Health & Ageing as senior adviser in population health (1999-2004), deputising for the Australian Chief Medical Officer as required. These are his personal views.

[4] For many health encounters, the major benefit for the patient comes from the reassurance of being listened to, and from hearing a diagnosis or prognosis, regardless of any specific treatment that might be offered. This non-specific benefit, often dismissed as a placebo effect, helps to explain why alternative practitioners are as popular as they are. (It is an irony that as medicine has become more scientific, its practitioners have had less time for the pastoral care and "laying-on of hands" that was the traditional mainstay of their practice.) Any future changes to health care delivery should seek to preserve the benefit of the personal encounter for the patient, while eliminating extra practices that add no additional benefit.