



strokefoundation

National Stroke Foundation

Submission to the McKeon Strategic Review of Health and Medical Research

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Introduction

The National Stroke Foundation (NSF) welcomes the opportunity to respond to the McKeon Strategic Review of Health and Medical Research in Australia.

As a leading Australian health NGO, the NSF believes that a viable and competitive health and medical research sector is vital if we are to continue to improve the delivery of evidence-based health services, programs and community support to Australians.

About the National Stroke Foundation

The NSF is the only national not-for-profit organisation working with governments, health professionals, carers, stroke survivors and all Australians to specifically minimise the impact of stroke, a disease which will affect one in six people worldwide in their lifetime and which affects one Australian every ten minutes.

The NSF has a very strong track record in developing well managed programs that deliver high quality results including the national clinical guidelines for stroke, the national stroke audit program and the StrokeLink program.

In delivering programs and services the NSF operates across the full spectrum of preventative health, acute care and sub acute patient support. Our mission to stop stroke, save lives and end suffering is strongly supported by the health and medical research sector. Particularly through research that builds knowledge about stroke and its insidious effects, discoveries that lead to new treatments and prevention strategies and research findings that help to guide development and evaluation of our programs and services.

The NSF has direct dealings with the National Health and Medical Research Council (NHMRC), most recently through our role in developing national clinical guidelines for prevention of cardiovascular disease (including stroke) and stroke management.

The NSF is also committed to directly funding high quality research and has developed a strategic research strategy which addresses gaps in knowledge and meets priority needs for stroke care.

On occasion the NSF is a partner in stroke related research proposals to the NHMRC and other funding bodies. In particular the organisation plays a strong role in supporting the translation of research findings into practical health services and programs to benefit Australians. Current examples of NHMRC funded projects include the Thrombolysis in practice study (TIPS) and the 'Stroke 123' partnerships grant.

Summary of Response

The NSF believes the Australian Government should continue to fund health and medical research in this country at, or preferably above the current level.

The current structure and framework of health and medical research in Australia has produced a consistent stream of quality, internationally competitive research findings. Nevertheless, the NSF believes that it is possible to deliver improved efficiency, productivity and focus through structural changes that promote collaboration and result in increased multi-disciplinary disease-focused approaches to research, particularly in areas of high population health burden.

The NSF believes that the strategic focus of national health and medical research should be guided by national health priorities – with particular consideration of the current burden of disease. High impact translational research should be boosted and there should be support for partnerships between researchers, policy makers and groups working on improving clinical practice.

Partnerships should be broad and the aim of collaboration should be to reduce research inefficiencies and to bring likeminded research groups together, across scientific disciplines and across institutes, universities and other research bodies, to tackle key health challenges. There is a role in this for other interested parties, including

health NGOs such as the NSF, whose knowledge, experience and sector networks can be used to add value and quality to the translation effort.

RESPONSES TO REVIEW QUESTIONS

1. Why is it in Australia's interest to have a viable, internationally competitive health and medical research sector?

Australia has a great track record of health research and Australian researchers have been responsible for some of the world's most influential medical discoveries. As a wealthy nation we carry an international responsibility to continue to publicly invest in investigator driven scientific research which consistently improves human health and wellbeing.

At a local level Australia's participation in health and medical research acts as a type of insurance policy for the nation. While we do punch above our weight contributing significantly to world research output, our involvement ensures a local understanding of global scientific activity.

Whether through international collaboration or simply through having both an ability and desire to monitor and explore global research publications, our participation in the international health and medical research community provides us with a window on global science. We have an appropriately educated and trained workforce able to understand and decipher world-wide medical discoveries. Our scientists can then advise policy makers and program/service delivery organisations on how best to apply these discoveries at home.

Funding our own medical research ensures that we can not only borrow and adapt international findings but we can also focus our efforts on local issues. Without medical research we would not understand properly what our own health priorities should be, let alone be in a position to develop, test and ultimately roll out locally specific solutions.

In addition to health and wellbeing gains that improve quality of life, public investment in medical research is also a very solid economic driver. It supports a large workforce with extensive up and down-stream multipliers. It contributes to development of a knowledge based economy that is crucial to our future prosperity. Research also serves to develop new opinion leaders in our community who can drive innovation and change to benefit our society.

2. How might health and medical research be best managed and funded in Australia?

The Australian health and medical research sector has grown significantly since the last major strategic review conducted by Wills in 1998. By more than doubling investment in the NHMRC over the past decade, subsequent Australian Governments have enabled the breadth of research to expand. Likewise, significant investment in research infrastructure has delivered, and continues to deliver, many new buildings across the country to house research teams.

This environment has fostered a consistent stream of internationally competitive research; however it is timely that the Australian Government pauses to reflect on whether the structure of research is efficient and productive. We should be asking whether sufficient expenditure is directed towards the right areas of immediately translatable research that will directly benefit Australians through the health system, especially given changes to our nation's health challenges.

As noted in the review Terms of Reference, the burden of disease in Australia has indeed altered, with chronic disease now the leading cause of morbidity and mortality. The NSF believes that this shift in disease burden is

not reflected in the current structure and funding framework for Australian health and medical research. Areas of importance such as research into treatment and prevention of chronic disease are underfunded. As a result we are missing an opportunity to discover and implement better preventive strategies and chronic disease care models to improve quality of life.

Recent improvements that have been made to treatment and care of chronic disease has led to many more people surviving serious health complications such as stroke. While many stroke survivors will make what is termed a 'full recovery' there are as many, if not more who will suffer from lifelong disability. This affects their ability to participate in society as they previously did and often requires a level of personal care – either in hospital or in a community setting.

With a significant portion of the chronic disease burden impacting on working age Australians (20% of strokes occur in Australians under 55) there is an impact from chronic disease on productivity and an opportunity cost if we are not able to assist these people back to work.

The current funding structure sees a large portion of research dollars going towards basic science and clinical research. While the NSF accepts and supports the vital importance of this research it results in a tiny proportion being directed towards epidemiological, health services research and prevention, areas which are fundamental to addressing the burden of chronic disease.

There must be recognition, for example, that many issues of interest and importance to survivors, or people living with chronic disease, are not best evaluated using research methods such as clinical trials. There are other areas of research that will lead to better understanding about treatment, intervention and methods of care and they should be supported.

A good example is the area of stroke fatigue, a condition suffered by many stroke survivors but one that very little is known about and which attracts very little research funding. Anecdotal evidence from survivors suggests that prescribed rest does little to alleviate fatigue symptoms. More research is needed to better understand this and many other vital areas for stroke and indeed other chronic disease survivors.

The NSF believes that changes to the funding structure of health and medical research is required to ensure that more funding can be provided for the areas of research described above. Basic science and clinical research should continue to be supported with an appropriate funding stream; however a separate allocation of funds should be made available for epidemiological, health services research and prevention.

A new funding structure should be complemented by changes to improve efficiency and productivity. We must reduce the amount of time researchers spend applying for grants and facilitate an increase in collaboration between research teams, groups and institutions with likeminded disease or population focus.

To reduce the inefficiency that comes through the onerous grant application process the Government should, where appropriate, provide funding for grants over a longer period. Research projects such as large population studies and surveillance projects often fall outside the current timeframes and would benefit from longer life spans. Also, where collaboration is involved there should be scope for longer term and larger grant applications.

The NSF has been working with the Stroke Society of Australasia for a number of years on a proposal for an Australian Stroke Research Network which is designed to build on existing stroke networks and provide a platform for an expanded, more efficient and higher impact national research program in stroke.

By bringing together professionals from across the stroke community including researchers, clinicians and other service delivery partners, it is envisaged that communication would be improved, knowledge and infrastructure would be built and shared and career pathways would be created. This would all lead to ultimately better care and management of patients and carers.

It is the NSF's view that support for co-operative research models such as the ASRN would be one way to improve efficiency through collaboration and facilitate a closer working relationship between cross-disciplinary

researchers, clinicians and others with knowledge, networks and experience to contribute.

3. What are the health and medical research strategic directions and priorities and how might we meet them?

The NSF believes that strategic directions and priorities for health and medical research should be guided and informed by the Australian Government's health priorities and in particular by the burden of disease.

As discussed in our response to the previous question there needs to be more focus on research outside the basic science including epidemiological, health services research and prevention. This research should be coordinated in a multi-disciplinary, disease focused manner. Currently there are disease areas with significant population health burden, such as stroke, that receive substantially less research focus than areas of lesser burden.

Stroke is Australia's second biggest killer after coronary heart disease and is a leading cause of disability. Approximately 1000 Australians suffer a stroke every week, around 40% of them die within 12 months and about 50% of survivors become dependent on others to help them with personal everyday living. Stroke kills more women than breast cancer and more men than prostate cancer. And yet it is vastly underrepresented in terms of research.

In 2010, funding for stroke research by the Federal Government via the National Health & Medical Research Council (NHMRC) represented only 3% of the total investment in medical research. A small sum when compared against cancer (23%) and cardiovascular disease research (15%).

Adopting health priorities is a fine policy position for government but recognition of where significant disease burden lies must be backed up by investment in research which builds understanding and leads to better treatment and care solutions.

The NSF believes that research into national health priorities is best tackled through an altered funding and management structure that provides scope for improved communication, development of networks and capacity building across all disciplines. Partnerships should be the basis for a disease focused approach and partners should be sought not only from the research sector but also including policy makers, clinicians and other health service and program coordinators such as health NGOs. By sharing knowledge, networks and experience it is more likely that the translational outcomes can be maximised.

We also believe that there should be consideration about including the views of consumers when developing and meeting strategic research priorities. Government should consider including consumer needs as a factor alongside scientific merit when selecting successful research applications.

The James Lind Alliance model in the UK provides a relevant international example. The non-profit organization, funded by the National Institute for Health Research brings patients, carers and clinicians together to identify and prioritise research priorities and shares this information with research funders.

4. How can we optimise the translation of health and medical research into better health and wellbeing?

The NSF plays an important role in the translation process, particularly through development and implementation of programs and services to support stroke prevention and care. Where possible our programs are guided by research and on occasion we have partnered with researchers to support translational outcomes and to participate in research funding applications.

It is our view that these types of partnerships offer the best prospects for translational success.

As the only national not-for-profit organisation working with governments, health professionals, carers, stroke survivors and all Australians to specifically minimise the impact of stroke, the NSF has a strong network of contacts across the stroke community, including in prevention, clinical networks, hospital stroke units and in the sub-acute space, comprising community care and allied health professionals. We also work closely with stroke survivors ensuring that we are acutely aware of how our activity contributes to improvements in their health and wellbeing.

These networks and the combined experience of our efforts provide a wealth of knowledge to support development of new research ideas as well as translation of research findings.

As discussed in previous questions the current structure sees limited funding being directed towards epidemiological, health services research and prevention and this must be an immediate focus.

We should be encouraging systems that place an imperative on the use of research that is proven to assist with translation. We should be facilitating partnerships between policy makers, researchers and groups working on improving clinical practice. Indeed clinicians and clinical groups should have a seat at the table supporting research groups that are focusing on translating research into practice. This ensures that uptake of new ideas can be fostered early and ongoing evaluation of innovative programs can be used to monitor and improve programs based on current evidence.

Finally we must never lose focus on the individuals whose health and wellbeing we are trying to improve. Involvement of health NGOs such as the NSF in the translation effort ensures a direct link with the community directly affected by chronic disease.