

Review of Health & Medical Research in Australia

Submission from MS Research Australia

1. General Information about (MSRA)

Our Mission is to accelerate Australian MS research toward the prevention, better treatments and a cure for multiple sclerosis (MS).

To ensure that the Australian MS research we fund plays to Australia's strengths and resources and in order to minimise any conflicts of interest, MSRA has a strong governance structure. Our research strategy aims to accelerate research activity in areas where Australian scientists can have the greatest impact in worldwide MS research. We work in close partnership with and encourage collaboration between a number of Australia's foremost university-based medical research centres.

The research focuses on three main areas:

- to better diagnose and treat MS
- to predict and prevent MS
- to propagate cell repair and regeneration

MSRA is both proactive in generating directed research (in the form of 'platforms' such as the MSRA Brain Bank and ANZgene) and reactive in responding to investigator-driven research applications.

We also work with the National Health and Medical Research Council (NHMRC) to facilitate the further development of MS research and funding nationally. The amount of funding invested by MSRA into MS research in Australia has been steadily increasing (Graph 1).

Graph 1. MS Research Spending by MSRA 2000 – 2012



2. MS in Australia – the burden of Chronic Disease on society

MS is a progressive disorder of the central nervous system (brain and spinal cord). It is the most frequent neurological disease in young and middle-aged adults and results in symptoms such as fatigue, pain, reduced mobility and coordination. These symptoms tend to develop over time towards significant disabilities. Current estimates show that 21,200 people are living with MS in Australia today. As a chronic illness, MS places considerable financial burden on families and society in general. A recent report on the Economic Impact of Multiple Sclerosis in 2010 was commissioned by and is available online:

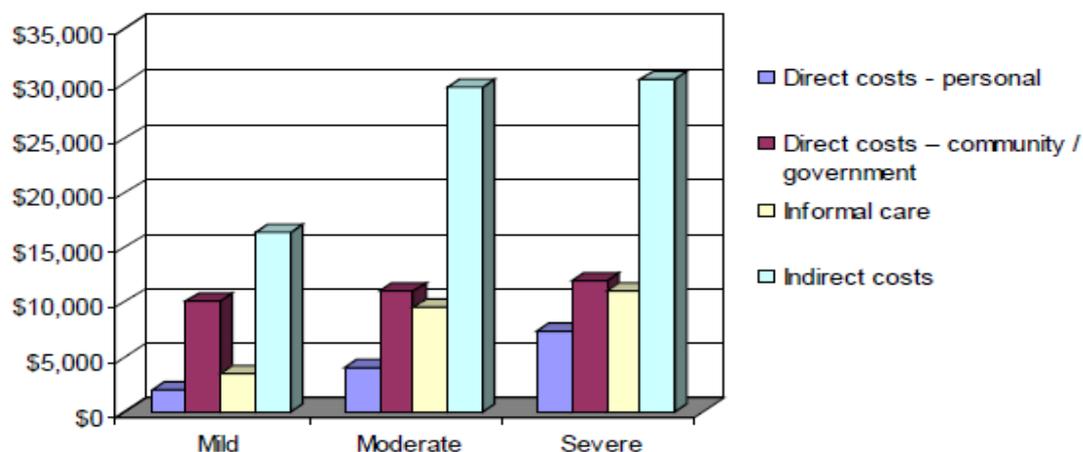
<http://www.msra.org.au/files/msra/docs/Economic%20Impact%20of%20MS%20in%202010%20Full%20Report.pdf>

This comprehensive report had the following conclusions:

- An estimated 21,200 Australians live with MS
- Prevalence of MS is increasing by 4% per year
- There are substantial health costs and indirect costs associated with MS
- Costs increase with severity of MS (Graph 2)
- Total cost of MS to the Australian economy is **\$1.04 billion per year**
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The potential to reduce these costs by finding better treatments or a cure is an enormous opportunity. Investment in research will pay for itself and reduce burden on the healthcare system. There are real opportunities to make significant breakthroughs in MS research in the coming years.

Graph 2. Cost of MS by severity – per person



Notes: Mild severity includes EDSS levels 1 - 3, Moderate includes 4 – 6, Severe includes levels 6.5 – 9. Nursing home costs are excluded as they are unable to be broken down by MS severity.

3. What are the key issues facing health and medical research in Australia?

There are a number of key issues and challenges facing health and medical research in Australia. It is vital that these be addressed if Australia is to continue to be one of the leading countries in this arena. These issues include:

- **Health and the ageing population**

The economic burden associated with health and ageing is expected to increase to over 7% of GDP by 2050. Investment in Health & Medical research, both via the NHMRC and new research funding initiatives has the potential to reduce this burden. It has been calculated that NHMRC investment will save \$966 million in health expenditure over the next 50 years.

Not only is the prevalence of MS increasing each year, the costs associated with MS increase as people living with MS age. The research spend on chronic diseases should be adjusted so that the amount is proportional to the burden of that illness on society.

- **The funding process**

There is an opportunity to gain more non-government funding for health and medical research by leveraging government funding and offering a 'matched' funding option.

The ARC offers '**Linkage**' grants for basic research and the NHMRC (for instance) should offer similar grants. Linkage grants enable charities, trusts and foundations to 'underwrite' grants on the condition that the government match their funding dollar for dollar. By being included in the peer review process, they are also offered a guarantee, and independent (3rd party) judgement, that the research they are funding is of the highest calibre.

MSRA has found these grants highly useful for securing additional funding from philanthropic sources and effectively leveraging government funds.

Also, the current NHMRC grant rounds are time consuming, both for the applicant and the reviewers. Whilst the process has a great deal of integrity, there are methods by which an improved efficiency could be gained.

For example, greater efficiency in the funding process could be achieved by calling for short expression of interest applications in the first round, followed by more detailed applications after initial review. Encouraging applicants to prepare a presentation of their grant proposal, followed by a face to face interview could reduce the need for onerous written applications. Efforts should also be made to streamline funding processes for researchers who are often required to submit the same proposal multiple times to different funding bodies.

MSRA operates in parallel with the NHMRC, with a similar application process – as an example of trying to reduce the effort involved from researchers.

- **Translation of research into policy and practice**

There is a real delay in getting research findings implemented into health policy and general best practice. There is a road block and not-for-profit organisations can play a vital part in this particular issue.

Not for profit organisations are ideally placed at the interface between patients, clinicians, researchers and the pharmaceutical industry.

MSRA by example, provides a means of communication of the latest research findings to patients and clinicians. We advocate for new pharmaceuticals to be government funded. We fund research and help researchers to publicise their findings more widely through the media. This vital role performed by not-for-profit organisations should be enhanced.

Specific grants to not-for-profit organisations should be implemented to fund the translation of evidence into policy and practice and to introduce new findings and practice guidelines

quickly into clinical practice. Not-for-profit organisations are bridging organisations between these key stakeholders. Working at this interface can quickly and effectively translate evidence from high quality clinical trials into practice through communication with all stakeholders.

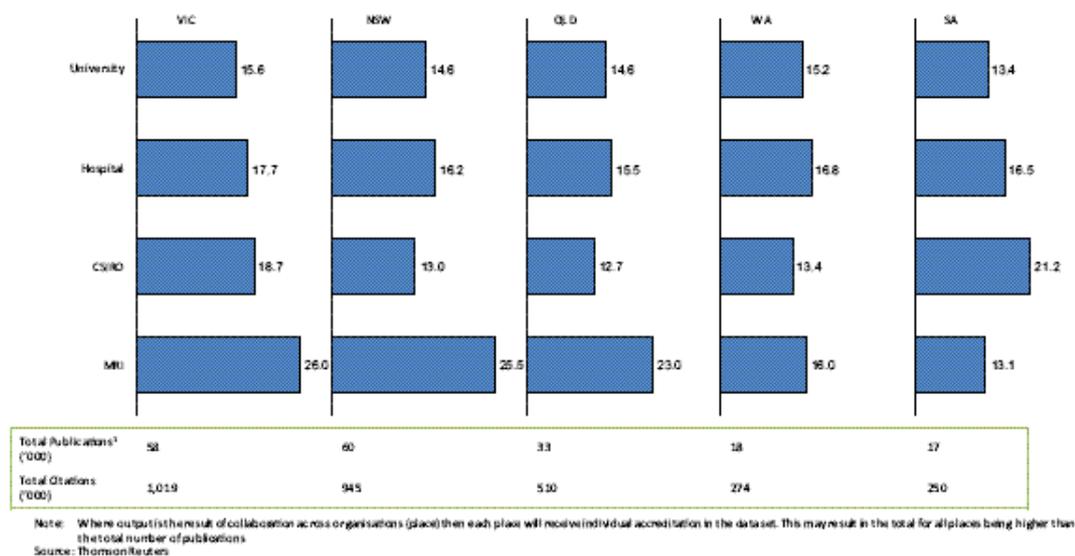
- **Politics & infrastructure**

There is wastage in Universities, with multiple laboratories having equipment used only sporadically and yet not shared between departments, or sometimes even within departments. Given that the majority of this equipment has been paid for through NHMRC grants this is an unnecessary inefficiency. In every University there is space and equipment not being used, usually the reason comes down to politics. Addressing this issue could promote internal collaboration and save precious funds. The NHMRC should periodically audit equipment and space usage within organisations to ensure equipment usage is maximised.

In the NSW Health and Medical Research 'Wills' Review, data were presented showing that 'Institutes' outperform 'Universities' on almost all measures of research output (Graph 3). The tighter management structure within Institutes helps to reduce politics and create multi-user infrastructure and thus less wasted resources. This has enormous implications for the future of Australian research funding.

Graph 3. Citations per publication University, Hospital, CSIRO and Medical Research Institute Comparison

Exhibit 8: Citations per Health and Medical Research Related Publication, by State, 2001 to 2011



Source: http://www.health.nsw.gov.au/resources/omr/review/pdf/nswhealth_msr.pdf

- **Collaboration**

Multi-disciplinary research is vital and at present the level of collaboration between sectors is insufficient. Through our experience with the NSW Office for Medical Research (OMR) we have found that Research Networks are a very cost-effective means of facilitating collaboration.

The MSRA funding for a Research Facilitator to coordinate the NSW MS Clinical Trials and Research Network has been secured from NSW OMR. This novel role is in its early stages but promises to be an outstanding way to leverage funds and ensure optimal communication and collaboration between the interface of the three key research stake holder groups comprising:

- not-for-profit organisations
- the pharmaceutical industry
- scientists/researchers/clinicians

The role of Research Facilitator is an ideal model for other disease areas and the focus on a specific disease area focuses efforts.

A research network brings together researchers from an array of disciplines to share their findings and collaborate in a 'disease-based' setting. For a modest investment, collaboration is enhanced; disease-focussed networks can facilitate this in a cost-effective and efficient manner.

Not-for-profit organisations can provide **co-funding** for such networks and have the advantage of being an independent body which reduces the impact of the 'competitive' element that sometimes discourages inter-university/institutional collaborations in Australia.

We urge the government to partner with the likes of MSRA to leverage the best possible research into MS (for instance). Building globally relevant research capacity is also imperative and strengthening research hubs and networks as well as providing research infrastructure support is vital.

There should be further exploration of 'Linkage' funding incentives for such projects that can also receive public funding and philanthropic contributions.

▪ **People resourcing/Capacity Building**

Much expertise is lost due to a lack of career based funding for academic researchers. There is a critical issue that needs to be discussed: is it better and more efficient to fund 'projects' or 'people'. Significant resources go into maintaining the NHMRC and ARC peer review processes. Academics invest many hours of their time reviewing projects, often for which they do not have the necessary in-depth expertise to review adequately.

By funding 'people' (building capacity), and trusting their research ideas, area of interest and ability to manage a productive research group, considerable resources could be saved.

It is anticipated that >6000 researchers employed in the Australian Health and Medical research workforce aged >40years are expected to leave in the next 10 years. Reasons cited include shortage of funding (91%), lack of career development opportunities (78%) and poor financial rewards (72%). [Schofield et al. 2011, Med Edu, 45, 200-7; Kavallaris et al 2008, MJA 188, 619-25]

In addition there is loss of expertise from a failure of women to continue to the higher levels of academia. Please see Graph 4 illustrating the loss of women at the higher levels from UNSW employment figures. Also note there has been improvement from 2000 to 2011, but there is still a significant difference between males and females at level 3 and above. It is vital that the government addresses this discrepancy. Above first post-doctoral fellowship level, no part-time funding awards are available. This is not conducive to family friendly working practices for either men or women, nor does it allow people with chronic illness or those who act as carers to easily continue their careers past the junior research level. This is discussed in the following article:

<http://www.florey.edu.au/uploads/articles/stopping%20the%20lady%20brain%20drain.pdf>

Graph 4. Illustration of loss of female academic researchers at higher level pay scales

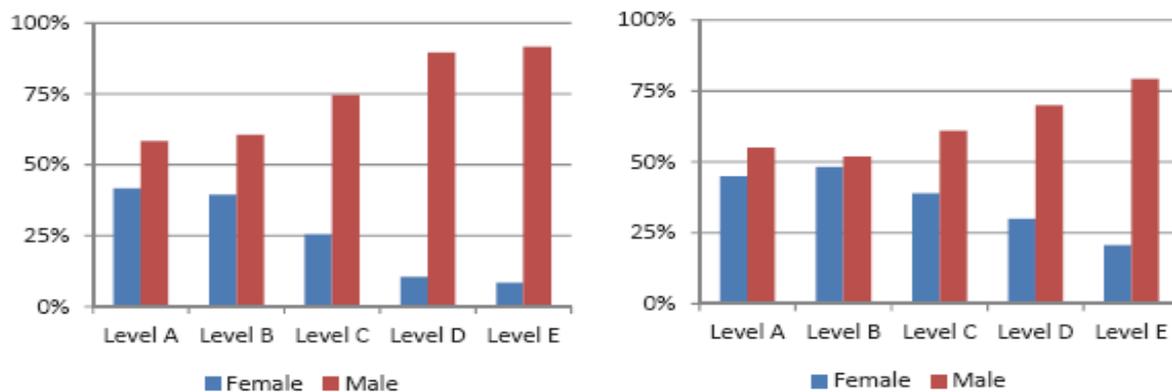


Figure 1: Workforce Profile 2000

Figure 2: Workforce Profile 2011

UNSW statistics downloaded from <http://www.hr.unsw.edu.au/equity/AWES.pdf> 07/03/12

4. Conclusions

- As a chronic disease, with onset early in life, the potential for improving the health of people with MS through high quality research is enormous.

Problem:

- MS imposes a substantial economic and social burden on the people with the condition and the community as a whole
- The burden increases with severity

Solution:

- Investment in research and innovations to delay or ideally prevent the progression of the condition could bring substantial rewards
- More investment in '**Linkage**' grants or other schemes involving 'Matching' of philanthropic investment with government funding – awarded conjointly with not-for-profit organisations and other philanthropic organisations would significantly leverage Government research funds
- Increased funding on chronic disease specific areas is required to be 'proportional to the burden'
- Fund coordination and facilitation between pharmaceutical companies, not-for-profit organisations, clinicians and researchers to ensure cross-fertilisation of research ideas and leveraged funding
- Offer specific grants to not for profit organisations to fund the translation of evidence into policy and practice. Not for profit organisations such as MSRA are ideally placed at the interface of patients, clinicians, researchers and the pharmaceutical industry to get new findings and practice guidelines quickly disseminated into clinical practice. Not-for-profit organisations are capable of bridging between these key stakeholders.

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