

## **MULTIPLE SCLEROSIS AUSTRALIA**

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# **Submission to the Department of Health Consultation on the Development of a Framework for the Secondary Use of My Health Record Systems Data in Australia**

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### **About Multiple Sclerosis Australia**

MS Australia (MSA) is the national peak body for people living with multiple sclerosis (MS) in Australia. Our role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country to support the development of:

- Research
- Advocacy and awareness
- Communication and information
- Services provided by our member organisations
- International collaboration

MSA advocates across all stakeholders, governments and communities, on behalf of our members, to represent people who are diagnosed with MS, their carers and the broader MS community.

### **Our Vision**

Is consistent with the vision of the Multiple Sclerosis International Federation – **'A world without MS'**

### **Our Mission**

MSA will support our members and work towards meeting the needs of people with MS, their families and carers. We will facilitate a national comprehensive representation of the Member organisations through advocacy and communication.

### **Our Purpose**

On behalf of our members and people with MS, our purpose is to develop:

- **Research:**  
Supporting ongoing research to pursue further knowledge in targeting prevention, improving treatment, enhancing quality of life and ultimately, to find a cure.
- **Advocacy and Awareness:**  
Although MS impacts people differently, there are common, fundamental issues for people affected by the disease. We are steadfastly committed to giving these people a voice and remain willing and able to work with government and the Australian society to champion issues in a dynamic policy environment to bring about change to the lives of people living with MS.
- **Communication and Information:**  
Utilising traditional, contemporary and innovative channels to source information and share it with people with MS, our member organisations and our key stakeholders.
- **Support for our member organisations:**  
As MS specialists providing and facilitating high quality services that span the life-time needs of people affected by MS and other degenerative neurological conditions, their families and carers – from the point of early symptoms and pre-diagnosis, that addresses their changing needs.
- **International Collaboration:**  
Representing the MS cause and promoting collaboration with our domestic and international partners.

## **Introduction**

MS Australia (MSA) is pleased to provide a submission to the Department of Health's Development of a Framework for the Secondary Use of My Health Record Systems Data in Australia.

The focus of the comments provided in this submission are on key areas that will impact on people affected by MS. As stated above, MSA's role is to work on behalf of all state and territory based member organisations to provide a voice for people living with multiple sclerosis across the country.

MSA's member organisations are:

- MSWA (covering Western Australia)
- MS SA/NT (covering South Australia and the Northern Territory)
- MS QLD (covering Queensland)
- MSL (Multiple Sclerosis Limited covering Victoria, NSW, ACT and Tasmania)

Each of these state-based organisations operates independently to provide a range of services to people living with multiple sclerosis and, in some cases, to a broader group of people with other progressive neurological diseases. These services vary from state to state and include: phone information support and advice, on-line resources, MS clinics, specialist MS nursing, physiotherapy, education and information workshops, seminars and webinars, psychology, financial support, accommodation, respite, peer support co-ordination, employment services.

Our submission is framed around a general response to the questions raised in the public consultation paper.

## **General comments**

Overall, MSA is very excited about the outcomes and possibilities that the introduction of the My Health Record System may bring about for the MS community. A common complaint from people living with MS is that they have to continually explain and re-explain their diagnosis, their symptoms, (many of which are invisible, such as fatigue, neuropathic pain, numbness, problems with continence, cognition and so on) and the treatments and medications they are taking, to various health professionals on their MS journey. This may be particularly frustrating, for example, when travelling, visiting accident and emergency departments following an exacerbation or when needing to change health professionals.

We believe that the introduction of the My Health Record system has the potential to largely address this need and we affirm the statement on page 1 of the Consultation Paper that, "the My Health Record system allows healthcare provider organisations to access from anywhere important summary health information about individuals like allergies, medical conditions and treatments, medicine details, test or scan reports in digital form in one place."

## **Agreement with the need for secondary use of data for research and advancing public policy**

In terms of secondary use of the data collected through the My Health Record system, we agree with the statement on page 2 of the Consultation Paper that, “Secondary use of health data has the potential to enhance future healthcare experiences for patients by enabling the expansion of knowledge about disease and appropriate treatments, strengthening the understanding about effectiveness and efficiency of service delivery, supporting public health and security goals, and assisting providers in meeting consumer needs”.

Adopting the “opt out” arrangement for participants and the resulting significant increase in participation and size of the dataset, also has great potential benefit to the MS community in improving the efficacy of treatments, determining effective early interventions (as soon as possible after diagnosis) and deeper understanding of the most effective services delivered by our state MS organisations.

As the Health Minister, the Hon Greg Hunt MP, said recently in a speech to the Royal College of GPs, “The benefits, if it’s done well, are of course individual patients will have their own lifetime health record. Individual patients will be able to be protected increasingly against adverse drug reactions, against the need to have duplicative testing, and the system will benefit especially from access to population health data.”

### **Opportunities for data linkages**

The opportunities for data linkages will be significant for the MS community and this may involve the re-identification of data as set out in paragraph 4.3.3 *Organisations requesting linkage of their own data cohort* of the Consultation Paper. As stated in this paragraph, “Such linkages will provide very important information about the effectiveness and safety of treatments and clinical care”.

There are two main data sets in Australia that collect information from people living with MS: MS Base (international) and the Australian MS Longitudinal Study (AMSL).

#### **MS Base**

<https://www.msbase.org/>

In collaboration with participating neurologists, the MSBase Foundation has established a unique, web-based platform, The MSBase Registry, which is dedicated to sharing, tracking and evaluating outcomes data in Multiple Sclerosis and other Central Nervous System demyelinating diseases.

The MSBase Registry is a facilitated global effort to share and track real-world MS data. With over 10 years of longitudinal data collection the Registry now contains a large pool of data that can be used to perform powerful research and ultimately improve clinical practice and quality of life for patients with MS.

The purpose of the MSBase Registry data collection is to conduct analyses that link patient characteristics and treatment with specific outcomes such as disease severity. The results are presented at international conferences and published in scientific journals. We hope that the research will improve outcomes for people with Multiple Sclerosis by changing clinical practice.

MS Base currently holds 55,791 patient records, has 414 members, involves 117 clinics, covers 33 countries and is currently undertaking more than 40 sub-studies.

MSBase makes its security and privacy policies, consent material and governance arrangements publically available via its web-site.

### **The Australian MS Longitudinal Study (AMSLS)**

<https://msra.org.au/australian-ms-longitudinal-study/>

The AMSLS is a survey-based research study that has been running since 2001 and now has over 3000 people completing research surveys each year. The study is designed to provide data of practical use for improving the lives of Australians living with MS.

The study is a partnership between MS Research Australia and the Menzies Institute for Medical Research (University of Tasmania). All Australians with MS over 18 years of age are invited to register with the study. Enquiries from researchers wishing to collaborate or utilise this research platform are also welcomed.

The Australian MS Longitudinal Study aims to collect and analyse self-reported data on matters of importance to people living with MS, through the use of well-designed and ethically approved surveys. This data can then be used to better understand the challenges of living with MS and facilitate the provision of services and advocacy for people with MS. The AMSLS also provides a resource (or 'Platform') for MS researchers who can access an established, well-characterised cohort of people with MS for ethically approved, predominantly social-and-applied, collaborative research projects. Researchers can collaborate with the AMSLS project managers to access the data that has already been collected to answer specific research questions, or to develop new surveys or include specific questions in ongoing surveys.

As for MS Base, the AMSLS make its security and privacy policies, consent material and governance arrangements publically available via its web-site.

As would be expected, both MS Base and the AMSLS have robust governance and ethics arrangements in place. These arrangements ensure that individual patient privacy is protected and also that MS patients are clear about how their data is collected and used.

Both MS Base and the AMSLS web-sites contain many examples of the research projects, including collaborative projects, which have been completed or are currently being undertaken.

### **Brain Health: Time Matters in MS report**

<http://www.msbrainhealth.org/about>

The *Brain health: time matters in multiple sclerosis* presents consensus recommendations on diagnosis, therapeutic strategies and improving access to treatment in MS. Its core recommendation is that the goal of treating MS should be to preserve tissue in the central nervous system and maximize lifelong brain health by reducing disease activity. The report calls for major policy changes aimed at achieving the best possible outcomes for people with MS and those who care for them.

*Brain health: time matters in multiple sclerosis* was developed by an international multidisciplinary group of experts under the chairmanship of Professor Gavin Giovannoni and has been endorsed by a number of professional associations and advocacy groups.

Set out below is a series of recommendations from the Brain Health report, for which the establishment of the My Health Record System and the secondary use of the data, will enable effective implementation.

### 3. Consult the most robust evidence base possible, and generate further evidence, in order to make good decisions about therapeutic and management strategies for MS.

<ul style="list-style-type: none"> <li>■ <b>Carry out economic evaluations of therapies and other healthcare interventions from a societal perspective</b>, considering the health benefits and costs to all parties, to improve assessments of true cost-effectiveness.</li> </ul>	Health technology assessors Reimbursement agencies Patient groups
<ul style="list-style-type: none"> <li>■ <b>Encourage the continuing investigation, development and use of cost-effective therapeutic strategies</b>, of approaches that reduce the costs of managing MS and of alternative financing models, to improve access to treatment.</li> </ul>	Regulatory authorities Healthcare providers Health technology assessors Reimbursement agencies
<ul style="list-style-type: none"> <li>■ <b>Agree and implement standardized data collection techniques, protocols and data sets</b>, nationally and internationally, to track clinical and subclinical events in routine practice. <b>Incorporate these into national and international MS registries and databases</b> to generate real-world evidence of the long-term effectiveness and safety of therapeutic strategies; such evidence can be used by regulatory bodies and payers, and will enable differences in practice patterns to be assessed and addressed.</li> </ul>	National and international bodies Healthcare providers Curators of registries and databases
<ul style="list-style-type: none"> <li>■ <b>Ensure that access to multiple sclerosis registries and databases is available</b> for those carrying out health technology assessments and economic evaluations.</li> </ul>	National and international bodies Healthcare providers Curators of registries and databases

## Conclusion

To ensure the effective linkage of data collected from the My Health Record system to large scale international and national databases such as MSBase and the AMSLS, and to maximise the potential for collaborative research, MS Australia is keen to see that the data is made available to Australian and international researchers and for there to be robust governance arrangements in place to ensure research is overseen by appropriate independent ethics committees and individual patient information is appropriately protected.

**KEY FACTS:**

- Multiple sclerosis (MS) is a neurological condition affecting the central nervous system (brain and spinal cord) that affects more than 23,000 people throughout Australia
- It is the most common chronic neurological condition diagnosed in young adults.
- MS is most commonly diagnosed between the ages of 20 and 40
- 75% of people diagnosed are women.
- MS varies significantly from person to person. For some people, it is a disease that comes and goes in severity with periods of unpredictable relapse and remission. For others it means a progressive decline over time. For all, it is life changing.
- Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems.
- There is no known cause or cure.