MULTIPLE SCLEROSIS AUSTRALIA
MULTIPLE SCLEROSIS RESEARCH AUSTRALIA

Submission to the Inquiry into the Health and Other Legislation Amendment Bill 2018 – Queensland Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee

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Deirdre Mackechnie, Chief Executive Officer, MS Australia

Dr Matthew Miles, Chief Executive Officer, MS Research Australia

MS Research Australia
PO Box 625
North Sydney NSW 2059
1300 356 467

www.msra.org.au
MS Research Australia ABN 34 008 581 431

MS Australia
Level 19 Northpoint Building,
100 Miller St
NORTH SYDNEY NSW 2060
T: 02 9468 8390
F: 02 9411 7456
www.msaustralia.org.au
Multiple Sclerosis Australia ABN 51 008 515 508

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 the disease, 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 this disease.
- **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.

About Multiple Sclerosis Research Australia

MS Research Australia is the largest not-for-profit organisation dedicated to funding and coordinating MS research in Australia.

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

As a member of the MS Australia network, MS Research Australia achieves our mission by working in partnership with relevant medical research institutes and scientists around Australia, encouraging collaborations and focusing on Australian strengths in this research. MS Research Australia is ultimately working towards *freedom from MS*.

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 top medical research centres.

MS Research Australia is guided by an informed scientific agenda to accelerate advances and focus on funding research that will increase our understanding of the triggers for MS, the biology driving MS and how we may prevent the ongoing damage caused by MS and repair existing damage that can reverse disability. We also encourage research that will lead to improvements in symptom management, rehabilitation and support services to help people with MS maintain quality of life. We currently fund over 50 investigator-led projects and 7 national collaborative platform projects to advance our understanding of MS.

Together with a robust governance structure, MS Research Australia believes this approach will result in further significant breakthroughs in the knowledge and effective treatment of MS and major steps toward understanding the cause and developing the cure.

Introduction

MS Australia (MSA) and MS Research Australia welcome the opportunity to provide a submission to the Inquiry into the Health and Other Legislation Amendment Bill 2018 – Queensland Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, January 2019.

The focus of the comments, suggestions and recommendations provided in this submission are specifically on key areas that will impact on people affected by MS, the proposed amendments to the Public Health (Medicinal Cannabis) Act 2016 and Health Act 1937.

MS Australia and MS Research Australia response to the proposed amendments - Public Health (Medicinal Cannabis) Act 2016 and Health Act 1937

There are currently 25,600 people living with MS across the country and this number is increasing. MS can be a particularly debilitating disease with an unpredictable disease course that affects people in different ways. For some it is a disease with periods of unpredictable relapse and remission. For others it is a progressive decline over time. For all, it is life changing.

As such, MSA and MS Research Australia together support any proven treatment that has been deemed safe by the Therapeutic Goods Administration and that helps to minimise the impact of the disease and allow people with MS to live more fulfilling lives.

A 2004 international survey of over 2,500 people with MS conducted by Australian researchers, indicated that around 10% of people with MS believed that cannabis was a factor that can help improve their MS symptoms.[1]

The most significant cannabis-derived product to have been studied for potential benefits in people with MS to date is the Sativex (nabiximols). Its principal active cannabinoid components are the cannabinoids: tetrahydrocannabinol (THC) and cannabidiol (CBD). Sativex is a mouth spray with proven benefits for muscle spasticity and motor control. Muscle spasticity is a significant problem for many people living with MS, affecting over 80% during the course of the disease and negatively impacting mobility and personal independence. Spasticity can cause pain, sleep disturbance and reduced mobility. These symptoms can significantly limit a person's quality of life as they have less energy, ability to complete everyday tasks and social activity. It can also lead to an increased reliance on carers and the health system if symptoms progress to a stage where mobility is significantly hampered or hospitalisation is required.

To date, available medications to treat spasticity for people with MS are not always effective and can have intolerable side effects. Sativex represents a potential new choice of symptom modifying therapy for people with MS who experience spasticity. To date, clinical trials of Sativex have indicated that it can reduce spasticity, pain and spasms and improve the quality of sleep. It is important to acknowledge that Sativex does have side effects that will vary with each case. These can include dizziness, tiredness, depression, memory loss and nausea.

In addition, anecdotes received from members of the MS community indicate that they are receiving benefits from the use of cannabis oil products to treat MS symptoms such as pain and spasticity.

There are risks to consider with the availability of medicinal cannabis products. All medicinal products derived from cannabis require strict regulation and standardised doses of active ingredients, to ensure products are safe and effective, and can produce reliable effects with a controlled risk of adverse events.

As such, MSA and MS Research Australia strongly support the regulatory framework under which medicinal cannabis products (such as those above) may be prescribed and dispensed to patients in Queensland while also preventing their unauthorised use. We agree that many of the original regulations and conditions suggested by Queensland Health are now duplicated with the changes

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[1] Simmons RD, Ponsonby AL, van der Mei IA, Sheridan P, *What affects your MS? Responses to an anonymous, Internet-based epidemiological survey*, Mult Scler. 2004 Apr;10(2):202-11.

to regulations surrounding medicinal cannabis at the Commonwealth level. In the interest of patients having more straightforward access to medicinal cannabis products we support the removal of duplicated requirements. We also agree the changes to scheduling that make medicinal cannabis products part of Schedule 8, rather than Schedule 9, as they were when the first legislation was written, means that in practice some controls are no longer required. We also note and supported the recent proposed changes to the schedule that will make nabiximols, such as Sativex, a schedule 4 entry, rather than a Schedule 8. The requirements of storage and sale of drugs under Schedule 4 provide adequate controls and protections for nabiximols and the Schedule 4 level of control mirrors that seen in other countries. Under Schedule 8, the stringent storage requirements has resulted in very few pharmacies dispensing this medication and is restricting access to Sativex for people with MS that require effective treatment for their spasticity.

Robust and reliable evidence is needed to determine the possible benefits and risks of cannabis-based products for managing symptoms of chronic illnesses such as MS. We note that Sativex is not a treatment to ‘cure’ MS, and while this treatment has clinical trial data and approval for spasticity, there may be other MS symptoms that may benefit from cannabis-based products which could be investigated in clinical trials. As part of any debate on this issue, MSA and MS Research Australia encourage the promotion of randomised controlled clinical trials to be conducted to determine the components, dosage and frequency of either cannabis or cannabis-based products and their efficacy and safety for managing a range of symptoms for people living with chronic conditions like MS.

As such, MS Research Australia and MSA also support the TGA framework set out for clinical trial approval to facilitate the treatment of patients enrolled in a recognised medicinal cannabis clinical research trials to ensure that medicinal cannabis products can be tested for efficacy and safety within in a safe and supportive medical environment. We agree that as the TGA pathways provide an appropriate safeguard for clinical trials, the Queensland approval process is no longer necessary.

MS Australia and MS Research Australia understand and acknowledge that people affected by MS will wish to investigate all options available to them to maintain their quality of life, whilst wanting the evidence-based reassurance that medications are safe, effective and affordable.

Conclusion

Both MS Australia and MS Research Australia are committed to supporting the provision of proven therapies for improving the lives of people with MS.

As stated earlier, our position on these issues is guided by a scientific, evidence-based approach and we advocate for a regulatory framework that will enable access to proven standardised formulations that have been clinically shown to be beneficial for specific medical needs (such as spasticity in MS where other medications are not effective or are contraindicated), while providing regulation that facilitates further research. We support the amendments as set out in this Bill in order to remove duplication by Queensland Health of checks that will be undertaken at the Commonwealth level and to eliminate the possibility of contradictory approval outcomes at different levels of government weakening the process.