

Monday 2 November 2020

The future of MS health care – new digital tool receives vital funding

The National Health and Medical Research Council (NHMRC) has announced \$1.4 million in funding for an innovative MS patient-centred digital health care tool – InforMS – as part of its prestigious Partnership Projects program.

The University of Tasmania's Menzies Institute for Medical Research, in partnership with MS Research Australia, is developing InforMS to help people living with multiple sclerosis (MS) better manage their symptoms. This digital patient-centred health care tool will create a paradigm shift in MS self-care, clinical care and research.

“InforMS will utilise modern monitoring technologies like mobile apps and wearables to collect valuable MS information,” Professor Ingrid van der Mei from the Menzies Institute said. “It will empower people living with MS by providing timely information to track their MS via their smart devices. This data can then be used to influence treatment decisions, monitor symptoms, and identify insights and disease trends to enhance MS research.”

Information collected through the InforMS tool will be invaluable for future MS research and treatment. From greater insights into the day-to-day impacts of MS to the effectiveness of treatment, this innovative system will provide access to data that was once beyond the reach of researchers, clinicians and people living with MS.

The first phase of the InforMS development project will utilise existing information from MS Research Australia’s Australian MS Longitudinal Study (AMSLS) – a research platform comprising a registry of people living with MS and their self-reported data. This will be used as the building block from which the new InforMS tool is to be developed.

Chair of MS Research Australia, Associate Professor Desmond Graham, said: “This important project could never have come to fruition if it wasn’t for the incredible support and involvement of several MS stakeholders. In particular, MS Australia and the MS State Societies, Kiandra IT, Atlassian and vital insight from people living with MS.”

“MS Research Australia aspires to Stop and Reverse MS in 10 years, and part of this exciting plan is to develop a patient-centred portal. The purpose of InforMS is to empower people with MS to be actively involved in the decision-making

process around treatments and management of their MS – it does this through providing clinicians and patients with timely information, allowing them to be more responsive” said Associate Professor Graham.

The partnership funding will enable testing, optimisation and implementation of the new digital InforMS tool.

Expert contributors to the InforMS project: **Professor Ingrid van der Mei, Professor Bruce Taylor, Professor Andrew Palmer, Professor Christopher Leigh Blizzard and Professor Dianne Nicol**, Menzies Institute for Medical Research, University of Tasmania; **Professor Helmut Butzkueven, Dr Vilija Jokubaitis**, Monash University, **Professor Simon Broadley**, Griffith University, **Belinda Bardsley**, MS Nurses Australasia.

Visit the InforMS webpage:

<https://msra.org.au/informs/>

More about MS:

- MS is an acquired chronic neurological disease with no known cure.
- There are 25,600 Australians living with MS and over 2.8 million people globally.
- Every week approximately 10 Australians, aged between 20-40 years old, are newly diagnosed with the lifelong condition.
- Three out of four people diagnosed with MS are women, with an average age at diagnosis of just 20 to 40.
- MS affects more young people than any other acquired chronic neurological disease.
- The economic impact annually per person living with MS with severe disability is \$114,813.

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