the NeuRA magazine

Issue 43 | Winter 2023

NeuRA scientists develop online tool to assess personal dementia risk in minutes

Fall-proof your knowledge!
TAKE OUR FALLS QUIZ

NEWS IN BRIEF:
Reimagining chronic pain

BACK PAIN MEDICINES: WHAT REALLY WORKS?

Ask a Researcher:
What's on the horizon with schizophrenia research?

5 Minutes
with consumer representative Kathryn Leaney

NeuRA
Discover — Conquer — Cure

Message from our Interim CEO

I have had the honour, over the years, of working with many 'consumers' or beneficiaries of research.

People affected by the diseases we research, either directly or indirectly, and who therefore have a passionate interest in the ability of medical research to change the health future.

I have learnt so much from listening to and getting to know these people: as a CEO it has always been very important to me to do that.

That is why I am very pleased to see our story on Kathryn Leaney, consumer representative, in this issue. NeuRA already benefits from the input of vast numbers of members of the community who participate in our clinical trials.

However, we are actively developing complementary strategies to increase our engagement with the communities we serve.

With the right methodologies in place it is not only possible but also desirable to have consumers identify unmet needs; help design the research studies to meet these; and evaluate the outcomes.

When we have our NeuRA all-staff meetings once a month, I also now invite a beneficiary of our research to address us – for this same purpose.

This is the best way for researchers to remain grounded in the reality of what research is intended to achieve: to improve lives, reduce suffering, and generate not just hope – but change.

Carole Renouf

Carole Renouf
Interim CEO
Neuroscience Research Australia

Researchers at NeuRA's Centre for Pain IMPACT have been awarded $4.5 million in grants to find new ways to treat chronic pain. Pictured here are Centre Directors Prof McAuley and Prof Sylvia Gustin.

Welcome to the Winter edition of NeuRA Mag!

As always, we are excited to update you on our latest research and discoveries.

This issue covers a wide range of topics, from the role of genetic variations in bipolar disorder to the future of chronic pain treatment. Our main feature article introduces CogDrisk, a free online tool developed by NeuRA scientists – based on robust evidence – to help individuals assess their dementia risk and learn practical ways to mitigate these factors.

We also have a story on back pain medicines, off the back of a comprehensive study carried out by researchers at NeuRA's Centre for Pain IMPACT to determine which medicines are the most effective for low back pain sufferers.

You'll also have the opportunity to meet Kathryn Leaney, a passionate advocate and supporter of medical research. And finally, we introduce a new column: 'Ask a Researcher' where one of our scientists answers a question based on the latest research evidence. This issue, it is on the topic of schizophrenia, but if you have a burning question you'd like answered, share it with us by email: media@neura.edu.au

We hope you find this issue both informative and inspiring, and we look forward to hearing your feedback. •

Bipolar disorder: Cracking the code

Did you know that one in 50 Australians develop bipolar disorder every year?

Here at NeuRA, our research into bipolar disorder is led by Associate Professor Jan Fullerton. Our research has contributed to the identification of certain genetic variations, or spelling differences in the human genetic code, that are more common in people with bipolar disorder. It is believed that people with more of these genetic variations are more likely to develop bipolar disorder than those with fewer of them. Genomic indexes that influence personality and wellbeing may also be important. Our researchers recently published a report showing that genetic information relating to bipolar disorder and other psychiatric illnesses tracks with family history, but genomic indexes of neuroticism and wellbeing can capture the initial presentation of mood and psychotic disorders independently of family history, helping researchers better identify those most at risk of developing bipolar disorder. •

Shining a light on supported decision-making

Dr Craig Sinclair, Conjoint Senior Research Scientist at NeuRA and Senior Research Fellow in the UNSW School of Psychology was recently invited to co-author a report released by The Disability Royal Commission titled 'Diversity, dignity, equity and best practice: a framework for supported decision-making'.

Drawing on his experience in supported decision-making for people with dementia, Dr Sinclair worked with collaborators from universities around Australia to propose recommendations on how to safeguard, empower and improve the wellbeing of people with cognitive disability.

"Dementia advocates have long been campaigning for greater inclusion and participation of people living with dementia. I was honoured to have been invited to contribute to this report, which I believe can make a positive impact on how people living with dementia are involved in decisions about their lives," said Dr Sinclair. •
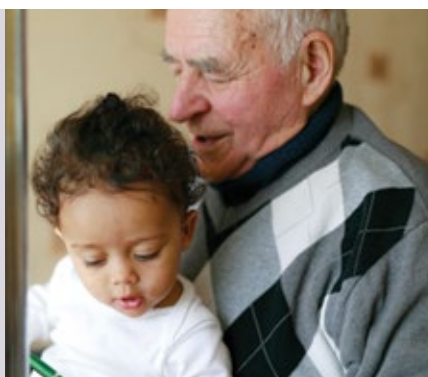
Test your skills!

1. **True or false:** Falls are the leading cause of injury-related deaths in Australia?

2. The best way to prevent falls in old age is by:
   a) regularly visiting the doctor
   b) improving balance and functional strength
   c) going into residential care

3. Every year, how much does the treatment of falls-related injuries in Australians aged 65+ cost the economy?
   a) $103 million b) $1.3 billion
   c) $2.3 billion

4. By working on preventing falls, older Australians will also:
   a) help maintain independence
   b) improve general health through increased physical activity
   c) improve mental health
   d) all of the above

◄ Answers: 1) True, 2) b, 3) c, 4) d

Transforming the future of chronic pain treatment

Researchers from NeuRA and UNSW have been awarded $4.5 million in grants from the Medical Research Future Fund (MRFF) to reduce pain and disability, and increase physical activity, in people living with chronic pain.

Today, there are 3.37 million Australians living with chronic pain, with 68.3 per cent of sufferers of working age. For the majority (56 per cent) of Australians living with chronic pain, their pain restricts their daily life and activities.

Professor James McAuley, Senior Principal Research Scientist at NeuRA and Senior Research Fellow at UNSW Medicine and Health, and Dr Matthew Jones, Postdoctoral Fellow at NeuRA and Senior Lecturer at UNSW Medicine and Health, will be testing whether a mobile app, and an online education and goal-setting program, can help people with chronic low back and neck pain.
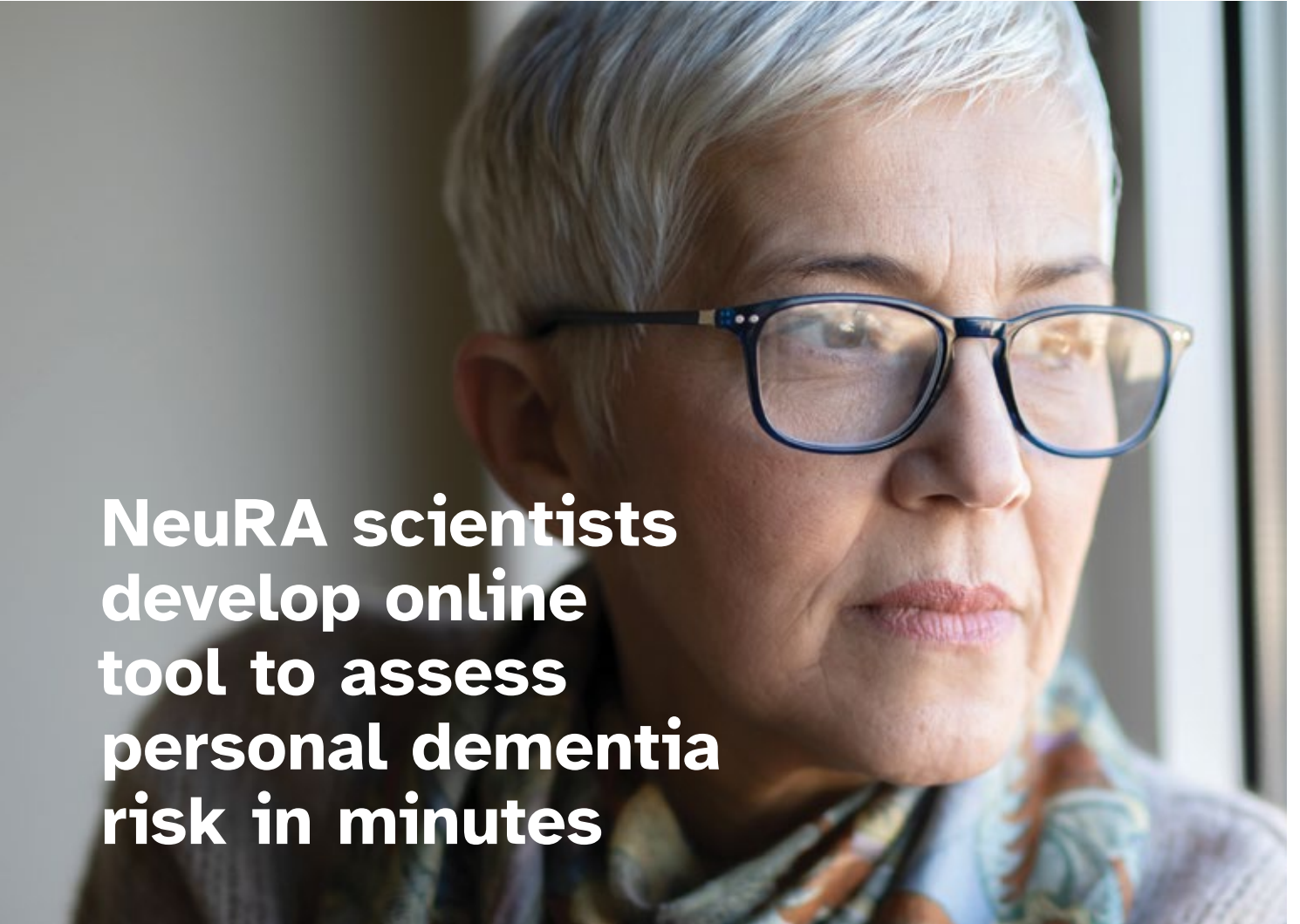
"At NeuRA, our researchers are focused on transforming lives through medical research and the vital work that Prof McAuley and Dr Jones are doing, combined with this funding support from MRFF, will ensure the latest neuroscience knowledge can translate to greater access to high quality health care across Australia," said Carole Renouf, Interim CEO at NeuRA. •

NeuRA scientists develop online tool to assess personal dementia risk in minutes

Dementia recently overtook coronary heart disease as the leading cause of disease burden among Australians aged 65 and over. Currently, over 55 million people are living with dementia around the world, with projections estimating a rise to 78 million by 2030. With such alarming statistics, it is little wonder why dementia prevention is front of mind for researchers and policy makers alike.

To address this urgent need, researchers at NeuRA and UNSW have developed a tool for assessing individual dementia risk that is both free and easy to use.

The online tool, called CogDrisk (cogdrisk.neura.edu.au), takes approximately 20 minutes to complete and provides a personalised dementia risk report that individuals can discuss with their doctor. Since its development in 2022, the team has been evaluating the tool by trialling it on four existing datasets, with the results recently published in The Journal of Prevention of Alzheimer's Disease. So far, analysis has found that CogDrisk is effective at predicting dementia.

"There's lots of information about the risk factors for dementia in the academic literature," says Professor Kaarin Anstey from NeuRA and UNSW's School of Psychology. "But there's a gap between just knowing the risks and actually being able to assess whether or not you have the risk, and then knowing what to do about it. CogDrisk was developed to address this."

The team collated the risk factors for dementia by conducting a systematic review of existing literature to combine all the cited risk factors. Some of the key risk factors that can be addressed in order to reduce dementia risk include insufficient physical activity, obesity in middle age, high blood pressure in middle age, smoking and poor diet.

Often risk assessment tools are developed on a single cohort and therefore fit a particular dataset and population, which doesn't work well when applied to other populations. What's unique about CogDrisk is the robust research that has informed its development. The process involved synthesising

the global literature on risk factors to develop the tool. In a second stage, the team evaluated the predictive validity of the tool on four different cohorts from existing medical studies, involving over 9,500 participants.

The data was matched against the key risk and protective factors outlined in the CogDrisk tool, including whether individuals have diabetes, depression and insomnia, information on their diet and eating habits, and how much they engaged in physical activity. These were then analysed against dementia cases that developed within the same cohort.

"Our statistical analysis shows it's a very robust and generalisable tool," says Prof Anstey. "It works across different countries and different data sets. And it's also quite comprehensive, it includes a lot of the newer risk factors that weren't previously included."

However, predicting dementia is more difficult than predicting some other diseases, partly because it progresses over two or three decades, and there can be a strong genetic component. "It's a multi-causal disease," says Prof Anstey. "But there are some important modifiable risk factors. Most people want to know what their risk factors are and want to do something about them once they know."

The team who developed the tool is hoping that it can be used in health care settings to make it easier for GPs and patients to get information on risk reduction. "Not only are there lots of risk factors, but dementia itself is very complex, and GPs are very busy," says Prof Anstey. "So we're trying to develop ways of making it easier for the public and GPs to get the right information."

Prof Anstey's team is now looking to translate the online tool into different languages to make it accessible to more people. They are also looking at developing a short form of the tool. "There's a lot happening in the research translation, as well as language translation space that we're working on," says Prof Anstey. ●

Professor Kaarin Anstey

Lower your dementia risk

Did you know it is estimated that around 40 per cent of our dementia risk can be reduced? Here are four ways to lower your risk:

1. Regular exercise: 30 minutes of moderate-intensity physical activity at least five days a week.

2. A balanced diet: A diet that is rich in vitamins, minerals and essential fatty acids can help protect your brain.

3. Prioritise quality sleep: Aim for 6-8 hours a night for optimum brain health.

4. Check your hearing: Speak to your doctor if you notice changes to your hearing. Hearing loss has been associated with increased dementia risk but researchers don't yet understand exactly why. ●

CogDrisk – Cognitive Health and Dementia Risk Assessment: cogdrisk.neura.edu.au

"It's a multi-causal disease," says Prof Anstey. "But there are some important modifiable risk factors. Most people want to know what their risk factors are and want to do something about them once they know."

From left: *Dr Michael Wewege and Professor James McAuley.*
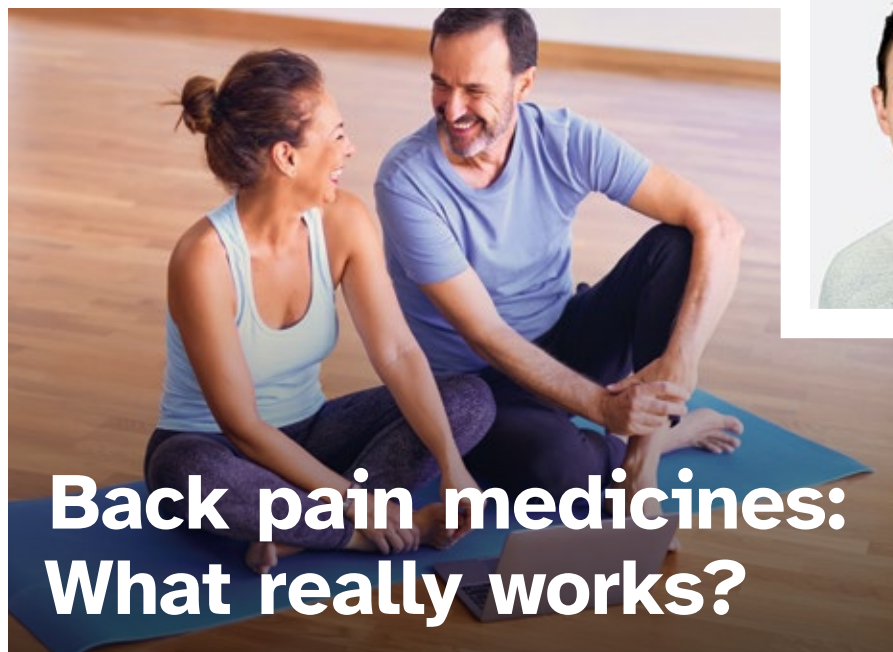
Back pain medicines: What really works?

Back pain continues to be the leading cause of disability worldwide, costing the Australian health system an estimated $4.8 billion annually. Musculoskeletal concerns, including low back pain, are the second-most common reason for GP visits after mental health concerns.

The most common way for Australians to manage their low back pain is to take an analgesic, or pain relieving medicine. Some of these medicines can be obtained over-the-counter and others require a prescription from a doctor.

But which medicines are best?

An international team led by researchers at NeuRA, UNSW Sydney, recently carried out a study to answer this exact question.

"We set out to do this study because GPs and their patients are deciding which medicines are best for low back pain," said Dr Michael Wewege, a research fellow at NeuRA and a lead author of the study. "But there are no formal guidelines to help answer this question and we thought the evidence base would be rich. Ultimately it wasn't."

The study, published in the BMJ, analysed 98 randomised controlled trials involving 15,134 participants in total published between 1964 and 2021 of adults with acute non-specific low back pain, which is defined as low back pain that lasts fewer than six weeks. These included trials that compared an analgesic medicine directly with another analgesic medicine or a placebo across a total of 69 different medicines or combinations.

The research revealed that despite the ongoing popularity of medicines to treat low back pain, considerable uncertainty remains around their overall impact on pain relief and safety. It was also found that some analgesic medicines could in fact increase the risk of adverse events or side effects, which can include nausea, dizziness and drowsiness.

Professor James McAuley, Director for the Centre for Pain IMPACT at NeuRA and UNSW's School of Health Sciences, said the study recognises the complexities in acute low back pain and treatment.

"Despite over 60 years of research, we are still uncertain whether any analgesic medicine provides meaningful pain relief for people with low back pain."

Current clinical practice guidelines recommend advice, reassurance, encouragement of physical activity, and self-management of symptoms as first-line care, whilst analgesic medicines and physical therapy are second-line treatments.

"Patients should be reassured that acute low back pain is very likely to resolve over time, regardless of whether or not they take medicines," says Professor McAuley.

"If analgesic medicines are required, clinicians should take a cautious approach and make this decision in consultation with patients on their individual needs and preferences."

Looking ahead, researchers hope that these findings will lead to larger, rigorous trials that can inform better decision-making. ●

What are analgesics?

An analgesic is a type of medicine that is used to relieve pain, which works by blocking or interfering with pain signals in our bodies. There are many types of analgesic medicines, but the most common include non-steroidal anti-inflammatory drugs (known as NSAIDs), paracetamol, opioids, anti-convulsant drugs, muscle relaxants and corticosteroids.

Kathryn Leaney

> " Most importantly, I help researchers to put their research into language that ordinary people can understand. I'll often say "What do you mean by that?" or "Please explain those acronyms!" "

5 Minutes
with Kathryn Leaney

For the past 10 years, Kathryn Leaney has been a consumer representative, driven by her passion to ensure that medical research reflects the perspectives of patients and their families, carers and communities.

What does it mean to be a consumer representative?

Firstly, the term consumer is not to be confused with someone who goes to the shops! In research settings, a consumer refers to any person who has a personal experience of a disease, either as a patient, a carer or family member or close friend, and they want to contribute to the medical research space.

A lot of funding bodies require cancer researchers to have two consumers involved, so I'm trying to help researchers understand what that means and how they can better work with consumers.

How did you first get involved in cancer research?

I was diagnosed with breast cancer in 2012 and through my experience of treatment, I felt that there must be better ways for people to get diagnosed and treated. This motivated me to become involved in cancer research and work with researchers.

Ultimately, I want to help researchers focus on the people they are aiming to help with their research and know that what they are doing will make a difference for those people.

Is there an advantage with not having a medical/scientific background?

I can ask those naive questions and get away with it. Most importantly, I help researchers to put their research into language that ordinary people can understand. I'll often say "What do you mean by that?" or "Please explain those acronyms!"

What advice do you have for others wanting to become a consumer representative?

I would really encourage it. It is very rewarding and you meet some amazing people. I became a consumer representative by joining Cancer Voices, a not-for-profit organisation that advocates for better services for people with cancer and also provides a consumer-researcher matching service.

Becoming a consumer representative involves completing four online modules covering basic research methodology plus a half-day meeting and by joining Cancer Voices, you can get matched with a researcher and start to make a difference. •

Ask a Researcher

This issue, Ishan Walpola, Honorary Research Associate at NeuRA and Associate Conjoint Lecturer at UNSW Medicine and Health (pictured), answers a question from one of our schizophrenia research supporters.

In your opinion, what is the most promising treatment on the horizon in the field of schizophrenia research?

In my view, medications targeting the dopamine D3 receptor system to treat negative symptoms (e.g. Cariprazine) are some of the most promising new treatments emerging for schizophrenia.

Medications available until very recently are quite effective at treating the positive symptoms generally associated with schizophrenia, i.e. hallucinations, delusions and the disorganised structure of thought and behaviour; unfortunately, they have fallen short in addressing the equally problematic negative symptoms of diminished speech production, motivation, pleasure, emotional reactivity and social interest – symptoms that severely limit equitable participation in society.

Additionally, pre-clinical studies suggest that reducing activity at the D3 receptor might facilitate the treatment of substance use disorder, which we know is highly co-morbid in individuals with schizophrenia.

While much more careful research needs to be done to understand the role of the D3 receptor in both schizophrenia and its treatment, these new medications offer a unique reason to be cautiously optimistic about future advances! •
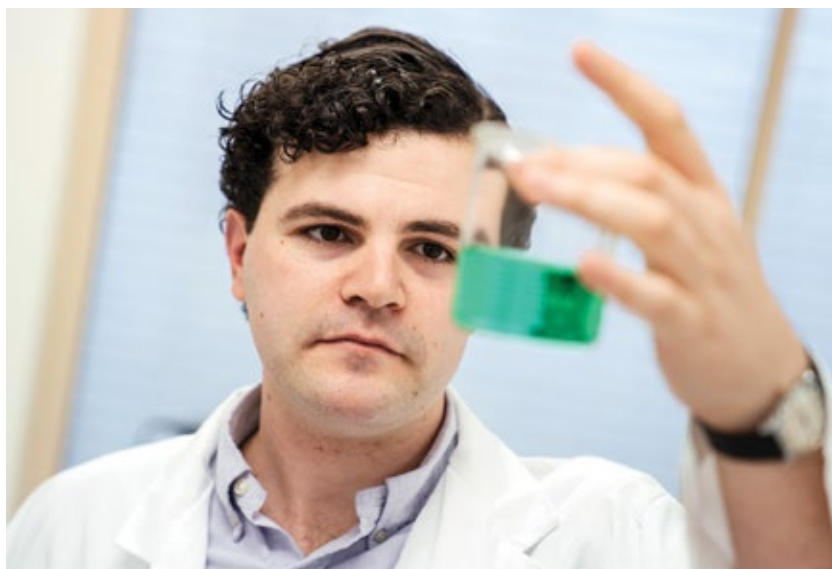
Do you have a question you'd like answered?

Whether it's about a specific area of our research or neuroscience in general, our researchers are here to help!
Send your burning questions to: media@neura.edu.au

Thank you for your continued support

Thank you so much to all of you who have given so generously to support our work at NeuRA. Every donation, no matter the size, helps to advance our understanding of the brain to ultimately help all Australians lead healthier, more fulfilling, independent and connected lives as they age.

Leaving a gift in your Will can be a wonderful way to make an enduring contribution, positively impacting the lives of those living with brain and nervous system disorders for generations to come.

If you would like to discuss leaving a gift in your Will to NeuRA in confidence, please contact NeuRA Gifts in Wills Officer, Lauren Moore on 1300 888 019, 02 9399 1122 or email us at bequests@neura.edu.au