

painaustralia

A BETTER FUTURE FOR PEOPLE LIVING WITH CHRONIC PAIN

2022-23 FEDERAL BUDGET SUBMISSION

DECEMBER 2021



Painaustralia is Australia's leading pain advocacy body working to improve the quality of life of people living with pain, their families and carers, and to minimise the social and economic burden of pain on individuals and the community.



Foreword



Carol Bennett, CEO, Painaustralia

Painaustralia is pleased to provide this submission to the 2022-23 Federal Budget process. Our submission is squarely focused on building a better future for the 3.4 million Australians living with chronic pain, along with their families and carers.

For these Australians, pain affects every facet of their lives. People living with pain have lower workforce participation and are more economically disadvantaged. They frequently face stigma, they are often socially isolated, and they have higher rates of depression, anxiety, and suicidal ideation. They may be dependent on medications to manage their everyday lives.

Many Australians living with pain have been unable to access high quality pain assessment and management, whether due to cost, geographic barriers, low awareness of treatment options, or lack of access to health professionals with the right knowledge and skills. We know there are serious gaps in addressing these issues.

The situation has been exacerbated by the Covid-19 pandemic, which has amplified the challenges for people living with chronic pain, whose starting point before the epidemic was already compromised. This adds even greater urgency to addressing the needs of these vulnerable Australians.

It is critical now, more than ever, that people living with chronic pain have support to self-manage their conditions; that they have timely access to appropriate, high quality care, close to home; and that pain researchers across Australia are connected and resourced to develop innovative treatments and solutions that make a real difference to the lives of people with pain. The proposals we put forward in this submission target these high priority areas of need.

Painaustralia is the national peak body working to improve the quality of life of people living with pain, their families and carers, and to minimise the social and economic burden of pain.

Painaustralia represents the interests of a broad membership that includes health, medical, research and consumer organisations.

Painaustralia has played a key role in ensuring that pain is an integral component in emerging health policy issues, including private health insurance, aged care and veterans' health. We are a respected voice for the sector and the 'go to' body for policy, advocacy and information on national pain issues. We have rolled out several multi-faceted consumer education and awareness campaigns, including in partnership with other health sector organisations. We are therefore in a unique position as we directly hear from people living with pain, and can put forward realistic and effective proposals to meet these needs.

Painaustralia is also privileged to have the support of our National Patron, Air Chief Marshal Sir Angus Houston AK, AFC (Ret'd), our Chairman, Major General Duncan Lewis, Painaustralia's Champions including Hayley Leake, Australian Survivor Winner 2021, Tara Moss, Best Selling Author, Veteran and Invictus Games competitor, Peter Rudland, ABC Medical Reporter Sophie Scott and Liesl Tesch AM MP and our Consumer Advisory Group representing diverse consumer interests.

We are putting forward three proposals for urgent consideration for 2022-23 Federal Budget funding:

- 1. A consumer tool – the “InControl” app – to improve self-management of chronic pain, and reduce dependence on medications.**
- 2. Better access to quality care for people with chronic pain across Australia through a National Pain Care Program, which will deliver care through a “hub and spoke” model based on collaboration between pain specialists and primary care professionals.**
- 3. A National Pain Research Alliance, to facilitate a co-ordinated approach to pain research in Australia and ensure translation of research to improve the lives of people living with chronic pain.**

These proposals are presented in detail below, and we commend them for Federal Government consideration in the 2022-23 Budget context.

PROPOSAL

1

A consumer tool – the “InControl” app

The Problem

Australia has seen a recent tightening of restrictions on opioid based medicines due to increasing levels of harm.

Approximately 86% of patients with chronic pain in Australia take at least one medicine to manage their pain. Of these, two-thirds do not receive any other form of management¹. Opioid use for the treatment of chronic pain has increased almost four-fold over the last two decades despite² limited evidence to suggest that long-term use of opioids is effective in resolving chronic pain or improving function³⁻⁴.

Chronic pain is often associated with psychological comorbidities, including post-traumatic stress disorder (PTSD), catastrophising, anxiety and depression^{5,6}. Pain catastrophising is a significant risk factor for developing chronic pain and disability.

We know that many people with chronic pain, who are dependent on medications, avoid seeking treatment to address their dependency. This may be due to fear of coming off medication, with low awareness of other approaches to manage pain; a perceived lack of confidentiality in seeking treatment; and perceptions of stigma. The consequences of this lack of uptake to treatment may be an increased risk of suicide, ongoing drug dependence and other harmful outcomes.

Given that pain medications remain a mainstay of chronic pain treatment in Australia, it is fundamental that people with pain themselves understand how best to manage their pain. Substantial evidence shows that people with chronic pain who are engaged in active approaches to manage their condition have less disability than those who are engaged in passive therapies, such as taking medication or surgery⁷. Challenging beliefs about pain treatment, including beliefs about the need for opioids, scans and surgery, helps build consumer resilience and produce better health outcomes⁸. Explaining the neuroscience of pain has also been shown to improve pain and movement and reduce fear⁹.

Some strides have already been made. The Federal Government provided welcome funding in 2019 for the implementation of several initiatives, including an integrated website for consumers, and information and education for health professionals; and Painaustralia has launched an updated national pain services directory, to help consumers find and access the right care. The Federal Government has also implemented a number of regulatory changes to reduce the harm caused by prescribed opioids. While these changes were necessary, the timing of the changes in the midst of the pandemic has impeded effective communication of their rationale, and of alternative strategies for pain management. This is unfortunate, especially as the changes may, in the short term, increase the risk of harm through rapid opioid dose reduction, which also poses risks including more severe pain and neuro-psychological effects.

A consumer survey of the impact of the opioid reforms on people with chronic pain undertaken by Painaustralia in July 2020 found that nearly all of the 595 respondents (92%) reported having been negatively impacted by the changes. Many expressed extreme distress¹⁰. In addition, a study commissioned by the Therapeutic Goods Administration (TGA) found that opioid literacy is low among current opioid consumers; that consumers overestimate the safety and effectiveness of their own opioid usage; and that there is limited consumer knowledge and understanding about the regulatory reforms¹¹.

There is a major gap in effective consumer information and education about pain issues and treatment options, which urgently needs to be addressed to improve the lives of people with pain and reduce the harms from over-use of medications such as opioids and some ‘low value’ treatments.

The Solution

Best practice guidelines for persistent pain indicate that education, active and psychological therapies, and self-management strategies should be a critical part of first line care¹². Increased patient activation and engagement has been associated with improved outcomes and reduced costs for people with chronic disease¹³. Improved community education and support for people living with pain has the potential to improve quality of life, reduce dependency on medications, and reduce the burden of pain-related presentations on the healthcare system.

A shift in focus from opioids to active self-management strategies, while slowly tapering and ceasing opioids as the patient’s ability to regain control and self-manage increases, is considered current best practice^{14,15,16}.



To support patient self-management and control of pain, we propose the development of a mobile and tablet application called **'InControl'** as a practical tool to help people living chronic pain to manage their pain and their mental health. The app will be developed by Painaustralia.

Use of apps to support patient self-management and control of their health issues has already gained significant traction worldwide. A few key examples of successful apps in Australia include:

- Healthdirect Australia's *healthdirect* app, which helps patients make informed decisions about their health;
- Breast Cancer Network Australia's (BCNA) *MyJourney* app, which has an associated symptom tracker;
- beyondblue's *BeyondNow* app, which helps people with mental health problems develop a safety plan to reduce suicide risk; and
- Asthma Australia's *Asthma* App, designed to support people with asthma and their families and carers.

Following the positive examples of such apps, Painaustralia's *InControl* app will be developed as a valuable tool for people living with chronic pain to gain better control over their health and wellbeing. Painaustralia will work closely with experts and stakeholders including chronic pain specialists, mental health experts, the Painaustralia Consumer Advisory Group, the Department of Health, and community-based support groups for people with chronic pain throughout the development of the *InControl* app.

The *InControl* app functions are likely to include:

- Tracking pain and activity to reflect the user's day, and increase the user's understanding of the impact of factors such as physical activity and dietary intake on their pain and mental health through user-friendly pain graphs and charts.
- Tracking the effects of medication on the user's pain levels.
- A pain map, to help to keep track of where pain is occurring in the body. The app will enable the user to send data to their doctor, pain specialists and other specialists if they choose to do so.

- **Guided Pain Relief Program:** A self-help program that will take the user step-by-step through every aspect of modern pain management, from understanding pain, to dealing with triggers, developing a pacing strategy, Cognitive Behavioural Therapy, and so much more.
- **National Pain Service Directory:** A valuable tool for people living with chronic pain, GPs and other health professionals looking to refer a consumer to a pain specialist or clinic. This is a tangible resource that supports access to best-practice, evidence-based pathways of pain management. This will be complemented by a geographical directory of other relevant services including mental health services.
- Guided meditations for pain relief.
- Exercises for chronic pain.
- Linking support pathways to peer support in the community: connecting people with chronic pain to community-based support groups in Australia through a directory map.

The investment

Development and implementation of the *InControl* app will require the following funding.

\$370,000 in 2022-23 for development of the *InControl* app, inclusive of costs for:

- Environmental scan and evidence review
- Consultation and content development
- Development of wireframe
- Creation of beta app and testing
- Functionality testing.

\$80,000 in 2023-24 to finalise functionality and marketing of the app.

\$50,000 in the out-years for ongoing evaluation and review, and continuous improvement and marketing of the *InControl* app.

PROPOSAL

2

A National Pain Care Program to improve access to quality care

The Problem

Many Australians currently have little or no access to specialist chronic pain services. This is due to the limited number of pain specialists and specialist pain services across the country, long waiting lists for care in the public system, and a lack of services in regional, rural and remote Australia. These specialist service gaps, combined with the lack of a community-based care model, has led to many people becoming dependent on GP-prescribed opioids to manage their pain while they wait for appropriate care.

It is estimated that up to 80% of people living with chronic pain are missing out on treatment that could improve their health, quality of life and workforce participation, including access to pain specialists and one-stop pain clinics that offer interdisciplinary care, and/or appropriate services at the primary care level. The public and private pain clinics that offer interdisciplinary care in one physical location are mostly located in the major capital cities, as are the specialist pain medicine physicians. In addition, there are only seven paediatric pain clinics in Australia, with none in Tasmania, the ACT or the NT; and the physiotherapy workforce, integral to interdisciplinary pain management, is in short supply in rural and remote areas¹⁷.

A recent review of pain services in Australia found that lengthy wait times are common, with some people waiting three years or more to access a service. Wait times were longest at clinics using public or combined funding models, and those offering pain management group programs. It appears that the most disadvantaged Australians experience the longest wait times, often far exceeding the recommended 6-month maximum wait¹⁸.

While limited access to appropriate care for chronic pain is an issue across Australia, it is particularly acute in rural and remote areas. People who live in regional and remote Australia are more likely to have chronic pain than those who live in major cities. For back pain, the most common form of pain, people who live outside major cities are 23 per cent more likely—and those aged 55 to 64 are 30 per cent more likely—to live with it compared with urban areas. Higher rates of pain may be associated with rural industries such as agriculture, mining, forestry and fishing which have higher rates of injury; and excess body weight—which is implicated in painful conditions such as osteoarthritis—is another factor¹⁹. Yet there are very few pain specialists and pain clinics in rural areas, meaning that Australians living in regional/rural communities have poor access to pain services²⁰.

It is critical that people with chronic pain are provided with appropriate services, education and support to manage their pain effectively in the community setting. Improved service models are needed to address the gaps created by the high burden of chronic pain in the community, the lack of specialist services in rural and remote areas, long wait times in the public system, and the lack of primary health care professional confidence and skills in pain management. Without action to improve access to appropriate care, too many Australians will continue to experience persistent pain, ongoing physical and mental health deficits, and delayed recovery and return to work after injury.

The Solution

There is well established evidence that a “hub and spoke” model for clinician education and case conferencing can improve access to appropriate care across a range of conditions including chronic pain, bring care closer to home, and deliver a range of benefits for patients, clinicians, and the community.

The National Pain Care Program we propose is based on the ECHO (Extension for Community Healthcare Outcomes) “hub and spoke” model initially established in 2003 in Albuquerque, New Mexico, and since disseminated worldwide. The ECHO model aims to promote management of people in their community, rather than in specialist clinics, primarily through the transfer of knowledge between subject matter experts (“hubs”) and primary healthcare clinicians (“spokes”). Overseas experience has demonstrated that the ECHO approach is effective in addressing many of the challenges practitioners experience in managing patients with chronic pain in primary care. The approach offers guidance to primary care practitioners for their most challenging patients, promotes knowledge acquisition and diffusion, and stimulates the development of a “community of practice”²¹.



In Australia, several hubs are implementing the ECHO model across a range of conditions, including chronic pain, utilising videoconferencing technology to facilitate case conferencing and clinician education²².

Benefits which have been identified across project sites include:

- Improvements in clinicians' perceived knowledge and skills in pain management;
- Improved clinician confidence in pain management, particularly with complex patients;
- Better perceived quality of patient care;
- Increased likelihood that clinicians will engage in multidisciplinary care and that they will seek input from other professionals; and
- Greater medication knowledge, and increased likelihood that clinicians will utilise non-pharmacological approaches to pain management²³.

Participant experience also suggests that the approach helps to build correlation and linkages between hospital-based services and primary health care services, improving the patient journey and reducing duplication; and that the education, supervision and case conferencing provided by the specialist hub supports local workforce development in primary health care²⁴.

To date, the hubs which have been operating in Australia have tended to be local/regional initiatives, largely reliant on short-term program funding or applied research funding. As the effectiveness of the model has been clearly demonstrated, it is now time to scale up these localised short-term approaches, and implement a long-term National Pain Care Program, based on the ECHO model, to improve access to appropriate care for people with chronic pain across Australia. A national approach is particularly important to ensure that under-served populations, including (but not limited to) those in regional, rural and remote areas, have equitable access to quality care for chronic pain.

It is proposed that Painaustralia will lead the development and co-ordination of the National Pain Care Program, working in conjunction with key stakeholders including existing ECHO chronic pain projects, pain specialists and specialist clinics, specialist colleges and primary health care professional associations, Primary Health Networks (PHNs), Local Health Districts (LHDs) or their equivalents, and academic institutions with relevant expertise and experience.

In developing the National Pain Care Program, Painaustralia will build on the knowledge and expertise which has been developed across Australia, both through the ECHO projects, and through initiatives such as Pain Revolution, which has been working to build a network of clinicians skilled in pain management through a Local Pain Educator program which is adding great value to service delivery in several locations in rural and remote Australia²⁵.

We will also take into account relevant international initiatives, including those being developed in Canada, which has similar geographical challenges to Australia, and which is working to design innovative service delivery models for chronic pain²⁶. In addition, we will explore the value of including telehealth services for patients within the model, given the potential benefits of telemedicine in chronic pain care, which include addressing psychosocial and motivational factors, offering convenience and efficiency for patients and providers, and filling gaps in transitional care²⁷.

The investment

The National Pain Care Program will require the following funding.

\$150,000 in 2022-23 for program design (including evidence review, consultation, and business plan development).

\$3.3 million per annum in out-years for program implementation, based on:

- **\$3.1 million** per annum for program implementation (based on a notional allocation of \$100,000 per annum across each of the 31 Primary Health Network regions to support promotion of the program, recruitment and induction of health professionals into the program, program administration, and local data collection).
- **\$100,000 per annum** for program-wide co-ordination.
- **\$100,000 per annum** for program-wide data collection and analysis, evaluation, and continuous quality improvement activities.

PROPOSAL

3

A National Pain Research Alliance

The Problem

As outlined in the National Strategic Action Plan for Pain Management, despite the significant impact of pain in the community, investments in pain research over the last 20 years have not been coordinated or prioritised. Nor has investment kept pace with the burden of pain, with pain research attracting only a fraction of the funding allocated to other high-profile conditions²⁸.

The experience of Painaustralia and its partners is that pain research in Australia is characterised by siloed disciplines and uncoordinated points of excellence, and by a disconnect between industry, clinical, academic and community capabilities. Academic research often fails to be translated into clinical practice. While some pain research is funded by NHMRC, there is a strategy vacuum, and a lack of focus on translational research. There is also inadequate focus on the consumer perspective, and limited consumer-led or consumer-informed research.

Strategic focus and investment are needed to optimise the impact of research on improving health outcomes. Australia has some of the leading pain researchers and the opportunity to be a world leader in this area.

The Solution

In line with the recommendations of the National Strategic Action Plan for Pain Management, we propose the establishment of a National Pain Research Alliance, which will link key partners and work across institutional and geographical boundaries to develop and implement a national pain research strategy.

As proposed in the National Action Plan, the Alliance will support a network of pain researchers, bringing together capabilities and driving trans-disciplinary approaches to “learn by doing” and “learn from others”. It will amplify the collective impact of the partners by harvesting capabilities across research, health professional and government sectors, and harnessing the value of the partners’ scientific, clinical and entrepreneurial resources. The Alliance will have a focus on translating research knowledge into better patient experiences and outcomes.

The initial focus of the Alliance will be to establish a national strategic plan for pain research, identifying priorities in collaboration with the pain sector, consumers and governments; following which mechanisms will be developed to allocate resources towards research which aligns with the strategy.

The establishment of the National Pain Research Alliance will enable the collaboration and open innovation needed to take Australia beyond the traditional and conventional pain management mindset as new approaches support experimentation and learning, and a continuous flow of knowledge and ideas that develops, attracts and retains talent and partners.

The National Pain Research Alliance will:

- Develop and implement a National Pain Research Strategy;
- Build a workforce capable of delivering rapid translation of research into practice;
- Create national capabilities to empower clinicians, scientists, and innovators;
- Integrate training, research and translation activities;
- Bring academic research and development together with industry research and development;
- Create a culture of engagement and collaboration across the sector; and
- Drive solutions from a consumer perspective, ensuring consumer experience and outcomes are central to the goals of the national research strategy.

The investment

The establishment of the National Pain Research Alliance will require the following investment.

Years 1 and 2 (2022-23 and 2023-24): \$400,000 per annum for recruitment of Alliance partners, establishment of governance and management structures, recruitment of core personnel, and development of the National Pain Research Strategy.

Out-years: \$20 million per annum for the implementation of the National Pain Research Strategy (including research grant funds and running costs).

Conclusion

The future for the 3.4 million Australians living chronic pain is in our hands. With guidance from the National Strategic Action Plan for Pain Management, we know what is needed to improve the lives of people living with chronic pain. We need to offer better support for self-management, so that people with pain can make informed choices about their treatment, and take control of their day to day lives. We need to develop and implement evidence based models of care which enable all Australians living with pain to access quality care for their conditions. And we need to empower Australian researchers to identify new and better methods to prevent and treat chronic pain.

Painaustralia offers solutions which address these needs and gaps. In this submission, we have outlined proposals for:

- An InControl app, which will help people with pain to reduce dependence on medications, and take control of their conditions. 3-year investment: \$500,000.
- A National Pain Care Program, to bring pain specialists and primary health care professionals together in a 'hub and spoke' model which can deliver quality pain care to all Australians. 3-year investment: \$6.75 million.
- A National Pain Research Alliance, to find better solutions for pain and to translate these solutions into clinical practice, ensure real-world uptake. 3-year investment: \$20.8 million.

Painaustralia looks forward to funding announcements in the 2022-23 Federal Budget, and we stand ready to work with our partners to bring these projects to fruition.

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painaustralia

Mailing address: PO Box 9406 DEAKIN ACT 2600

Phone: 02 6232 5588

Email: admin@painaustralia.org.au

Website: www.painaustralia.org.au