painaustralia NATIONAL STRATEGIC ACTION PLAN FOR PAIN MANAGEMENT

> CONSULTATION SUMMARY COMPANION DOCUMENT

2019

Purpose: A summary of consultation activities that have informed the development of the National Strategic Action Plan for Pain Management

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# SUMMARY

Painaustralia, the national peak body working to improve the quality of life for people living with pain, their families and carers consulted widely to understand broad views on the goals and priority actions to be included in the National Strategic Action Plan for Pain Management between June and September 2018.

The key consultation activities included:

- Public online survey open between 23 July and 17 August
- Consumer-specific consultations
- Stakeholder Workshop
- One on one discussions
- Stocktake of pain management activities

The consultation confirmed the need for action and nationally coordinated policy setting.

The need for national leadership and investment to govern and oversee the implementation of a national approach to pain management was strongly supported. This includes the formation of a National Pain Leadership Group, endorsement by all Australian Governments of the National Pain Strategy and Action Plan and a role for Painaustralia as the peak national pain advocacy body to coordinate national activity.

Greater awareness of pain and pain management by both consumers and health practitioners, more timely and affordable access to consumer-centred multidisciplinary services and research into pain and new treatments have emerged as key priorities.

This document outlines further details on the consultation activities and key findings.

# KEY ACTIVITIES AND FINDINGS

# ONLINE SURVEY

Painaustralia developed and published an online survey through Survey Monkey which was open to the public for response between 23 July and 17 August 2018. The survey was widely promoted through social media, the Painaustralia website, Painaustralia e-newsletter and stakeholder networks.

1,142 responses were received, 69% identified as consumers, 24% identified as health practitioners and 8% identified as carers. Most responded as individuals (96%) with only 4% responding on behalf of an organisation.

Painaustralia included specific questions in this survey to examine community understandings, beliefs and attitudes about pain and the priorities for pain management. The survey also sought views on progress with implementing the 2010 National Pain Strategy.

#### **Progress since 2010**

The survey findings demonstrate that although people value the goals identified in the 2010 National Strategy, community perceptions around progress made on these goals is low, with more than half of the respondents noting that the quality of life for people living with pain has not improved. Commentary from consumers also highlights the many barriers that still exist, significantly around appropriate access and affordability of pain management services.

Some areas have made progress, with consumers noting the value of consumer resources e.g. websites and other information sources. Many consumers note that seeking information on their own health care and self-management has been helpful.

#### **Emerging Goals**

Respondents identified other emerging areas and priorities which may be addressed through the Action plan including prevention and early intervention (63.91%), reducing the impact of pain on the workforce and ability to participate in community (62.83%).

#### **Research Priorities**

In considering research priorities that would be most helpful in increasing our understanding of pain and its treatment, consumers prioritised research aimed at better understanding how many people live with chronic pain, the nature of chronic pain and pain management and treatment options other than medication.

In addition, the role of medicinal cannabis and Cognitive Behavioural Therapy (CBT) in chronic pain management as well as the importance of diet and nutrition for people living with pain was high priorities.

#### **Priorities for Action**

Respondents identified measures that are most important to improve the quality of life for people living with pain, with telehealth programs and consumer awareness campaigns gaining strong support.

Many respondents highlighted barriers to accessing pain management outside of the public system due to high costs.

# CONSUMER-SPECIFIC CONSULTATION

The voice of consumers was critically important in shaping a consumer-centred Action Plan.

Painaustralia funded the Consumers Health Forum of Australia (CHF) to host a Consumer Pain Roundtable to gauge views on the priority areas for the Plan.

Due to significant interest, a roundtable and a group teleconference were held to ensure those consumers who were unable to attend in person were able have their voice heard during this consultation process.

Participants were recruited through CHF and Painaustralia's extensive networks. Expressions of interest remained open for two weeks. Thirteen people were chosen to attend the Roundtable held in Canberra on 18 September 2018 and 7 people participated in the teleconference held on 20 September 2018.

A CHF-nominated consumer representative was chosen through an Expression of Interest (EoI) process to provide a conduit between the consumer consultation and the stakeholder workshop held on 27 September 2018 and sitting fees and travel costs were paid to ensure this representation.

Representatives from each State and Territory (except for Tasmania), remote and regional areas as well as metropolitan areas attended.

Representatives were from varied experience and knowledge including people who (or their family member) live with chronic pain, carers of people living with pain, consumer representatives and CEOs of organisations which represent consumers living with pain including the Australian Pain Management Association, Chronic Pain Australia, Scriptwise and ACT Pain Support.

#### **Key findings**

Overall, consumers welcomed the Action Plan while emphasising the need to reflect a broad vision of pain and not be limited to chronic pain. Consumers strongly agreed that the vision and principles of the Strategy and Action Plan should reflect consumer centred care and partnering with consumers in the design and provision of services and partnerships with consumers, communities, families and workplaces were considered essential.

Four key priority areas were identified for action in both discussions including:

- 1. Access and Affordability: Support for chronic pain to be recognised as a condition in its own right including under GP management plans to facilitate access to multidisciplinary services and mandated recognition of chronic pain under private health insurance.
- 2. Training for Consumer Advocates: More support for people to become consumer advocates through a consumer advocacy strategy, self-advocacy kits and/or trained peer-to-peer mentors to help those living with pain.
- 3. Education and Awareness: National strategy needs to be provided at all levels to reduce stigma and increase awareness of pain, including seeking funding for a consumer engagement strategy that informs consumers to make decisions about their pain treatment, together with resources to support consumers such as a national database where consumer stories can be shared, covering the spectrum of lived experience.
- 4. Support: Develop and raise awareness of community-based services such as online and face-to-face support groups as well as a national helpline. Develop resources for carers, particularly young carers who are supporting people with pain, recognising their role in health settings and connecting them to support groups and services.

# NATIONAL STRATEGIC ACTION PLAN FOR PAIN MANAGEMENT WORKSHOP

Painaustralia hosted a stakeholder workshop on 27 September 2018 in Canberra to review progress in developing the National Strategic Action Plan for Pain Management and reach consensus on Action Plan priorities.

The workshop was facilitated by national ABC medical journalist, Sophie Scott and strategist, Rosie Yeo and brought together clinicians, multidisciplinary health practitioners, key groups with interests in rural health, palliative care and other experts. A consumer representative nominated by CHF also attended. A full list of participants is attached

This Workshop built on the outcomes from a Stakeholder Roundtable hosted by Painaustralia in June 2018 with eminent health experts to stocktake progress since the 2010 National Pain Strategy and assess and prioritise core components for the development of the Action Plan.

This Roundtable agreed that the National Pain Strategy sets out a clear framework for best practice pain management, provides the guiding principles for the Action Plan and noted progress in a more skilled health workforce and improvement in the quality of pain services. It determined much more needs to be done to inform consumers, expand access to interdisciplinary care and understand pain and its treatment through better supported and connected research.

The National Action Plan contains 52 recommended actions. The agreed top 10 consensus priorities are outlined in the table below.

PRIO	RITY
1	Establish the <b>National Pain Leadership Group</b> to inform and support the Minister for Health on the delivery and ongoing evaluation of the Action Plan and the national adoption and delivery of the 2010 National Pain Strategy.
2	<b>COAG Health Ministers to endorse the National Strategic Action Plan on Pain</b> to deliver the goals of the 2010 National Pain Strategy.
3	Fund and implement a <b>community awareness campaign</b> on pain and pain management treatment and support options, with materials and messages developed in partnership with consumers, health professionals and community groups.
4	Build an <b>interactive and comprehensive national website and app</b> for consumers, carers and health practitioners – a 'one stop shop' providing a gateway for best practice evidence-based pain education and information in Australia.
5	Include pain assessment, reassessment and management principles in accreditation standards for hospitals, hospices, residential aged care facilities and community nursing regulated by the Australian Commission on Safety and Quality in Health Care.
6	<b>Establish a new National Institute of Pain Research.</b> This body would link key partners and work across institutional and geographical boundaries to develop a pain research strategy (similar to the National Institute of Dementia Research model).
7	Develop an <b>overarching education strategy</b> to promote evidence-based, pain management education across health practitioner disciplines, through undergraduate, postgraduate and continuing education.
8	Map and review pain services by location in collaboration with states and territories, Primary Health Networks and consumers to identify areas of most need and those with limited services.
9	<b>Recognise pain as a complex condition in its own right for the purposes of a Medicare-</b> <b>supported pain management plan</b> – with access to 10 individual services and 10 group services per calendar year based on clinical discretion (a similar level of support as the Better Access Mental Health Care program).
10	<b>Determine a single validated assessment and monitoring tool for chronic pain</b> for use by GPs, practice nurses etc. that combines existing best practice assessment techniques and the biopsychosocial approach.

### PROCESS

The Workshop participants considered all recommendations contained within the draft National Action Plan in order to identify the highest priority actions. High priority actions are those which:

- Have a positive impact for consumers
- Will be the most effective investment of effort and resources
- Will ensure that consumers and carers are given a strong voice
- Are evidence-based
- Can be widely supported and endorsed.

#### **ROUNDTABLE PARTICIPANTS**

#### PARTICIPANT

- Ms Carol Bennett CEO, Painaustralia
- Mr Bob Buckham Manager Strategic Policy, Pharmaceutical Society of Australia
- **Dr Meredith Craigie** Dean, Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists
- Mr Matt Croger Representative, Australia Physiotherapy Association
- Mr Mark Diamond CEO, National Rural Health Alliance
- Dr Chris Hayes Director, Painaustralia
- Ms Fiona Hodson President, Australian Pain Society
- Assoc. Prof Malcolm Hogg Director, Painaustralia
- Dr Simon Holliday Representative, Royal Australian College of General Practitioners
- Dr Graeme Killer AO Director, Painaustralia
- Dr Frank New Representative, Royal Australian and New Zealand College of Psychiatrists
- **Dr Grant Pegg** A/g Head, Pharmacovigilance and Special Access Branch, Therapeutic Goods Administration
- Ms Kate Reed Nurse Practitioner Clinical Advisor, Palliative Care Australia
- Mr Robert Regan Chairman, Painaustralia
- **Assoc. Prof Adrian Reynolds** Past President, Australasian Chapter of Addiction Medicine, Royal Australasian College of Physicians
- Ms Elizabeth Robinson Consumer Representative, Consumers Health Forum
- **Mr Kevin Thompson** Assistant Director, Chronic Disease Policy Section, Department of Health **APOLOGIES**
- Ms Sue Elderton National Policy Manager, Carers Australia
- Dr Richard Kwiatek Representative, Australian Rheumatology Association
- Ms Jacinta McDonald Director, Chronic Disease Policy Section, Department of Health
- Adj Prof John Skerritt Deputy Secretary, Health Products Regulation Group, Department of Health

#### **OBSERVERS**

- Ms Louise Moes Director Policy and Engagement, Painaustralia
- Ms Priyanka Rai Policy and Communications Manager, Painaustralia

#### FACILITATORS

- Ms Sophie Scott National Medical Reporter, ABC
- Ms Rosie Yeo Director, Public Affairs Network Pty Ltd

# ONE ON ONE DISCUSSIONS

Painaustralia also held one on one discussions with key organisations and individuals to discuss the priorities in pain management to inform the Action Plan, including:

- Arthritis Australia
- Australian Pain Society
- Australian Pain Management Association
- Australian Physiotherapy Association
- Brain Foundation
- Carers Australia
- Chronic Pain Australia
- Faculty of Pain Medicine, Australian and New Zealand College of Anaesthetists
- Institute of Bone and Joint Research, University of Sydney
- MS Australia

# STOCKTAKE OF PAIN MANAGEMENT ACTIVITIES

Painaustralia consulted widely with States and Territories, Primary Health Networks and medical colleges to bring together the stocktake of activities that are taking place to provide pain management services.

The stocktake found that while various states and territories have made policy decisions in response to the 2010 National Pain Strategy, it has been 'ad hoc' rather than a consistent national approach. Specific pain management plans or strategies have been developed in NSW, Queensland and SA. These include additional investments in pain services, information sharing and websites, benchmarking of pain services and the development of models of care that improve access to integrated services and align with the 2010 National Pain Strategy.

Some Primary Health Networks have also made pain a priority, with a focus on integrating pain services through online portals at point of care to equip health practitioners with resources and referral pathways. PHNs have also supported professional development, education and training modules including in regional areas, outreach pain services in regional and remote areas and increasing skills in pain management at the primary care level in regional settings.

The pain sector is well supported by the Faculty of Pain Medicine, the Australian Pain Society and the Pain Management Research Institute that each provide specific activities to strengthen clinical practice, education and research. Pain medicine is an independent medical speciality and our education and research programs are internationally recognised.

This stocktake highlights that further work and initiatives are required to address the issues of locational disadvantage in accessing pain management, the need for data and better understanding of the prevalence of pain and the proximity to specialist services and the important link between pain management and quality of use of medicines.

It highlights the urgent need for an Australia-wide, strategic policy response to pain that is coordinated at a national level, that recognises the disparate responses to pain across the country and brings forward the opportunity for wholesale adoption of best practice models of care. The development of a central information hub to drive nationally consistent messaging and access to best practice information is critical for practitioners and the community.

The complete findings of the stocktake are available in a separate companion document.