

## INFORMATION FOR PARTICIPANTS

### Chronic Pain Australia: National Pain Survey

Chronic Pain Australia invites you to take part in an online survey to better understand the experiences of people living with pain and those who care for them. The survey will ask you about your experiences living with pain, and the awareness, accessibility and affordability issues associated with pain. This information sheet tells you what taking part involves and will help you to decide if you want to take part.

#### What is the project about?

The purpose of the survey is to explore your experiences living with pain, whether you experience pain yourself or you care for someone who does. Understanding this experience can help Chronic Pain Australia (CPA) inform various stakeholder audiences, help determine advocacy topics and the direction of consumer-led research.

#### Where is the project being done?

The National Pain Survey is an online survey conducted through REDCap.

The National Pain Survey is led by the CPA Board of Directors, in particular Ms Nicolette Ellis (President), Ms Fiona Hodson (Vice President) and Dr Katherine Brain (Secretary).

#### Who can participate in the project?

This project is suitable for:

- Adults (aged 18 years and over) living in Australia who lives with chronic pain
- Adults (≥ 18 years) living in Australia who cares for someone aged 18 years and over and experiences chronic pain

#### What choice do you have?

Participation in this study is voluntary. You do not have to take part. If you do take part, you can stop or withdraw from the survey, at any time without giving a reason. Once you complete and submit the survey, your responses cannot be withdrawn because your response is anonymous.

#### What would you be asked to do if you agree to participate?

If you agree to participate in this project, you will be asked to complete an online (approx. 20 minutes). The questions will ask you about your experiences living with pain or caring for someone who does, the stigma associated with chronic pain and the awareness, accessibility and affordability issues associated with pain.

#### What are the risks of participating?

Some questions are sensitive. If you feel uncomfortable you can skip questions and/or stop at any time. You can also contact Lifeline on 131 114 or PainLink on 1300 340 357 if you want to seek further support regarding any of the issues raised.

**What are the benefits of participating?**

Understanding the experiences, wants and needs of people living with pain and those who care for them will help CPA to accumulate meaningful and consumer informed understanding of topical issues. This will inform CPA's activities, stakeholder engagement, advocacy topics and research direction. While we intend that this survey will improve awareness, advocacy and treatment options for chronic pain in the future, it will not be of direct benefit to you.

**Will the project cost you anything?**

Participation in this study will not cost you anything, nor will you be paid.

**How will your privacy be protected?**

The survey is anonymous so we will not be able to identify you when reviewing your survey response. Your response will be treated confidentially.

You can choose to leave your contact details for media purposes. This is optional and if you choose to provide this information it will be separated from your response and securely stored separately so your survey response remains anonymous. This will be done by one of the three Board members listed in this information statement.

The survey results will be published in a report by CPA and may be presented at a conference or in a scientific publication, but individual participants will not be identifiable in such publications or presentations.

All participant's personal information will be accessed, used and stored in accordance with Commonwealth Privacy Laws, NSW Privacy and Personal Information Protection Act 1998 and the NSW Privacy and Personal Information Protection Regulation 2019. The online survey software is REDCap, a secure online data management tool, hosted by Hunter Medical Research Institute. REDCap can only be accessed by registered users and is password protected.

**Further Information**

If you would like to know more at any stage, please feel free to contact CPA via [national.office@chronicpinaustralia.org.au](mailto:national.office@chronicpinaustralia.org.au)

This information statement is for you to keep. Thank you for considering this invitation.



Nicolette Ellis (CPA President)

**Complaints about this research****Ethics:**

This research has been approved by the Hunter New England Human Research Ethics Committee of Hunter New England Local Health District, Reference 2023/ETH00640.

**Complaints about this research:**

Should you have concerns about your rights as a participant in this research, or you have a complaint about the manner in which the research is conducted, it may be given to the researcher, or, if an independent person is preferred, please contact the HNE Research Office, Hunter New England Local Health District, Level 3, POD, HMRI, Lot 1 Kookaburra Circuit, New Lambton Heights NSW 2305. Telephone: 02 4921 4140. Email: [HNELHD-ResearchOffice@health.nsw.gov.au](mailto:HNELHD-ResearchOffice@health.nsw.gov.au) and quote the reference number 2023/ETH00604.

