Participant Information Statement

People with lived experience of blood pressure measurement and/or management

Research study: Co-designing a Consumer-Based Blood Pressure Toolkit

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1. What is this study about?

This study aims to design a blood pressure (BP) Toolkit to support people to manage their blood pressure. The 'BP Toolkit' aims to support people in measuring blood pressure and provide practical advice on how to interpret blood pressure readings and take action to manage blood pressure. The BP Toolkit will be co-designed with people who have lived experience of blood pressure management and primary healthcare practitioners. This process will ensure that the BP Toolkit meets the needs of everyone who will use it.

It is your choice to participate in this study. You will not be disadvantaged if you choose not to take part.

2. Who is running this study?

The study is being carried out by the following researchers:

- Dr Niamh Chapman, Senior Research Fellow, School of Health Sciences, University of Sydney.
- Kaylee Slater, Research Fellow, School of Health Sciences, University of Sydney.
- Eleanor Clapham, PhD Candidate, Menzies Institute for Medical Research, University of Tasmania.
- Carol Batt, Consumer Advisor, Menzies Institute for Medical Research, University of Tasmania.
- John Stevens, Consumer Advisor, Menzies Institute for Medical Research, University of Tasmania.
- Associate Professor Carissa Bonner, Research Fellow, Faculty of Medicine and Health, University of Sydney.
- Dr Dean Picone, Senior Research Fellow, School of Health Sciences, University of Sydney.

- Professor Alta Schutte, Co-Chair Australian Cardiovascular Alliance National Hypertension Taskforce, University of New South Wales.

3. Who can take part in the study?

You have been invited to take part in this study because you have lived experience of managing blood pressure. To be eligible to participate in this study you must be over the age of 18 years old, live in Australia, and have **one or more** of the following:

- A diagnosis of high blood pressure by a health professional
- Experience in managing blood pressure for the purpose of informing care (e.g., to inform medication dose)
- Currently taking medication for blood pressure
- Actively measure your blood pressure as part of your health management.

4. What will the study involve for me?

If you decide to take part in this study, you will be asked to:

1. **Use this link** to complete a short online questionnaire to ensure you are eligible to take part in the study.
2. If you are eligible, you can provide your consent to take part in this study using the same link. You will be automatically directed to the consent page after you complete the eligibility questions.
3. Provide your contact information so that the study team can contact you to organise a workshop at a time convenient for you.
4. Complete a short survey containing basic demographic questions. You will be automatically directed to this survey after you provide consent.
5. Attend a 3-hour in-person workshop with up to 15 people who have experience managing their blood pressure. The workshop will be audio recorded and transcribed verbatim. Field notes will be taken by trained researchers to record contextual factors relevant for analyses.

Please note that completing the online form via the link above does not guarantee you will be able to take part in the workshop. We need a diverse range of people to take part in the workshops to help design the BP Toolkit so that it can meet the needs of many different people. A member of the research team will contact you to either arrange for you to participate in a workshop or let you know that we have reached capacity for participants.

Using the link provided we will collect your consent, your contact information and basic demographic information (such as your age, gender, postcode) and your experience in managing your blood pressure. During the workshop you will be asked to discuss your

opinions and relevant experiences to assist the design of the proposed BP Toolkit. Topics discussed might include:

- How you prefer to learn about health topics.
- Where you prefer to access health information.
- What information is important to you when measuring and/or managing blood pressure.
- Feedback on the draft BP Toolkit.

5. Can I withdraw once I have started?

Being in this study is completely voluntary and you do not have to take part. Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.

If you choose to take part in the study, but then change your mind, you are free to withdraw from the study prior to data-analysis. To withdraw from the study please contact a study staff member using the contact details provided below. If you choose to withdraw, we will stop collecting information from you, however once data is de-identified and data analysis has been completed, you will no longer be able to withdraw your data from the study.

6. Are there any risks or costs?

Aside from giving up your time, we do not expect that there will be any risks or costs associated with taking part in this study.

7. Are there any benefits?

You will be reimbursed for any expenses related to taking part in the study in the form of an electronic money gift card.

8. What will happen to information that is collected?

By providing your consent, you are agreeing to us collecting information from or about you for the purposes of this study. All information collected within this study will be confidential and secure. All data will be stored electronically on secure University of Sydney databases within Australia (no data will be stored in hard copies). Only approved researchers will be able to access the data. All identifiable data will be stored in the secure databases. Identifiable data will be de-identified during the analysis processes and when included in published content.

The data collected for this study will only be used for research approved by an ethics committee. The results will be published in academic journals and presented at scientific conferences. We will also share the results with people who take part and community organisations to support people to access and use the BP Toolkit to manage their blood pressure. You will not be individually identifiable in the dissemination of the results.

We will use Zoom to transcribe workshops. This will involve sharing your information with Zoom. We will not share this information with anyone else without your consent unless we are required to do so by law. Zoom is owned by Zoom Video Communications Inc. and is located in San Jose, California, US.

We will store this information and dispose of it securely following the University's Recordkeeping Policy. For more details about how your information will be handled please see the University's privacy webpage. Sharing research data is important for advancing knowledge and innovation. A de-identified set of the data collected in this study may be made available for use in future research.

9. Will I be told the results of the study?

If you have any questions or concerns about the responses, you have provided at any time during the study please contact a team member by using the contact details provided below. You have the right to receive feedback about the overall results of this study. During the consent process, you will have the opportunity to choose whether you wish to receive a summary of the results at the end of the study. This feedback will be in the form of a brief summary sent via email.

10. What if I would like more information?

When you have read this information, the following researcher(s) will be available to discuss it with you further and answer any questions you may have:

- Dr Niamh Chapman, Senior Research Fellow, School of Health Sciences, University of Sydney. **Niamh.Chapman@sydney.edu.au**

11. What if I have a complaint or any concerns?

The ethical aspects of this study have been approved by the Human Research Ethics Committee (HREC) of The University of Sydney [ethics reference: 2024/HE000528] according to the National Statement on Ethical Conduct in Human Research.

If you are concerned about the way this study is being conducted or wish to make a complaint to someone independent from the study, please contact the University:

Human Ethics Manager
human.ethics@sydney.edu.au
+61 2 8627 8176.

This information sheet is for you to keep