

Exploring the lived experience of people with cerebrospinal fluid (CSF) leak in Australia and New Zealand



People aged 18 years or older, with a diagnosis of spinal CSF leak and have undergone treatment in Australia and New Zealand, are invited to participate in a research study to understand the experiences of people with CSF leak in Australia and New Zealand.

Detailed information regarding the purpose of the study and what is involved for participants can be found in the Plain Language Statement, which is accessible via the QR code/link below.

There are two phases of the study. You can participate in one or both phases:



- **Phase 1:** An anonymous survey to understand the symptoms, diagnosis, treatment, and current impact of CSF leak. The survey takes approximately 60 minutes and is conducted online. At completion of the survey, if you opt-in to provide your contact details for a giftcard, your survey responses will no longer be anonymous.
- **Phase 2:** A one-to-one interview to understand the experiences and challenges, disability and effects on quality of life, and resources/support/information when seeking CSF leak diagnosis and treatment. The interview will take no more than 1.5 hours and is conducted on Zoom or phone, and recorded for transcription purposes.

If you are interested in participating in the survey (Phase 1 of the study), please scan the QR code or go to go.unimelb.edu.au/p6jp to:

- (1) read the Plain Language Statement,
- (2) read the Survey Consent Form, and
- (3) explicitly confirm your consent before entering the survey



At the end of the survey, if you are interested in being contacted for a potential one-to-one interview (Phase 2 of the study), you can leave your name and email address.

Please note that your participation in any part of this study is entirely voluntary. Your decision to participate, or not participate, will not affect your clinical care or the way you are treated by any person or organisation in any way.

If you have any questions about the study, please contact Dr Bao Nguyen, Department of Optometry and Vision Sciences, The University of Melbourne on (03) 9035 8553 or email bnguyen@unimelb.edu.au