

AUSTRALIAN HEADACHE EPIDEMIOLOGY DATA



Australian Headache Epidemiology Data

Annual report

January 2023

This research has been made possible through grants from:



On behalf of the AHEAD researchers, we'd like to sincerely thank you for supporting this pilot headache epidemiology study.

This document contains an update on our study activities for 2022.

We look forward to sharing the outcomes of this important study in due course.

Best wishes,

Dr Emma Foster and Professor Alessandro Zagami,
Lead investigators of the AHEAD study.

Our team

At the commencement of the study, we formed an expert multidisciplinary team from Australia consisting of pre-eminent researchers in the field of Headache Medicine, Epidemiology, and Public Health. Our team consists of the following members:

Senior neurologists

Dr Emma Foster PhD FRACP, committee member of the Australian and New Zealand Headache Society, Neurologist specialising in Headache Medicine, and Early Career Researcher developing expertise in health economics and outcomes research.

<https://research.monash.edu/en/persons/emma-foster>

Associate Professor Alessandro Zagami MBBS, MD, FRACP, inaugural President of the Australian and New Zealand Headache Society, Neurologist, with extensive clinical and research experience in the field of Headache Medicine.

<https://brainsciences.unsw.edu.au/people/associate-professor-alessandro-zagami>

Dr Elspeth Hutton PhD FRACP, president-elect of the Australian and New Zealand Headache Society, Head of The Alfred Headache Service, Neurologist, with extensive clinical and research experience in the field of Headache Medicine.

<https://research.monash.edu/en/persons/elspeth-hutton>

Senior research coordinator

Ms Christine Cormack, Senior Research Coordinator has extensive experience in Neurological Diseases clinical trials.

Senior biostatistician

Dr Zhibin (Ben) Chen CStat PhD, Neuroscientist, Chartered Statistician (Royal Statistical Society, UK), NHMRC Public Health Early Career Fellow at Monash University, with expertise in outcomes research, statistical modelling, epidemiology, and health economics with a specific focus on neurological diseases.

<https://research.monash.edu/en/persons/ben-chen>

Senior health economist

Associate Professor Zanfina Ademi MPH PhD, Lead Health Economist with Epidemiology and Public Health expertise, specialising in economic evaluations alongside clinical registries to support decision modelling.

<https://research.monash.edu/en/persons/zanfina-ademi-delaney>

Consumer advocate and Senior researcher

Professor Claire Wakefield MPH PhD, Professor at the School of Women's and Children's Health at UNSW, Director of the Behavioural Sciences Unit at Sydney Children's Hospital, Co-Director of the Kids to Adults Chronic Illness Alliance, and Continental President (Oceania) for the International Society for Paediatric Oncology. Professor Wakefield provides invaluable insights to the AHEAD study from the perspective of someone with lived experience of migraine. In addition, Professor Wakefield contributes immense expertise as a senior researcher herself, leading studies to improve quality of life for people living with illness.

<https://research.unsw.edu.au/people/professor-claire-elizabeth-wakefield>

International collaboration

We have sought expert input for this study from international collaborator, Professor Timothy Steiner BSc PhD MBS LLM MA MSc DIC MRCP FFPM. He is past-President of the European Headache Federation and past-General Secretary of the International Headache Society, and has worked in the field of headache medicine for 40 years with his principal research interests relating to public health aspects of headache. Professor Steiner is the Director of the Global Campaign Against Headache that operates in official relations with the World Health Organization. The Global Campaign designed the self-report Headache-Attributed Restriction, Disability, Social Handicap and Impaired Participation (HARDSHIP) questionnaire, on which our study questionnaire is based. He has provided expert oversight regarding our study methodology.

<https://ihs-headache.org/people/timothy-j-steiner/>

Presentations

Australian and New Zealand Headache Society Annual Scientific Meeting – Platform Presentation (November 2022)

Study materials

Study questionnaire

Our team has met frequently over 2022 to ensure the study questionnaire will fulfil our aims for closing the largest knowledge in Australian headache medicine, by collecting prevalence, burden, and treatment gap data. Our questionnaire will follow the Headache-Attributed Restriction, Disability and Impaired Participation (HARDSHIP) questionnaire designed by expert consensus and used in >20 countries. This is the best-established instrument worldwide for capturing population prevalence of migraine and medication overuse headache. In addition, after extensive consultation, the internationally validated generic health-related quality of life instrument, EQ5D, will be used to enable direct comparison between migraine, medication overuse headache, and other conditions.

The questionnaire has been prepared in printed and electronic formats.

Researchers have conducted semi-structured interviews with people with lived experience with migraine to ensure optimal wording and layout of the questionnaire in both hard-copy and electronic formats.

Study website

The official webpage is hosted by Monash University, and may be viewed at: <https://www.monash.edu/ahead-study>

It presents a written summary of the study. A study timeline will be displayed once the questionnaires are mailed out, and people may 'track' the study's progress. A summary of findings will be made available on the website once they are available.

Study logo

To enhance visibility and recognition of this study, Monash University researcher Ms Kathryn Kallady has gifted the creation of a study logo. This is displayed on the front of this document, and on AHEAD study materials. Ms Kallady is an educational & developmental psychologist, and a talented illustrator and graphic designer with a focus on supporting neurosciences communication. Further details regarding her illustrative work can be found at: <http://www.psykallady.com> and @psych.babble.bobble on instagram.

Study YouTube

A brief YouTube 'explainer' video has been created to describe the study aims. This will appear on the study landing page of the electronic questionnaire and on the study webpage. It can be viewed here: <https://youtu.be/x05WY5NJGO0>

Study timeline

Please find below an updated study timeline. Several milestones were slightly delayed in 2022, as we widely consulted national and international experts in public health and epidemiology research to ensure we have the best possible questionnaire, methodology, and statistical analysis plan for meeting our study aims.

Milestone	Achieved	If no, date to be completed
Formation of AHEAD national study team	Yes	
Compilation of study questionnaire, including formal permissions from Lifting the Burden and EuroQol groups to use HARSHIP and EQ-5D instruments	Yes	
Semi-structured interviews with consumers to inform questionnaire layout and formatting	Yes	
Finalisation of hard-copy questionnaire	Yes	
Finalisation of electronic REDCap questionnaire	Yes	
Creation of study webpage	Yes	
Creation of study YouTube	Yes	
Statistical analysis plan for selection of addresses to meet study aims	Yes	
Secure mailing house for printing and mailout of questionnaires	Yes	
All necessary ethics and governance approvals	Yes	
Random selection of 20,000 residential addresses to ensure proportionate representation from households across VIC and NSW, based on population in each local government area	Yes	
Preparation of methodology manuscript for presentation	Underway	Late January 2023
Printing of questionnaires, study introductory letters, study envelopes		Mid-January 2023
Mail out		Early-mid February 2023
Closing date for return of questionnaires		31 March 2023
Received completed questionnaires		Mid-April 2023
Entering data from hard-copy questionnaires		Mid-April to mid-July 2023
Cleaning data and statistical analysis		From mid-July to mid-August 2023
Preparation of results manuscript for publication		August-September 2023
Preparation for national study mailout		September 2023

Once again, we would like to sincerely thank you for your support for this important study.