

PLAIN LANGUAGE STATEMENT



Plain Language Statement

Date: 10/11/2025

Full Project Title: Healthcare Experiences of People with Multiple Sclerosis or Inflammatory Bowel Disease in Australia

Principal Researcher: Dr Lisa Grech

Graduate Researcher: Miss Connie Janiszewski

Associate Researchers: Prof Antonina Mikocka-Walus; Dr Catherine Emerson; Dr Subhadra Evans; Dr David Skvarc; Dr Kate Kloot; Assoc Prof Simon Knowles; Ms Amy Skiller

This Plain Language Statement provides information about this research project.

Its purpose is to explain what is involved in clear and simple terms, so you can decide whether you would like to take part.

Please read carefully and contact the research team if you have any questions (contact details are provided below).

We also suggest downloading and saving a copy of this Plain Language Statement for your records.

What is the purpose of this research project?

We are conducting a research project to explore the healthcare experiences of people with multiple sclerosis (MS) or inflammatory bowel disease (IBD), with a focus on experiences of diagnosis and management within the Australian healthcare system.

This research project is conducted by researchers with lived experience of MS or IBD and was co-designed with a Lived Experience Advisory Committee to ensure it reflects the priorities of people with MS and IBD.

Who can take part in this research project?

This research project is open to adults aged 18 years and over who have a confirmed diagnosis of MS or IBD and have accessed the Australian healthcare system for diagnosis or management.

What does the research project involve?

If you decide to take part, you will first complete an online survey to check your eligibility. The survey will ask a few basic questions about your demographic and health information and should take about 10 minutes to complete. By submitting the survey, you agree to take part and allow the research team to view your responses. If you prefer, you can choose to answer these questions over the phone.

If you are eligible, the graduate researcher will contact you and ask you to provide documentation to confirm your identity and diagnosis (for example, a referral letter, a prescription, or a test result). This does not need to be recent, and you may remove any sensitive information you do not wish to share. The graduate researcher will review the document for confirmation only; it will not be stored.

You will then be invited to take part in an online interview, which will take about one hour. The demands, risks, and potential benefits described in this Plain Language Statement will be explained again. If you agree to take part, you will be asked to give verbal consent at the beginning of the interview. The interview will focus on your healthcare experiences, including your interactions with healthcare professionals during diagnosis and management. You will receive a brief overview of what the interview will cover beforehand (reading this is optional).

The interview will take place via Zoom using a secure, password-protected connection, and you will be asked to have your camera turned on. The interview will be audio and video recorded (although the video recording will be deleted immediately and not stored) and transcribed.

After the interview, you will receive a short summary of what was discussed so you can confirm that your views have been accurately represented. You may also share any additional healthcare experiences if you wish. Providing feedback or additional information is optional.

What are the risks of taking part in this research project?

Reflecting on your healthcare experiences may sometimes feel uncomfortable or upsetting.

If you become distressed, the graduate researcher can contact a registered psychologist on the research team, who can provide guidance on appropriate support options. You are also encouraged to speak with your general practitioner, who can refer you to specialists such as psychologists or psychiatrists.

If you need further support, you can contact:

- Lifeline on 13 11 14 (available any time)
- MS Plus on 1800 042 138 (available Monday to Friday, 8:30am to 5:00pm)
- Crohn's & Colitis Australia Helpline on 1800 138 029 (available Monday to Friday, 9:00am to 5:00pm)
- If you are in immediate danger, call 000.

What are the benefits of taking part in this research project?

You may not experience direct personal benefit from taking part in the research project, but your participation will help improve understanding of healthcare experiences and may contribute to future improvements in healthcare in Australia.

If you take part in an interview, you will receive a \$50 Prezzy digital gift card via email to thank you for your time and contribution. To provide this gift card, your name and email address will be shared with Prezzy and managed in accordance with their privacy policy. If you prefer not to share your details with Prezzy, please inform the research team to discuss alternative reimbursement options.

What will happen to the information collected about me?

All research data will be stored electronically in Deakin University's secure Research Data Store, and only the research team will have access.

Your contact details from the online survey will be stored separately in a password-protected file and will be permanently deleted once all communication related to the project is complete.

A separate, password-protected file will link your contact details to your participant code. This file will be permanently deleted once you confirm your interview summary, or if you do not reply to that email within one week.

Although the interview will be audio and video recorded, only the audio recording will be securely stored until it has been transcribed by Zoom and verified by the researcher, after which it will be permanently deleted. The video recording will be deleted immediately and will not be stored. A back-up audio recording will also be made but will be deleted immediately and not stored.

Information you provide in the interview will be de-identified (your name and personal details removed) before the transcript is stored.

The de-identified interview transcript will be used to generate a short summary of your interview using the AI Assistant in NVivo 15, which does not retain data. The transcript will then be analysed by the researcher.

De-identified information may be used in a future research project, subject to ethics approval, to develop a scale measuring healthcare experiences.

All research materials will be kept for eight years and then securely destroyed in accordance with Deakin University's policies.

Will I be told the results of this research project?

You can choose to receive a plain language summary of the research findings. You can indicate this preference in the online survey, and the summary will be emailed to you once it is available.

The project findings may also be published in academic journals and presented at conferences. You will not be personally identified in any publications or presentations.

Can I withdraw from the research project?

Your participation is voluntary. Choosing not to take part, or deciding to withdraw later, will not affect your relationship with the research team or Deakin University.

You can withdraw from the research project at any time before you confirm the short summary of your interview by contacting the graduate researcher. If you withdraw before this point, any data collected will be securely destroyed. However, once you have confirmed the summary, or if you do not reply to that email within one week, withdrawal will no longer be possible because your interview will have been included in the analysis and your information will no longer be identifiable.

Who is conducting this research project?

This research project is being conducted by Miss Connie Janiszewski as part of a Doctor of Philosophy (PhD) degree. The researcher is supported by a Research Training Program Scholarship funded by the Australian Government.

The project is being carried out by the following researchers:

- Miss Connie Janiszewski, Graduate Researcher, Faculty of Health, School of Psychology, Deakin University
- Dr Lisa Grech, Senior Research Fellow, Faculty of Health, School of Psychology, Deakin University
- Prof Antonina Mikocka-Walus, Deputy Head of School, Faculty of Health, School of Psychology, Deakin University
- Dr Catherine Emerson, Associate Lecturer, Faculty of Health, School of Psychology, Deakin University
- Dr Subhadra Evans, Associate Professor, Faculty of Health, School of Psychology, Deakin University
- Dr David Skvarc, Senior Lecturer, Faculty of Health, School of Psychology, Deakin University

- Dr Kate Kloot, Senior Lecturer, Faculty of Health, School of Medicine, Deakin University
- Assoc Prof Simon Knowles, Associate Professor, School of Health Sciences, Department of Psychological Sciences, Swinburne University of Technology
- Ms Amy Skiller, Lecturer, Faculty of Health, School of Nursing and Midwifery, Deakin University.

What if I would like more information?

If you have any questions or would like more information, please email healthcare.experiences@deakin.edu.au.

You may also contact the following researchers:

- Miss Connie Janiszewski, s225083108@deakin.edu.au
- Dr Lisa Grech, l.grech@deakin.edu.au.

What if I have a complaint about this research project?

If you have any concerns or complaints about any aspect of the research project, the way it is being conducted, or questions about your rights as a research participant, you may contact:

The Human Research Ethics Office, Deakin University, 221 Burwood Highway, Burwood Victoria 3125, Telephone: 9251 7129, research-ethics@deakin.edu.au.

Please quote project number 2025/HE001228.