THE UNIVERSITY OF AUCKLAND
Te Whare Wānanga o Tāmaki Makaurau
NEW ZEALAND

SCIENCE
SCHOOL OF PSYCHOLOGY/TE KURA MĀTAI HINENGARO

Science Centre, Building 302
2nd Floor, Room 231
23 Symonds Street, Auckland,
New Zealand

Waipapa Taumata Rau/The University of Auckland
Private Bag 92019
Auckland 1142
New Zealand

Participant Information Sheet

Project title: Experiences of Chronic Pelvic Pain
Student researcher: Michaela Callaway
Supervisor: Professor Virginia Braun

Tēnā koe – and thank you for your interest and taking the time to read this information about my project on chronic pelvic pain (CPP) in Aotearoa New Zealand.

Who am I?

My name is Michaela Callaway. I am a Master's student in the School of Psychology at Waipapa Taumata Rau (The University of Auckland). My project is supervised by Professor Virginia Braun, a Pākehā academic who specialises in gender, sexuality, and health.
I have personal experience of CPP, and of seeking and receiving treatment, so I come to this project as an insider – recognising that as a Pākehā (cisgender) woman my experiences are not universal. My research is informed by a concept called reflexivity, which means I consider how my positions affect how I do the research and interpret the stories I hear.

Why this project

This research project seeks to understand and contextualise the experiences of people living with CPP in Aotearoa New Zealand. There is comparatively little understanding of CPP, and until recently seeking diagnosis and healthcare have been often complex and challenging. We need to build up understanding in order to influence health care practices.

Project aims

My aims with this project are to understand and contextualise people's experience of both living with CPP and navigating and receiving healthcare for CPP in Aotearoa New Zealand. I am interested in understanding how CPP affects people in their personal, social, familial, spiritual, sexual, and working lives, how healthcare is understood and experienced, and whether and how people make sense of CPP in terms of disability and living with an invisible chronic illness.

Participation criteria

- You have experienced chronic pelvic pain anywhere below the stomach and into the pelvic area that has been present and persistent (even if it comes and goes) for at least one year.
- You are actively receiving treatment – either medical or alternatives, for chronic pelvic pain.
- You are 18 years or older.
- Live in Aotearoa New Zealand and have received all treatment for chronic pelvic pain in Aotearoa New Zealand.
- You speak conversationally fluent English.

Invitation to participate

If you meet these criteria, I am delighted to invite you to participate in this research! Any participation in this project is voluntary, and upon reading this information sheet and asking any additional questions, you may decline the invitation to participate (you will still be invited to get a copy of the results, should you wish). Please feel free to ask any questions you might have.

Project procedures

Participation in this research project involves taking part in a confidential interview, which will be conducted over Zoom. This interview will be arranged for a time that suits you, and will likely take somewhere between 1-2 hours, maximum.

You will be invited to engage in personal Tikanga protocols, cultural or spiritual practices to open and close the interview space, should you wish.

The conversation will cover a range of experiences and perspectives – listed in the aims above – but will be relaxed and conversational. If the conversation becomes upsetting, you are able to pause, or end, the interview if need be. We also have the provision of stopping the interview and resuming it, at a later point, if need be.

You will also be asked to provide some demographic/health information about yourself, on a short questionnaire. This is so that I have an understanding of the spectrum of people who have been involved in the study.

After your interview I will also supply you with a list of health resources, these include organisations that could prove useful in your journey with CPP, mental health support services and Māori health services.

At the completion of the project a summary of findings will be available, should you wish to receive it. The option to receive a summary will be in a consent form provided to you, if you agree to take part in this research.

Risks and benefits

This project is low-risk and unlikely to result in any harm. For you as a participant, the risks of harm are low, and your privacy and confidentiality are protected through the research processes.

At a societal level, this research will contribute to a very limited but growing field of chronic pelvic pain research in Aotearoa New Zealand and will hopefully help inform better understanding and healthcare practices related to CPP.

I hope you will find discussing your experiences with CPP interesting and useful on a personal level. If you wish to have a copy of the audio/video recording of your interview (for personal reference), you will be able to indicate this on the consent form. I will also offer you a summary of the results of the analysis if you wish to receive it (once the project is completed in about a year or so). I hope this will be a taonga for you, and to share with your loved ones if you wish. The nature of this qualitive research is open and comes from the stories I hear, but we anticipate using a method called *thematic analysis* which is based on developing understandings across everyone’s experiences. This means I cannot anticipate what the analysis will conclude. Given the ‘overall’ focus, your individual experiences may only partially be reflected in the final analysis. Depending on the stories and experiences shared and analytic process, there may be parts of the analysis and conclusions that do not reflect your perspective.

Confidentiality & use of data

Confidentiality is of the upmost importance in this project. The information you choose to share with me will remain confidential (securely stored on a secure University of Auckland network drive, or password protected PC drives, separate from your consent form). Your identity as a participant will be anonymous – this will be achieved by removing or changing details that could make you identifiable from your interview and providing you with a different name – a pseudonym – in quoting anything from you in the analysis. Demographic data will be used in summary form to provide a description of the participant group; broad categories (e.g., age, ethnicity) might be used in reporting quotes, but not in a way which would risk identification.

Quotes from your interview may be included in academic reports, such as my thesis, journal articles and presentations. These will be anonymised, as noted. Slightly longer anonymised sections may also be shared in confidential academic research group sessions.

Right to withdraw

If you do choose to participate, you have the right to withdraw at any time, and not to discuss any particular question, during the interview, without providing any reason. Upon completion of the interview, you will be able to withdraw from the research, or withdraw some of the data you have provided, for up to one month following the interview.

Data storage, retention, destruction, and future use

If you participate in this project, your interview on Zoom will be video & audio recorded. The audio from the recording will be transcribed verbatim into textual data for analysis. I (Michaela) will be the transcriber, ensuring that the data remains confidential to the research team. The audio/video recordings will be securely stored on a password protected computer/on a secure University of Auckland network drive.

The textual data (transcribed interviews) will be anonymised – personal and potentially identifying information changed – before any printing or sharing of segments for consultation during academic research group sessions. The transcription will be the primarily form used for analysis and will be securely stored when not being used for analysis (in hard copy or digital form). Any resulting outputs, such as academic publications or presentations, will only present anonymised short data quotes.

All data will be stored on a password protected computer/on a secure University of Auckland network drive.

Consent forms will be securely stored separately from the data. Data and consent forms will be retained for at least 6 years, and until all interest in the project is completed. When this time is lapsed, all data will be destroyed securely.

Funding

This project is not funded.

Please note
If you are a student of the researcher, we give our assurance that your participation or non-participation in this study will have no effect on your grades or relationship with the University and that you may contact your academic head should you feel that this assurance has not been met.

Thank you for considering participant in this project. Having read this Participant Information Sheet – please get in touch to let me know if you have any queries or things you'd like to discuss; if you already know you'd like to participate; or if you know you *do not* wish to participate. I will follow up in a few days if I haven't heard from you.

For any questions regarding anything in this information sheet or on the project please contact:

Student Researcher:
Michaela Callaway
School of Psychology, The University of Auckland
Email: mcha617@auckland.ac.nz
Phone: 021 2025390

Supervisor
Professor Virginia Braun
School of Psychology, The University of Auckland
Email: v.braun@auckland.ac.nz

The **Head of School of Psychology** is:
Professor Suzanne Purdy
Email: sc.purdy@auckland.ac.nz

For any queries regarding ethical concerns, you may contact:
AHREC Chair contact details: For concerns of an ethical nature, you can contact the Chair of the Auckland Health Research Ethics Committee at ahrec@auckland.ac.nz or at 373 7599 ext 83711, or at Auckland Health Research Ethics Committee, The University of Auckland, Private Bag 92019, Auckland 1142.

Māori cultural support or to lodge a complaint:
If you require Māori cultural support, talk to your whānau in the first instance.
Alternatively, you may contact the administrator for He Kamaka Waiora (Māori Health Team) by telephoning 09 486 8324 ext 2324.
If you have any questions or complaints about the study, you may contact the Auckland and Waitematā District Health Boards Māori Research Committee or Māori Research Advisor by phoning 09 486 8920 ext 3204.

Approved by the Auckland Health Research Ethics Committee on 11/11/2021 for three years. Reference number AH23493.