



Participant Information Sheet (for women)

Study title:	Does patient storytelling enhance empathy in medical students for women’s health care	
Principal investigator:	Name Parimala Kanagasabai Department Obstetrics, Gynaecology and women’s health, UOW Position Research Fellow	Contact phone number: 049185044 aubstory@otago.ac.nz

Introduction

Kia Ora and thank you for showing an interest in this project. Please read this information sheet carefully. Take time to consider and, if you wish, talk with your whānau or friends, before deciding whether or not to participate.

If you decide to participate, we thank you. If you decide not to take part, it will not influence your medical care and we thank you for considering our request.

What is the aim of this research project?

We aim to develop and test a patient storytelling programme for medical students in a women’s health setting. We wish to test and compare two programmes, in-person storytelling and digital (recorded) storytelling.

Who is funding this project?

This research is funded by Otago University Medical Education Research Fund.

Who are we seeking to participate in the project?

We are seeking women over 18 years who have experienced changes in the regularity, frequency, heaviness or duration of blood flow of their normal menstrual pattern (periods). The medical term for this is “abnormal uterine bleeding (AUB)”. Women included could have any of the following symptoms:

1. Heavy menstrual bleeding flow.
2. Prolonged bleeding (>8 days)
3. Infrequent bleeding (>38 days)
4. Frequent bleeding (<24 days)
5. Very light flow or no bleeding.

If you participate, what will you be asked to do?

You will be invited to share your experience of menstrual bleeding as part of a panel/group of 3-4 women. Your story will be shared with a small voluntary group of medical students. The purpose of this is to help medical students understand how this bleeding impacts on you and why you are seeking healthcare. We will see if your story helps guide their understanding of abnormal bleeding.

You could either choose to be part of the in-person storytelling group or the digital storytelling group.

Women belonging to the in-person storytelling group will share stories face to face with medical students. All women will be given an equal opportunity to share their stories (approx 10 mins each).

Women belonging to the digital storytelling group will share their story and it will be recorded using a camera. The stories will be recorded and edited by an internal University videographer. We will seek feedback of edited recorded videos from women. The digital stories will then be played for medical students.

Women can bring their whānau/ support person if they wish to and their comments are welcome during the storytelling session. Māori women who would prefer to share their stories in Te Reo can do this and a Māori researcher will be available to translate the stories into English.

A storytelling guideline for potential storytellers is provided in page 4. Researchers can help you prepare your stories before the research session if you like. A researcher can meet with you (via phone, zoom or in person), discuss your story, go through storytelling guidelines and discuss presenting stories in person or to a camera. A Māori researcher will be available to discuss stories in Te Reo.

After storytelling, you and whānau will be interviewed about your experience of sharing stories and the feasibility (practicality) of conducting this programme for the wider medical students.

Your participation is voluntary. No aspect of your medical care will be affected by either refusal or agreement to participate. There is no expectation of women to participate in ongoing or regular student teaching.

You will be provided with a voucher of \$50 in appreciation of your participation. We will reimburse parking expenses. Refreshments and kai will be provided after the sessions.

Is there any risk of discomfort or harm from participation?

You may feel distressed while sharing your stories. You can pause, stop and return or withdraw if you wish to at anytime. A gynaecologist is available if you wish to discuss your health concerns with them. We are able to arrange a taxi home if required.

Māori women concerned about their health condition can also contact Mana Wāhine. Contact: Tira Albert. Address: Kokiri Marae 7-9 Barnes St, Seaview, Lower Hutt 5014. Ph: 04 920 1460.

What data or information will be collected, and how will they be used?

Personal information such as age, ethnicity, type and duration of period problem and contact details will be collected. We will record stories of women in the digital panel for playing it to the students. The interview session will also be recorded. The personal information, digital stories and interview recordings will be deleted after the research is complete. Data arising from the study will be stored for a period of 10 years.

For any women interested in future studies, we will store their personal contact details if they consent to this.

What about anonymity and confidentiality?

Women in the digital panel will have the opportunity to review the recording before playing it to the students. An internal University videographer will have access to the video recorded stories only for the purpose of editing the recordings.

Only the small number of researchers will have access to your personal information, recorded digital stories and interviews. The data will be securely stored in a password protected computer at the Department. Any personal identifying information will remain confidential between participants and the researchers. It will not appear in any spoken or written report of the study.

If you agree to participate, can you withdraw later?

You may withdraw from participation in the project anytime before its completion.

Any questions?

If you have any questions now or in the future, please feel free to contact either:

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Name Rebecca Grainger Position Associate Professor Department Medicine, UOW	Contact: rebecca.grainger@otago.ac.nz
Name Judy Ormandy Position Senior lecturer Department Obstetrics, Gynaecology and women's health, UOW	Contact: 04 918 6858

Please let us know if you would like to talk to a Māori researcher and Ms Karleigh O Connor will contact you and communicate in Te Reo.

This study has been approved by the University of Otago Human Ethics Committee (Health). If you have any concerns about the ethical conduct of the research you may contact the Committee through the Human Ethics Committee Administrator (phone +64 3 479 8256 or email gary.witte@otago.ac.nz). Any issues you raise will be treated in confidence and investigated and you will be informed of the outcome.

Storytelling guideline

1. The goal of storytelling is to promote empathy and understanding towards experience of women living with period problems.
2. Please share your feelings of living with period problems.
3. Please use “I” statements and first person language.
4. You may use these outlines in your stories:
 - a) How and when did your period problems start? Did you discuss it with family or friends?
 - b) What impact have your periods had on your day to day life? E.g home life, work, relationships, socially? How does this make you feel?
 - c) How was your experience with health care providers (GP) and how did you feel? You may talk broadly about impact of your spiritual-religious beliefs, values and historical factors such as migration, colonisation, racism and marginalisation on your engagement with health practitioners.
5. You may focus on one event or incident that had a major impact on you.
6. You may use notes/ scripts for your storytelling session.
7. You may choose what health information you use in your storytelling and choose not to reveal some details.
8. You may include a concluding message to students that summarises your feelings of living with period problems.
9. Storytelling is emotionally challenging and it is normal to have surfacing emotions. You may pause, stop and return or withdraw if you wish to at anytime.