

PARTICIPANT INFORMATION SHEET

PROJECT TITLE: The Language of Pelvic Pain in Women

HUMAN RESEARCH ETHICS COMMITTEE APPROVAL NUMBER: H-2017-100

PRINCIPAL INVESTIGATOR: Dr Susan Evans

Dear Participant,

We would like to invite you to participate in a research project into the language of pelvic pain in women.

What is pelvic pain?

Pelvic pain is pain felt in the pelvis, the part of your abdomen below your belly button. This project focuses on pelvic pain in women. Pelvic pain affects about 10% of all women, and has many different causes. Despite being common, it is still not well understood by health professionals or the wider community.

Why study the language of pelvic pain?

Language is the key means for communicating and understanding pain for both health professionals, patients and the community.

What do we hope to achieve?

Have you ever felt your doctor, family, or friends just didn't understand you when you tried to describe your pain? We'd like to change that. This project studies the words and language that women use when they talk about their pelvic pain. We'll use the results to help health professionals and your communities understand women just like you and your pelvic pain better. The project will also help people who've never experienced pelvic pain know what it means. Your help with this survey has the potential to make a difference to women with pelvic pain just like you.

Who is undertaking the project?

This project is being conducted by: Gynaecologist and Pain Specialist Dr Susan Evans; Emeritus Professor of Applied Language Studies Roland Sussex; and Medical Student Ms Eleanor Schofield.

Why am I being invited to participate?

We are looking for women in Australia and New Zealand, aged 18 years or older, that we can learn from. We'd like you to tell us in your own words about your pelvic pain and your pain experiences. We will use computer software to analyse the information we receive from you and other women to learn more about the language of pelvic pain, how it helps us to understand pelvic pain, and how it helps health care professionals to diagnose and manage pelvic pain.

What will I be asked to do?

You will be asked to complete this online survey with 3 sections:

- Introductory questions about yourself, your pain with periods, any other pelvic pains, and pain you may have with sexual activity. This helps us learn more about you and your medical history. There are text boxes so that you can write short notes about aspects of your pain, what it is like, and what it means to you. Please do use these text boxes to tell us the details of your pain and your experiences.

- A writing section, where we ask you to write more fully about your pain in your own words. We'd like you to describe the pain, what it feels like, when you get it, what makes it better, what makes it worse, your experiences describing it to other people, the experience of the pain itself, and the impact that pelvic pain has had on your life, and on the lives of those around you. In this section, please write as much as you can, or choose to. The fuller the information that you give us, the better we will be able to understand your pain and how it affects you and your life.
- A short depression and anxiety rating scale, to see if your mood or anxiety affects the way you describe and talk about your pain.

How much time will the project take?

The questionnaire should take about 20-30 minutes to complete.

Are there any risks associated with participating in this project?

There is a small risk that answering questions about your pelvic pain may be distressing to you. Contact information for organisations that can help you with pelvic pain, anxiety, depression or sexual abuse is provided at the end of the survey.

What are the benefits of the research project?

There are no direct benefits to you as the participant. However, this research aims to improve the knowledge and awareness of how women describe pelvic pain in Australia and New Zealand, and to use that knowledge to improve treatment. To do that we need to enhance communication between women and their health care providers, and we need your help.

Can I withdraw from the project?

Participation in this project is voluntary. Data entered into the survey is anonymous even to the investigators, and so once submitted will not be able to be withdrawn from the survey.

What will happen to my information?

Data collected from this project will be kept on a computer in a secure password-protected file and can be seen only by the investigators on this project. The data that you provide in the survey will be anonymous, so there is no way that you can be identified except by the investigators themselves. Your data will only be identified by a code number.

In the survey you will also be offered the chance to collaborate further with this investigation. In this case you will need to contact Ms Eleanor Schofield by email at eleanor.schofield@student.adelaide.edu.au. You will then be added to a list and contacted as further research projects become available.

We will use the data to investigate and analyse the type of language women use to describe their pelvic pain. The results of this project will be published in scientific peer-reviewed journals and may be presented at conferences. Participants can request a copy of the published outcomes once the project is completed by emailing us at susan.evans@adelaide.edu.au. Data from this project will be kept for a minimum of 5 years and may be used for other studies in the future.

Who do I contact if I have questions about the project?

If you have questions about the project, please direct them to the principal investigator:

Principal Investigator - Dr Susan Evans
 Email: susan.evans@adelaide.edu.au
 Phone: 08 8363 2811

What if I have a complaint or any concerns?

The study has been approved by the Human Research Ethics Committee at the University of Adelaide (approval number H-2017-100). If you have questions or problems associated with the practical aspects of your participation in the project, or wish to raise a concern or complaint about the project, then you should consult the Principal Investigator. If you wish to speak with an independent person regarding a concern or complaint, the University's policy on research involving human participants, or your rights as a participant, please contact the Human Research Ethics Committee's Secretariat at the University of Adelaide on:

Phone: +61 8 8313 6028

Email: hrec@adelaide.edu.au

Post: Level 4, Rundle Mall Plaza, 50 Rundle Mall, ADELAIDE SA 5000

Any complaint or concern will be treated in confidence and fully investigated. You will be informed of the outcome.

Yours sincerely,

Dr Susan Evans

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Emeritus Professor Roland Sussex

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Ms Eleanor Schofield

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CONSENT FORM

Please keep this consent form for your records.

1. I have given my informed consent by answering “yes” to the first question of the online survey and continuing to answer the questions.

2. I have read the Information Sheet and agree to take part in the following research project:

| | |
|--------------------------------|------------------------------------|
| Title: | The Language of Pelvic Pain |
| Ethics Approval Number: | H-2017-100 |

2. I am 18 years or older, identify as female and am a resident of Australia or New Zealand.

3. I am satisfied that I understand the project as described above. My consent is given freely.

4. I understand that the purpose of this research project is to improve the quality of medical care as it relates to pelvic pain. However, I also understand that my involvement may not be of any benefit to me.

5. While information gained during the study may be published or presented at conferences, my responses are anonymous and I will not be personally identified.

6. I understand that I am free to withdraw from the project at any time without penalty.

7. I am aware that I should keep a copy of this Consent Form and the Participant Information Sheet. It is my responsibility to keep these files.