Participant Information Sheet

Version : 1

Study Title: How do individuals with Vaginismus experience and make sense of cervical screening procedures, and what can their lived experiences tell us about improving healthcare in this population?

Researcher: Sian Spencer-Bray

I would like to invite you to take part in a research study that is being conducted as part of my Master's degree in Health Psychology. Before you decide if you would like to consider taking part, we would like you to understand the focus of the research and what it would involve for you. If you have any questions about the research after reading the following information, please contact me at the email address provided at the end of this document as I would be happy to discuss the study with you and answer any questions you have or clarify anything as needed.

What is the purpose of the research?

This research is being conducted as part of my Master's degree in Health Psychology. The focus of the study is to understand the experiences and possible barriers for individuals with Vaginismus when considering access cervical screening. The research is being supervised by Dr Daniel Gaffiero and Dr Vicki Staples who are experienced and highly qualified academics at the University.

Why have I been invited to participate?

You have been invited to take part because;

- You are 18 years or older
- You have experienced vaginismus (whether self-identified or diagnosed)
- You have undergone, attempted or been invited to a cervical screening appointment
- You are comfortable discussing these experiences in an interview

Do I have to take part?

It is entirely your decision whether you agree to take part in the research or not. Participation in the research is entirely voluntary, you do not have to give a reason if you decide not to take part and your decision will be respected.

If after reading this information sheet you decide not to take part please let me know and we can withdraw you from the interview process.

If you do decide to take part, you will be asked to give your consent to confirm you have understood what taking part involves (described below) and how the information you provide (data supplied) will be used and your rights as a participant (data subject).

To take part in the study you will be asked to provide some basic demographic information relating to age, sex, gender, ethnicity, and social class. This information helps us to understand who has taken part in the research overall and to assess the relevance of the findings. We routinely ask about age, sex, gender, ethnicity, and social class as these have potentially important influences on health and health-related experiences and outcomes.

What will happen to me if I take part?

After completing the consent information and demographic questions, you will be asked to take part in an interview, either in person or online. This will last between 40-60 minutes depending on how much you would like to share about your experience. You will be asked questions about your experiences, views and beliefs surrounding cervical screening in relation to your vaginismus. Your interview will be audio recorded, with your permission. You can pause, skip any questions or end the interview at any time.

Once your interview is completed the recording will then be written up to produce a transcript (written record). The transcripts will be anonymised by using a psydonym rather than your real name and any identifying details such as the names of people or places will be amended to protect your identity. This will then be used to explore themes and relationships to help answer the research question.

What will happen if I change my mind?

If you change your mind before completing the study, you can contact me and let me know. You can also withdraw any data you have provided for up to 2-weeks after having completed the study. You do not need to provide a reason for changing your mind or wanting to withdraw your data.

What are the possible disadvantages and risks of taking part?

Due to the focus of the research the content of some of the interview questions and discussions may be difficult to talk about. Some participants make find talking about their

experiences potentially upsetting. Please be assured that you do not have to talk about anything that you find too uncomfortable and can move on to another question or decide to stop at any point during the study. In addition, sources of additional information and support for issues associated with this research focus are provided at the end of the study as part of the debriefing.

What are the possible benefits of taking part?

There are no immediate personal benefits of taking part, although many participants find taking part in research an interesting and rewarding experience. In addition, the findings of this research may help to develop our understanding of barriers that individuals with Vaginismus may experience when accessing cervical screening and therefore your contribution could help us to understand how to improve current healthcare procedures for individuals with Vaginismus.

What will happen to the results of the research?

The findings of this research will be prepared for assessment in the format of a journal article manuscript and an academic poster. It is also hoped that the findings may be presented at relevant conferences or published in an academic journal so that other academics and clinicians can learn from the research. Individual participants will not be identified in any assessments or publications.

Due to the nature of the research we will intend to utilise direct quotes provided. To help protect the anonymity of participants names and specific details will be changed; however, given the personal nature of these quotes, full anonymity cannot be assured.

! Please read the following information carefully as it outlines the use of your data and your rights. As a legal statement it includes some odd terms such as “data subject” which refers to you as a participant in the research. If any of the information is unclear, please do not hesitate to contact the student researcher or the data protection officer.

Privacy Notice

If you agree to take part in this research project the information that you supply will be recorded and processed in line with the UK GDPR / Data Protection Act 2018 / EU GDPR.

Data collected will be used by the student researcher as part of an empirical research project that contributes to their Master’s degree in Health Psychology. The University of Derby is the data controller.

Pseudonymised data from this project may be used in future publications.

We retain the data for a minimum period of 7 years after such time it will be securely destroyed. Data will not be retained for longer than is necessary.

As part of our research, we would like to ask questions that are considered special category data. Our lawful basis for processing this data are: Article 6 legitimate interest and Article 9 your explicit consent.

As a data subject you can request withdrawal of consent and withdrawal of any data providedwithin 2-weeks of providing your data by contacting Sian Spencer-Bray. After this period data are anonymised and we will be unable to extract your individual data.

Our Data Protection Officer (DPO) is James Fussell on 01332 591954. Alternatively, you can email gdpr@derby.ac.uk.

Further information on how we handle your information and details of our DPO can be found on our website: https://www.derby.ac.uk/its/datagov/privnotice

Additional Information

The supervisors of this project, who also have access to the data, are highly qualified and experienced and have been very careful to discuss with the student the necessary processes to ensure the security of your data. An independent Ethics review has been completed on behalf of the School of Psychology Research Ethics Committee and approval granted to conduct the study [insert your study reference number here, e.g. ETH2122-XXXX].

We are obliged to:

- Not seek more information from you than what is essential and necessary for this research;
- Make sure that you are not identified by using ID codes or minimise identification through the use of pseudonyms [delete as appropriate];
- Use your anonymised / pseudonymised data for the purposes of this study and for any relevant publications that arise from it;
- Store data safely in password-protected databases to which only the named researchers have access.

Further information about the project can be obtained from the research student Sian Spencer-Bray or if you have any concerns about the conduct of this research you can contact their research supervisor Dr Daniel Gaffiero or Dr Vicki Staples, University of Derby, Kedleston Road, Derby, DE22 1GB.

Further information

Information shared in the interview will be treated confidentially. However, in the event of information being disclosed relating to unsafe practice or harm to yourself or others,

such information may be communicated to the relevant authorities. In such instances you will be made aware of any breach of confidentiality.

Next steps and contact details:

Thank you for taking the time to read this information and for considering participation in the research. If you agree to take part in the study, please complete the consent information on the next page.

Student Researcher Contact Details:

Name: Sian Spencer-Bray

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Research Supervisor Contact Details:

Name: Daniel Gaffiero

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