

Participant Information Sheet

Adenomyosis Across the Life Course: A Qualitative Interview Study

Qualitative Interviews (Online via MS Teams)

You are invited to take part in a research study being conducted at Leeds Beckett University. Before you decide whether you would like to participate, it is important that you understand why the study is being carried out and what taking part would involve. Please take time to read the information below. Contact details are provided at the end of this document if you have any questions.

The legal basis under which this research project will be undertaken is that of legitimate interest. The research project is of interest to Leeds Beckett University.

Why is this research study being conducted?

Adenomyosis is a gynaecological condition that can have a significant impact on women's physical health, emotional wellbeing, fertility, and quality of life. However, women's lived experiences of adenomyosis are not well understood, and there are currently limited patient-centred tools to measure the impact of the condition or to support shared decision-making about treatment.

This study aims to explore women's experiences of living with adenomyosis, including its impact on daily life, quality of life, and experiences of healthcare. The findings will be used to inform the development of two new patient-centred resources:

- a patient-reported outcome measure (PROM) specific to adenomyosis, and
- a patient decision aid (PtDA) to support women and clinicians in treatment decision-making.

Why have I been invited? And how long will it take?

You have been invited to take part because you are aged 16 years or over and have a confirmed or suspected diagnosis of adenomyosis. Your views and experiences are important, regardless of where you are in your diagnostic or treatment journey.

If you agree to take part, you will be asked to participate in a one-to-one interview conducted online via Microsoft Teams. The interview will last approximately 60–90 minutes. You will be sent this Participant Information Sheet and a Consent Form in advance. Please return a signed copy of the Consent Form by email before the interview.

At the start of the interview, the researcher will explain what the interview will involve and give you the opportunity to ask any questions. You will then be asked to:

- confirm that you have read and understood this Participant Information Sheet

- give consent to take part in the study
- give consent for the interview to be audio/video recorded

What will I be asked to do?

If you agree to take part, you will be asked about your experiences of living with adenomyosis. In the first part of the interview, you will be invited to talk about your experiences in your own words, including when your symptoms began and how the condition has affected you.

The researcher will then ask more specific questions about:

- the impact of adenomyosis on your quality of life, daily activities, and emotional wellbeing
- fertility and reproductive decision-making (if relevant to you)
- experiences of diagnosis, treatment, and healthcare services
- what outcomes and information matter most to you in relation to adenomyosis care
- your views on what should be included in a new adenomyosis-specific PROM and patient decision aid

Some questions may be personal or sensitive, for example:

- your experiences of seeking help or receiving care
- how adenomyosis has affected how you feel about yourself or your future

In the final part of the interview, you will have the opportunity to add anything else you feel is important and to ask any questions.

You will also be asked to complete a short demographic questionnaire, including questions about characteristics such as your age, ethnicity, gender and education. You do not have to answer any question you do not wish to; you may skip questions or select '*prefer not to say*'.

Do I have to take part?

No. Taking part in this study is entirely voluntary. If you agree to take part, you must confirm you are aged 16 years or over. You may 'pass' on any question or withdraw from the research session without giving a reason. This will not affect your legal rights or result in any negative consequences.

If you withdraw during the interview, the interview will be stopped and any data collected up to that point will be deleted. If you wish to withdraw after the interview has taken place, please do so within **4 weeks**. To withdraw, simply contact the Project Lead at g.l.jones@leedsbeckett.ac.uk and all your data will be deleted from the University's secure systems.

What happens to my data?

The interview will be audio/video recorded and transcribed. Your name will be replaced with a pseudonym (a fictitious name), and identifying details will be removed or altered (for example, specific ages, locations, or healthcare settings).

All research and personal data will be stored securely on Leeds Beckett University servers; it is made secure through the Multi Factor Authentication (MFA) provided by Leeds Beckett University. Only the research team will have access to the data.

All personal data will be destroyed **10 years after the interviews**.

Will taking part benefit me?

Your participation in the research project will contribute to improving our understanding of adenomyosis and to the development of patient-centred tools that may improve care in the future. Some people also find it helpful to talk about their experiences in a supportive and non-judgemental setting.

Will my identity be kept confidential?

Yes. All information you provide will be treated confidentially and stored securely. During the study, the information will be stored securely on password protected computers, in restricted access folders. We will never use your name or any identifying details. We will give you a pseudonym (a fictitious name) and remove personal information so that no one outside of the research team will be able to identify you from the data. You will not be identifiable in any reports, publications, or presentations arising from this study.

The only exception to confidentiality would be if you disclosed information suggesting that you or someone else was at serious risk of harm. In such cases, concerns would be discussed with the research supervision team and appropriate University safeguarding procedures followed. You would be informed if this occurred.

For further information on how we ensure Confidentiality and Data Protection compliance, including General Data Protection (GDPR) and Data Protection (DPA), **please click this link:** [Confidentiality and Data Protection compliance](#).

Are there any risks to taking part?

There are no anticipated safety risks as the research session. It will take place online, where no other people will be able to overhear our conversation, and where you, the participant, and me, the researcher, will be at a location that is convenient and safe.

Taking part in this study is not expected to cause any discomfort or distress, but if such feelings do arise, after the research session, you can access advice or support at:

- **The Adeno Gang** – <https://www.adenogang.com>,
contact@theadenogang.com

- **Wellbeing of Women** – <https://www.wellbeingofwomen.org.uk>,
hello@wellbeingofwomen.org.uk, Tel: 020 3697 7000
- **Women's Health Concern** - <https://www.womens-health-concern.org/>, Tel: 01628
890199
- **Endometriosis UK** – <https://www.endometriosis-uk.org>, Helpline: 0808 808 2227
- **Pain UK** – <https://painuk.org>, info@painuk.org
- **Mind** – <https://www.mind.org.uk>, Helpline: 0300 102 1234

In addition, the interview will be conducted with care, empathy and without judgment. I will check in with you regularly throughout our conversation to see how you're doing, and you will be able to take as many breaks as you need.

What happens to the information provided?

The information you provide during the research study is called **research data**. Any research data from which you can be identified, for example your name, email address and interview audio recording, is known as **personal data**. This will be pseudonymised using fictitious names instead of real names. Other identifying information will be changed (as stated above). We may use quotations from our conversation; again, identifying information in the quotes will be changed.

Names and contact information will not be shared with any other organisation, institution or third party.

Will the research be published?

The findings based on this research study will be shared and shown in a final report and may be shown in research outputs e.g. academic publications and conferences. You will not be identifiable in any way through these activities.

Leeds Beckett University is committed to disseminating its research for the benefit of society and the economy. In support of this commitment, Leeds Beckett University has established an online archive of research materials including research projects and those outputs that are of interest are sometimes shared in digital and hardcopy as exemplar to other students/staff and/or staff of organisations/institutions.

Who has reviewed this project?

This study has been reviewed and approved by Leeds Beckett University's research ethics procedures.

Who do I contact if I have a question, a concern about the study or I wish to complain?

If you have any questions about any aspect of this study or wish to complain, the contact details are below, and we will do our best to answer.



Researcher: Georgie Forshall

Email: g.forshall@leedsbeckett.ac.uk

Project Lead: Prof. Georgina Jones

Email: g.l.jones@leedsbeckett.ac.uk

If you have any questions about how the ethics policy and procedures of Leeds Beckett University relate to this project, please contact the research ethics coordinator at Leeds Beckett.

Local Research Ethics Coordinator: Dr Lauren Smith

Email: l.m.smith@leedsbeckett.ac.uk