**Women’s Health and Wellbeing Services for Women aged 40-65 years in East Sussex**

We would like to invite **everybody** who self-identifies as a **woman aged 40-65** years who **lives in East Sussex** to take part.

**Participant Information Sheet (Women’s Focus Groups)**

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You are being invited to take part in a research study. **It is up to you whether you would like to take part**. Before you decide, it is important that you understand why the research is being done and what it will involve. Please read this information carefully and discuss it with others if you wish. Please ask a member of the research team if anything is unclear or if you would like more information*.* Dr Kiersten Simmons is the Lead Researcher for this study.

**Summary**

In this study we will ask you about your views and experience of **women’s health and wellbeing services**, including cervical and breast screening, contraception, menopause care, infection testing, sexual dysfunction care, incontinence services, and any other women’s health and wellbeing services that you think are important for women aged 40-65 years, living in East Sussex. In this research study we will use information from you. We will only use information that we need for the research study. Everyone involved in this study will follow all privacy rules and keep your data safe and secure. If you do decide to take part, you will be free to withdraw from the study at any time. We will let very few people know your name or contact details, and only if they really need it for this study. At the end of the study, we will save some of the data in case we need to check it. We will make sure that no-one can work out who you are from the reports that we write.

**What is the purpose of the study?**

We would like to understand your views on what should be on offer in terms of women’s health and wellbeing services in East Sussex. We know that some women aged 40-65 years living in the UK find it difficult to access the women’s health and wellbeing services that they feel they need. **The aim of this study is to explore how women’s health and wellbeing services could be improved, and which are the things that make it easier and more difficult for women aged 40-65 years to access health and wellbeing services in East Sussex.**

Using focus group discussions and interviews, we would like to find out:

* What women feel services should provide.
* Whether some groups of women face extra challenges to accessing services.
* Whether women feel that they would benefit from different education or public messages about women’s health and wellbeing services.
* How the healthcare system and health care professionals can best work with women aged 40-65 years to improve women’s health and wellbeing services.

**What will happen to me if I take part?**

If you agree to take part in the study, the Researcher will ask you **to choose between taking part in a focus group or an interview**. You have indicated a wish to take part in a focus group, but you will be free to change to an interview if you change your mind.

The Researcher will telephone or email you and ask you to **choose which group you would prefer to take part in** (group of mixed women, group of women who identify as belonging to ethnic minorities (excluding white minorities), group of women who identify as trans or non-Binary, group of women who identify as living with a disability). The Researcher will then give you a **range of dates** to choose from. You will be asked whether you would prefer to take part in either a **local face-to-face group or an online group** via a secure platform (Microsoft Teams). There will be approximately 4-6 participants in each group.

When the groups have been identified, the Researcher will telephone you or email you, as per your preference, to let you know the **location** for the focus group. If the time or location of the focus group does not suit you, the Researcher will offer you alternative suitable groups or the option of taking part in an interview.

At the beginning of the group, after we have all **introduced** ourselves, we will ask you to fill in a **demographics form** (questions such as age, gender identity, postcode, ethnicity). This is to ensure that when we are analysing the results, we can check whether we have included a wide range of women from different backgrounds. **The Focus Group session will last 60-90 minutes** and will be run by the Researcher. For some groups, a woman with lived experience of women’s health and wellbeing conditions, who has been trained, will help the Researcher to run the group. You will be asked to discuss in a group, broad questions about how and where you would like women’s health and wellbeing services to be provided, and who by, and what would encourage and discourage you from accessing women’s health and wellbeing services. **There are no right or wrong answers** – it’s your experiences and views that we are interested in. You should **only answer the questions that you feel comfortable with**. The focus group will be audio recorded so that we can accurately recall what you have said.

You will be offered **refreshments, and we will give you a £25 high-street voucher** to compensate you for your time and travel or internet costs. If accepting the voucher will affect you in a negative way, for example if you must declare it for, for example benefit payments, and you would prefer us to give you direct compensation for the actual cost of taking part (such as travel, internet, time, up to a maximum of £25) please talk to the Researcher at the end of the focus group. We will also ask for your permission to keep your details so that we can contact you about further research that you may be interested in being involved with.

**Why have I been invited?**

You have been asked to take part because you are **aged 40-65 years and self-identify as a woman and live in East Sussex**. We hope that by hearing about your experiences, and sharing your views, we can learn how to improve women’s health and wellbeing services.

**Do I have to take part?**

No. It’s up to you. If you do decide to take part someone from the research team will contact you, and you will be given this information sheet and the consent form to read. At the beginning of the focus group, you will be asked to sign your agreement to take part on the consent form, or if this is not possible, we will audio record your verbal agreement. Whether you decide to take part or not will not affect your care through the NHS. If you decide to take part and then change your mind, you are free to withdraw at any time without having to give a reason.

**Data Protection and Security: How will we use information about you?**

We will need to use information from you for this research project. This information will include your **name and contact details**. For the demographic questionnaire, in which all the questions are optional(you can take part in the study without completing these questions), we will ask for: your post-code, age, gender, and ethnic group. We will use this information to do the research. People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. **We will keep all information about you safe and secure.**Once we have finished the study, we will keep some of the data so that we can check the results.

* If you agree to take part, we will need to record your **name and contact details** to arrange a **time** for the Focus Group.
* Your name will be given a **code number** and will be **stored separately** from the rest of your demographic details (gender identity, age, ethnicity, postcode etc), and these details will also be stored separately from the research data (audio recordings of the focus groups, written script from the focus group recordings, analysis of the focus groups). The link document between your name and the code number that you are allocated will also be stored separately.
* All the data will be **stored securely** on a University Hospitals Sussex NHS Foundation Trust password-protected encrypted network. The audio files will also be stored on the University Hospitals Sussex NHS Foundation Trust password-protected encrypted network. Only the main study team will have the password to the password-protected encrypted network, which enables access to the data set (name and contact details, code number, demographic details, research data), and we will follow the University Hospitals Sussex NHS Foundation Trust data storage guidelines and the UK’s data protection act.
* A third-party company, which has signed a confidentiality agreement with the University Hospitals Sussex NHS Foundation Trust, will put the audio data (which will not include any information which can identify you) into written form. The audio recordings will be destroyed using confidential data destruction measures when the anonymised transcripts have been created. The focus group results (which will not include any information which can identify you) may be seen by authorities who check that the research has been conducted correctly. **We will write our reports in a way that no-one can work out that you took part in the study**. Identifiable information (name, contact details, postcode, demographic details) will be stored securely on the University Hospitals Sussex NHS Foundation Trust password-protected encrypted network for 6 months following the completion of the study and then destroyed using confidential data destruction measures. The digital data from the study (with consent forms and audio recordings of consent, stored separately from the rest of the data) will be stored securely using University Hospitals Sussex NHS Foundation Trust facilities for 5 years and then destroyed using confidential data destruction measures.

**What are your choices about how your information is used?**

* You can stop being part of the study at any time, without giving a reason. If you decide that you would no longer like to take part in the research, then please contact a member of the research team. If you do decide to withdraw consent for the use of your data, it will not be possible to remove any data that has already been collected from the Focus Groups.
* We need to manage your records in specific ways for the research to be reliable. This means that we won’t be able to let you see or change the data we hold about you.

**You can find out more about how we use your information:**

* at [www.hra.nhs.uk/information-about-patients/](https://www.hra.nhs.uk/information-about-patients/)
* our leaflet available from: http://www.hra.nhs.uk/patientdataandresearch
* by asking one of the research team
* by asking the sponsor of the study: Mr Scott Harfield on 01273 696955 Ext: 67497 or scott.harfield@nhs.net
* by sending an email to uhsussex.crf.reception@nhs.net
* by ringing us on 01273 663522

**Confidentiality will be respected,** subject to legal constraints and professional guidelines. For example, if we hear anything that makes us worried that you or somebody else might be in danger of harm, or if there is evidence of wrongdoing such as crime or malpractice, we would have to inform relevant agencies. If this were the case, we would inform you of any decisions that might limit your confidentiality.

Everybody who takes part in the focus group will be asked to indicate that they agree that everything that is said in the focus group must be kept confidential, and that they will not pass on information from the discussion to others outside of the focus group.

**What will happen to the results of the research study?**

When we have collected all the results for this study, we will analyse them and then publish and present the results. **You will not be identified in any publication or presentation**. Direct quotes may be used when describing general study findings, but these will not have your name, or any other identifiable information attached.

**What are the possible benefits of taking part?**

* The findings from the study may not be directly useful to you however some people **enjoy taking part in studies** where they can share their views and experiences.
* The findings will add to our knowledge about how to improve women’s health and wellbeing services. It is hoped that in better understanding women’s views on women’s health and wellbeing services, and the factors that help and hinder women from accessing women-specific services, researchers and clinicians **will be able to find ways to make it easier for women aged 40-65 years living in East Sussex to access the care that they need**. This will hopefully lead to better health care outcomes for these women.

**Will there be any risks or other implications of taking part in this study?**

* It is possible that talking about this might make you feel upset or bring to your mind past experiences that you have not thought about for a long time. Also, talking within the focus group might make you feel tired.
* You can stop at any time, or you can also change to an interview if you find you do not feel comfortable in the group setting. You can talk to us, someone else who you trust like friends or family, or an independent person, if you have any concerns.

**What if there is a problem?**

* If you have a concern about any aspect of the study, **you should speak to one of the researchers** using the contact information below. They will do their best to answer your questions.
* If you remain unhappy you can contact the Patient Advice and Liaison Service (PALS) using the contact details below.

**What if I would like to find out the results of the study?**

If you would like to learn more about the findings of the study, please tick the appropriate box at the bottom of the consent form. If you select this, at the end of the study we will email or post you a summary of the results or invite you to an information-sharing event. These will describe group findings and will not include any individual information.

**Who is funding this research?**

This research is funded by the University Hospitals Sussex NHS Foundation Trust as part of a PhD project which is investigating how to improve services for women aged 40-65 years who live in East Sussex. Dr Kiersten Simmons (Doctor and Lead Researcher) will be guided by a steering committee at Brighton and Sussex Medical School, University of Sussex, which is: Professor Carrie Llewellyn, Professor Collins Iwuji, Professor Stephen Bremner.

**Who has reviewed the research?**

The study protocol and all the documents that we are using have been reviewed by a group of local women aged 40-65 years. They have also been reviewed and approved by the Research and Development department of University Hospitals Sussex NHS Foundation Trust and by the East of England Research Ethics Service Committee Ref no: 24/EE/0032

**Contacts for further information**

If you have any questions about the study please contact Dr Kiersten Simmons (Lead Researcher), Kiersten.simmons@nhs.net or 07955356974

The sponsor organisation of the project is University Hospitals Sussex NHS Foundation Trust.

I**f you would like to talk to someone independent about the research**, you can contact your local Patient Advice and Liaison Service (PALS) on: uhsussex.pals@nhs.net and 01444 448678 (Brighton and Hove) or esh-tr.patientexperience@nhs.net/ and 0300 1315309 (Conquest) or esh-tr.patientexperience@nhs.net/ and 0300 1314784 (Eastbourne).

**If you would like to access support services**, your GP or local Sexual Health Services are often able to offer support. Examples of local support groups include Brighton Women’s Centretelephone:07842 311 406 and website: [womenscentre.org.uk](https://womenscentre.org.uk), Women’s Voice (East Sussex) website: <http://womens-voice.org.uk/>, Healthwatch East Sussex telephone: 0333 101 4007 and website: <https://healthwatcheastsussex.co.uk/>, The Trust for Developing Communities email: info@trustdevcom.org.uk

**Thank you for reading this information sheet**