



## Participant Information Leaflet

### **eternal: healthcare for girls and women with cerebral palsy across the life course**

#### **Invitation**

We would like to invite you to take part in our research study. Before you decide whether or not to take part, it is important for you to understand why the project is being carried out and what it will involve.

Please read the following information about the purpose of the research and how the findings will be used. There are also details about what we would ask you to do if you agreed to take part. Please get in touch with any questions or if you would like further information.

#### **Background and description of the study**

Girls and women with cerebral palsy (CP) experience age-related changes to their body earlier than those without CP. The wear and tear of living with CP can begin to cause other physical difficulties as people get older. These might include muscle spasms, pain, and stiffness in the joints. Girls and women could experience problems relating to sexual and reproductive health such as early periods or menopausal symptoms. They may face several barriers to good quality healthcare and may not have their health needs met when required.

The aim of this research is to help nurses and midwives to understand better:

- How the effects of CP change as women get older.
- The experiences of sexual and reproductive healthcare for girls and women with CP across the life course (adolescence, adulthood and older life).
- What helps and hinders access to good quality sexual and reproductive healthcare for women with CP.
- What are the biggest challenges to good quality sexual and reproductive healthcare for girls and women with CP?

#### **Who the *eternal* study team want to talk to and why:**

We would like to talk to girls (aged 14-17), young and middle aged women (18 to 54) and older women (ages 55 and over) from across the UK who identify as having CP.

We want to hear stories about:

- What has changed as women with CP get older.
- Experiences of sexual and reproductive healthcare for girls and women at different stages of the life course.

#### **What to do to take part?**

If you are interested in taking part in the *eternal* study you will be invited to participate in an interview with Dr Sonali Shah, the project researcher. Before interviews you will need to complete and sign a consent form. Most interviews will last for about 30-60 minutes. They can be longer or be done in stages, depending on individual access needs. The interview will be quite informal so you can talk about the topic in your own way. Interviews will be recorded and transcribed. Only the researchers and a professional transcriber will have access to the interview transcripts.

If you want to you can bring three or four personal photos or images to their research interview, around the themes of ‘being a girl/woman’, ‘disability/having CP’ and ‘health/healthcare’ to help tell your story. The photos will only be seen by you and the interviewer. You can take them back afterwards. Participation in the project is voluntary.

### **How will we use information about you?**

We will need to use information from you for this research project. This information will include:

- your initials
- name
- contact details

People will use this information to do the research or to check your records to make sure that the research is being done properly.

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 name 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 we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

We want to share the results locally, nationally and internationally through journal papers, presentations and workshops with health practitioners, disabled communities and researchers. This is to inform future health policies and practices on how to make reproductive and sexual healthcare accessible for disabled women in general and women with CP in particular.

Some of the information will be used to produce online educational materials for nursing students and professionals about what is needed to provide good quality healthcare to girls and women with CP, and other lifelong conditions.

Any photographs you choose to use in the interview will not be used in the final materials.

The educational materials will include a 25 minute documentary film, based on interviews with the women and nurses. If you are interested in also being involved in the film, please tick the box on the consent form. In the summer term, we will make contact about the documentary film. All those involved will receive a second consent form.

### **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, but we will keep information about you that we already have.
- 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.
- If you agree to take part in this study, you will have the option to take part in future research using your data saved from this study.

### **Where can you find out more about how your information is used?**

You can find out more about how we use your information

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)

- at [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- our leaflet available from <https://www.birmingham.ac.uk/schools/nursing/research/eternal-healthcare-for-girls-and-women-with-cerebral-palsy-across-the-life-course.aspx>
- by asking one of the research team
- by sending an email to [researchgovernance@contacts.bham.ac.uk](mailto:researchgovernance@contacts.bham.ac.uk), or
- by ringing us on 0121 4142900.

### ***Eternal study team contact details***

The core members of the research team are based at the School of Nursing, University of Birmingham. They have significant experience carrying out research in relation to sensitive topics. Dr Sonali Shah is a research fellow and has conducted research around disability, human rights and access to services for fifteen years. Julie Taylor is a Professor of Child Protection and Director of Research at the University of Birmingham in partnership with Birmingham Women’s and Children’s Hospital NHS Foundation Trust. Dr Caroline Bradbury-Jones has research interests in health inequalities, reproductive health and gender based violence. The project steering group includes experts within healthcare and rehabilitation, social science and disability studies, and includes adults with CP

For enquiries about the study and participation please contact



Dr Sonali Shah  
 email: [s.shah.3@bham.ac.uk](mailto:s.shah.3@bham.ac.uk)  
 Tel: 0121 4142900

If you would like to make a complaint or to raise a query about the conduct of the research team, please contact: Professor Julie Taylor – Director of Research, School of Nursing [j.taylor.1@bham.ac.uk](mailto:j.taylor.1@bham.ac.uk)

**Thank you for taking the time to read this information sheet and for considering taking part.**