# INFORMATION SHEET FOR FACILITATORS

*IRAS No: 305830*

You will be given a copy of this information sheet.

## Title of project

An Integrated Psychosexual Intervention for Sexual Difficulties in People with Multiple Sclerosis (PIMS): A Feasibility Study.

## Invitation for participation

We would like to invite you to participate in an interview to evaluate and discuss your experience of delivering the psychosexual intervention sessions.

This study is being sponsored by King's College London and South London and Maudsley NHS. It is funded by the National Institute for Health Research (NIHR). Before you decide whether to take part, it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following and discuss it with others if you wish. You can contact the study team if you have any questions or would like more information.

## Why are we doing this research?

Sexual challenges can be a hidden and difficult symptom associated with MS – 50-80% of people with MS are affected by this.

You have helped to facilitate the first psycho intervention designed to target this for people with MS being treated in the NHS. We want your feedback on your experience of delivering this intervention. This will help us evaluate what improvements should be made before designing a larger study.

## Why have I been invited?

You have been invited to take part as you are a clinician who works with people with MS and you have facilitated either the Psychosexual Education or PIMS intervention sessions.

## What will happen if I take part?

- You will be asked to complete a consent form – this can be done on Qualtrics, a GDPR compliant survey software.
- You will be contacted by a researcher to arrange an appropriate date and time to have an interview
- Interviews will be audio/video recorded and transcribed verbatim via Microsoft Teams (or telephone)
- Interviews will take around 30 minutes to complete
- This interview is to:
    - Understand your experience of the intervention and study process

- Hear your feedback on what you found helpful (or not helpful)
- Gain insight on possible improvements in the future

- We may use direct quotes from your interview but will remove any personally identifying information

## Do I have to take part?

No. Participation is completely voluntary. You should only take part if you want to. If you decide to take part, we will ask you to sign a consent form and give you a copy to keep.

## What are the possible risks?

- The interview will take time to complete and requires commitment to the arranged date and time.
- The interview may involve discussing intimate issues around sex, relationships, and intimacy, which may be uncomfortable.

## What are the possible benefits?

- The interview will allow you an opportunity to reflect on the process and your experience with training, intervention delivery, and clinical supervision
- Your experiences will help us adapt the PIMS intervention to be better suited for integration within the NHS and reduce burden on clinicians as much as possible
- We anticipate the results from this study will allow us to:
  - Improve the knowledge of how MS affects sexuality and intimacy
  - Inform healthcare practitioners about how to help people with MS manage their condition
  - Inform future research on sexual challenges in MS

## How will we use information about you?

We do not need to access any information from your medical records.

The personal information we will ask from you will include:

- Name
- Date of birth
- Contact details
- Your clinical role and place of work

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 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 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.

## 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 will not 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/
- our leaflet available from https://www.kcl.ac.uk/research/support/rgei/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research
- by asking one of the research team
- by sending an email to the Data Protection Officer, Albert Chan, info-compliance@kcl.ac.uk

Research data will be kept for 10 years after the study has ended.

## What will happen with the results?

- We will write to you via email at the end of the research and inform you of the main findings
- Results will be written up for publication in scientific journals and presented at international conferences
- We will hold a public engagement event at the end of the project to share findings with the wider community
- Results will also be disseminated through relevant MS charities and organisations
- Results are due to be shared at the end of 2023.
- Any results will be anonymised so that you cannot be identified

## Who should I contact for further information?

If you have any more questions or require more information about the project, please contact the project manager:

Dr Ashley Brown

Email: ashley.brown@kcl.ac.uk

## What if I have further questions, or something goes wrong?

If this project has harmed you in any way or if you wish to make a complaint about the conduct of the project you should first contact the research team at King's College London using the details below for further advice and information. If something does go wrong and you are harmed during the research you may have grounds for legal action for compensation against King's College London and/or NHS Trust, but you may have to pay

your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

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