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PARTICIPANT INFORMATION SHEET

Study title: An exploration of men's experience and use of treatments for erectile dysfunction (ED).

We would like to invite you to take part in a research study. Before you decide whether you would like to take part it is important that you understand why the research is being done and what it would involve for you. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

Current research suggests that when treatment of erectile dysfunction (ED) is successful then both the man and his partner experience improvements in their quality of life. However, it has also been indicated that levels of adherence to treatment (such as Viagra) for ED are low, potentially reducing beneficial aspects of the medication. Therefore this research study aims to explore aspects that you find helpful or unhelpful when it comes to using treatment for ED. As a result the study asks about information which is of a personal nature including your racial and ethnic background as well as data concerning your health and sex life.

Why have I been invited?

You have been invited to take part in the study because you have been prescribed treatment for ED. We are seeking approximately 209 people to take part in this study.

Do I have to take part?

No, taking part in the research is voluntary. It is up to you to decide whether or not to take part. If you do decide to take part, you will be asked to sign a consent form. You are still free to withdraw at any time and without giving a reason. Nobody will be upset if you do decide not to take part. T

What will happen if I take part?

If you decide to take part in the study you will be asked to complete an online survey that asks about your wellbeing and your views about ED and the treatment you have been prescribed. The questionnaire will take approximately 20 minutes to complete.

What are the possible disadvantages and risks of taking part?

Erectile dysfunction can be a sensitive subject and questions in relation to it can be of a personal nature. However, you can refuse to answer any question that you feel is too sensitive or if at any point you feel that you no longer wish to participate you can decide to withdraw from the study.

What are the possible benefits of taking part?

We do not expect there to be any direct benefits for you in taking part, but by taking part you will potentially be helping to inform improvements to treatment for future patients.

Will my taking part in the study be kept confidential?

All information that is collected from you during the course of the research will be kept strictly confidential. Only the research investigators who are running the study will have access to the study data.

If you would like help with any of the issues that you have reported in the questionnaire, please tell your doctor or nurse who will be able to refer you to appropriate support services.

The data that we collect will be stored anonymously on a password protected computer system and in locked filing cabinets at City, University of London and will only be available to the research team.

When the study is complete, data will be kept for a further 10 years and will be archived at City University London secure storage facility.

What will happen to results of the research study?

The research study is part of a PhD thesis and therefore will be written up for this purpose. In addition the research will be written up for publication in a relevant academic journal. For all written reports and relevant publications the anonymity of all participants will be maintained.

If at any point during the study you lose capacity to take part, the data you have provided up until that point will remain within the study.

What will happen if I don't want to carry on with the study?

If you decide at any point during your participation in the study that you wish to withdraw, you can contact any of the research team to discuss this. It would be useful for us to use the information you have given us up until that point in the study; however, if you wish for us to destroy the data, this can also be arranged.

What if there is a problem?

If you have any problems, concerns or questions about this study, you should ask to speak to a member of the research team (please see contact details at the end of this form). If you remain unhappy and wish to complain formally, you can do this through the University complaints procedure. To complain about the study, you need to phone 020 7040 3040. You

can then ask to speak to the Secretary to Senate Research Ethics Committee and inform them that the name of the project is: An exploration of men's experience and use of treatments for erectile dysfunction (ED).

You could also write to the Secretary at:

Anna Ramberg
Secretary to Senate Research Ethics Committee
Research Office, E214
City University London
Northampton Square
London
EC1V 0HB
Email: Anna.Ramberg.1@city.ac.uk

City University London holds insurance policies which apply to this study. If you feel you have been harmed or injured by taking part in this study you may be eligible to claim compensation. This does not affect your legal rights to seek compensation. If you are harmed due to someone's negligence, then you may have grounds for legal action.

Who is organizing the research?

The research study is being organised by researchers at City University London along with urologists at Barts Health NHS Trust, King's College Hospital NHS Foundation trust, University College Hospitals NHS Foundation trust.

Who has reviewed the study?

This study has been approved by the Newcastle and North Tyneside 1 Research Ethics Committee (Reference number 207576)

Further information and contact details

If you want some general information about taking part in research please contact the Patient Advice Liaison Service (PALS) at PALS@uclh.nhs.uk

Should you require any further details please contact the lead researcher or a supervisor at the following:

Lead researcher: Paul Williams, paul.williams@city.ac.uk; tel: +44 (0)20 7040 0244

Supervisor: Dr Kathleen Mulligan, kathleen.Mulligan.1@city.ac.uk; tel: +44 (0)20 7040 0889

Supervisor: Dr Hayley McBain, email: hayley.mcbain.1@city.ac.uk; tel: +44 (0)207 040 0870

Data Protection Privacy Notice: What are my rights under the data protection legislation?

City, University of London is the data controller for the personal data collected for this research project. Your personal data will be processed for the purposes outlined in this notice. The legal basis for processing your personal data will be that this research is a task in the public interest, that is City, University of London considers the lawful basis for

processing personal data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes and all research with human participants by staff and students has to be scrutinised and approved by one of City's Research Ethics Committees.

Further, City considers the processing of special category personal data will fall under Article 9(2)(g) of the GDPR as the processing of special category data has to be for the public interest in order to receive research ethics approval and occurs on the basis of law that is, inter alia, proportionate to the aim pursued and protects the rights of data subjects.

The rights you have under the data protection legislation are listed below, but not all of the rights will apply to the personal data collected in each research project.

*right to be informed *right of access *right to rectification *right to erasure *right to restrict processing *right to object to data processing *right to data portability *right to object *rights in relation to automated decision making and profiling

For more information, please visit www.city.ac.uk/about/city-information/legal

What if I have concerns about how my personal data will be used after I have participated in the research?

In the first instance you should raise any concerns with the research team, but if you are dissatisfied with the response, you may contact the Information Compliance Team at dataprotection@city.ac.uk or phone 0207 040 4000, who will liaise with City's Data Protection Officer Dr William Jordan to answer your query.

If you are dissatisfied with City's response you may also complain to the Information Commissioner's Office at www.ico.org.uk

Thank you for taking the time to read this information sheet.