

PARTICIPANT INFORMATION SHEET

Title of the Study: Sexual Health Communication: Perspectives from Indian Cervical Cancer Survivors, Male Partners, Oncologists and Nurses

Investigator(s): Dr. Mahati Chittem (Associate Professor, Department of Liberal Arts, IIT Hyderabad, India); Hiba Siddiqui (PhD Scholar, Department of Liberal Arts, IIT Hyderabad, India & Senior Psycho-oncologist, Max Super Speciality Hospital, Saket, A Unit of Devki Devi Foundation)

1. Introduction

You are invited to take part in this research study which aims to gain an understanding of the experiences of sexual health communication from the perspectives of cervical cancer survivors, male partners, oncologists, and oncology nurses.

Please read the information sheet carefully and completely, and feel free to ask any questions about the details given in this sheet. You may also wish to speak with your treating physician, relatives, friends, or a healthcare professional regarding this study.

Once you understand the details of this study, and if you agree to take part in this, you will be asked to sign the consent form. By signing the form, you indicate that you understand the information and that you are freely giving your consent to participate in this research study.

You will be given a copy of the participant information sheet and the consent form to keep, if you wish to, as a record.

2. What is the purpose of this research study?

An understanding of the experiences of sexual health communication and training needs of the participants will help healthcare professionals eventually address the unmet communication needs with availability of evidence-based understanding.

3. Procedure of the study

After you read this sheet and sign the consent form, you will be asked to provide some information such as your age, gender, education, occupation and some details regarding the medical history. You will then be asked to answer a few questions regarding your experience of sexual health communication along with barrier and factors facilitating the same, during or post completion of treatment and recovery. This interview will be audio recorded and used for the research process only.

4. What does participation in this study involve?

We would like to understand the experiences regarding sexual health communication from the perspectives of cervical cancer survivors, male partners, oncologists and oncology

nurses. We will be interviewing 80 such participants, 20 in each cohort from various hospital and oncology clinics in Delhi-NCR, India.

Your consent for participation will be asked and you are free to change your mind, withdraw consent and withdraw from the study at any point of time for any reason without justification or penalty.

You will be asked basic information about yourself (age, employment status, education etc.) and about your or your spouse's medical history. An individual interview will then be conducted with you which is estimated to be around 45-60 minutes in duration. We will take verbal assent from you prior to the interview.

5. Privacy and disclosure of information

All information that we collect from you throughout this research project will be kept strictly confidential. Your name and any identifying information will be removed from all documentation. You can be assured that you will be anonymous throughout the research project and in all subsequent documentation and publications that emerge from the study.

The interviews will be kept for a duration of up to 6 years, after which, they will be destroyed. During this time, they will be stored on a password protected secure server at the Department of Liberal Arts, IIT Hyderabad. De-identified (anonymous) copies of the interview transcriptions will also be stored securely at IIT Hyderabad.

6. What are possible benefits and risks?

Although there is no intended direct benefit for participants, we believe that the results could help healthcare workers and physicians to address some of the needs and improve the patient and survivors' healthcare experience focusing on improved sexual health communication post completion of treatment.

Participation in the study itself presents little risks. There may be a slight possibility that during the interview you may become upset by reflecting on your experiences. The interview may be paused or stopped at any time and contact details of a psychological counsellor, other than the PI and co-PI in Delhi-NCR will be offered where appropriate. After the interview if you feel any sense of unease or distress, please feel free to get in touch with the researcher on the contact details given below.

7. Do I have to take part in this research study?

No. Participation is completely voluntary. If you do not wish to take part, you are not obliged to. If you do agree to participate, you can withdraw at any time without comment or penalty.

Your decision whether to take part or not to take part, or to take part and the withdraw, will not affect your relationship with your healthcare team, IIT Hyderabad or any other organization involved in the research.

Before you make your decision, the research will be available to answer any questions you have about the research project. You can ask for any information and clarifications you want. Sign the consent form only when you have had the chance to ask your questions and received complete and satisfactory answers.

8. Publishing results and future use

It is anticipated that the results of this study will be used, published and/or presented in a variety of forums. In any publication and/or presentation, information will be provided in such a way that any participants cannot be identified. This data may be used in the future but the researchers will ensure maintenance of complete confidentiality of participant details.

9. The Reviewing Human Research Ethics Committee

The ethical aspects of this research study have been reviewed and approved by the ethics committee in this hospital and by the institutional ethics committee at IIT Hyderabad, India.

10. Further information and who to contact

If you want any further information, have questions or concerns about taking part in this study, you can contact the following people:

Principal Investigator	Dr. Mahati Chittem	+91 8978901111 mahati@la.iith.ac.in	
Co-investigator	Ms. Hiba Siddiqui	+91 9911175205 la21resch14001@iith.ac.in	

PARTICIPANT INFORMED CONSENT FORM

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Participant's name:

Address:

The details of the study have been provided to me in writing and explained to me in my own language. I confirm that I have understood the above study and had the opportunity to ask questions. I understand that my participation in the study is voluntary and that I am free to withdraw at any time, without giving any reason, without the medical care that will normally be provided by the hospital being affected. I agree not to restrict the use of any data or results that arise from this study provided such a use is only for scientific purpose(s). I have been given an information sheet giving details of the study. I fully consent to participate in the above study.

Signature of the participant: _____ Date: _____

Signature of the Principal Investigator: _____ Date: _____

Signature of the witness: _____ Date: _____