University College London Hospitals NHS

NHS Foundation Trust

Patient Interview Topic Guide

Title of Project: Developing a Stepped Approach to Improving Sexual Function after Gynaecological Cancer: a feasibility study. (SAFFRON)

Introduction for Patients

Suggested script for researcher: This research aims to provide interventions to women experiencing sexual difficulty after treatment for gynaecological cancer and assess the feasibility of conducting a larger trial of its effectiveness. We wish to understand through the eyes of the patient the experience of participating in the trial and receiving novel treatments while on the study.

Researcher: Reassure patient that they do not have to answer any question they feel uncomfortable with and they can stop the interview at any time. This will in no way affect their care.

Researcher: Emphasise that this is about getting their views across & that all responses are anonymised & confidential. Responses will not be shared with their health care team.

Researcher: Talk through patient information sheet if patient/wishes

Record date, patient ID

I'd like to start by asking you about your condition and your care.

1 **Could you briefly tell me about your cancer and the treatments you received, and the most important ways that they affect you?**

Encourage focus and impact on quality of life

2 **What types of care do you currently have for your cancer?**

Encourage brevity and focus on major health (+/- psycho-social care) interventions

3 **Can you describe how you heard about the study**

By poster/leaflet; word of mouth; Dr or nurse in clinic.

4 **Can you describe how you made the decision to consent to be screened to enter the trial?**

As appropriate, probe to clarify:

- Who were the main people involved in presenting the study and assisting you to make the decision?
- Were all aspects of the trial made clear to you at this time? If not, what was missing.
- Were there aspects of the trial as described to you that you felt more or less comfortable about?

5 **All women on the study received psycho-educational materials. Please can we talk in more detail about the beginning of your time on the study when you first received the psycho-educational materials?**

Can you describe how it was when you received this information? Can you tell us the factors that influenced you positively?

As appropriate, probe:

- Overall did you find these materials helpful? Would you recommend them to someone else?
- Were you able/unable to express your views / ask questions?
- Were your preferences/wishes regarding your care taken into account at this time?
- Which if any factors made a difference to how you took up the information; whether you used it afterwards? Why?
- Any perceived concerns / benefits eg nature of psycho educational materials; the way they were introduced etc;
- Extent to which uptake of materials was influenced by personal characteristics e.g. belief systems, autonomy, etc.
- Extent to which personal characteristics interacted / were mediated by context e.g. their relationship with key health professionals / being part of the trial; uncertainty surrounding management options for their cancer and getting help for sexual difficulties etc.

6 **If woman was on control arm:**

How did you feel when you heard that you would not receive the new treatments?

Probe:

- Did the offer of 'treatment as usual' seem fair to you?
- Did the initial materials pack help you? Did you feel that you had benefitted from the materials even though you had not had access to the full nurse/psychology delivered treatments?

- **Would you have preferred to be in the treatment arm of the trial?**

7 **If woman was on treatment arm**

What treatments did you receive? Nurse only? Psychology only? Both?

Probe:

- What was the experience of treatment like? Helpful? Difficult? Explore the time issues, arrangements for therapy issues including travel; burden on family; benefit / or worsening of relationship with partner, family members, other; increased understanding of self/body/sexuality; understanding of what is normal after treatment for cancer;
- Was there a difference for you between the nurse sessions and the psychology sessions (if had both)? If so, can you say what it was?
- Which treatment did you find most helpful? Can you try to explain why?
- If you had the opportunity to choose one of the treatments you received, which would it be? Can you try to explain why?

8 **ALL WOMEN**

Is there anything about being on the trial and your care that you know now, that you would like to have known before/when your participation first began?

As appropriate, probe:

- To know the details of the questionnaires
- If in trial arm - Time in counselling/psychotherapy, recuperation issues, communication with the MD clinical team; impact on partner etc.
- How might this information have changed your decision to participate?

In the trial, patients are recommended to change to more or less intensive treatments based on their final score to answers on a questionnaire that asks directly about sexual function

9 **What were your experiences of completing this questionnaire and receiving your score?**

As appropriate, probe:

- How was the score given; opportunity to discuss score and your feelings in relation to it?
- What were your preferences/wishes regarding your care?

10 **All WOMEN**

During the trial you were asked to complete a number of questionnaires at different time points. Can you tell me how that was for you?

As appropriate, probe:

- Number of questionnaires;
- assistance to complete; purpose not clear;
- suitability of questions/questionnaires;
- any questionnaires/particular questions that presented difficulty.

11 **ALL WOMEN**

Did you understand the idea of 'stepped care' within the study?

As appropriate, probe:

- Was it explained to you?
- Did you experience being 'stepped up'? If so, how did you understand the reasons?
- Do you think you got the level of care/intervention that was right for your difficulties?
- Of all the help you received as part of the research, which did you find most helpful? Was there anything offered that you found unhelpful? Can you try to explain why?

12 ALL WOMEN

What were/are the important things about your experiences during the trial that you would want the research team to consider when planning a larger trial?

As appropriate, probe:

- Defined benefits & concerns e.g. effects of treatments.
- Intervention specific issues e.g. quality of life (pain, impact on relationship and independence/dependence etc);
- Timing and settings for treatment delivery; length of talking therapies; adjustment time when treatment stops; enormity of difficulties; quality of life etc.

13 ALL WOMEN

What information should be fed back to you about the results of this trial?

As appropriate, probe:

- Factors which influenced participants to consent;
- Why patients withdrew;
- Other patients experiences;
- Views of the staff involved;
- Feasibility.

Finally, is there anything else about how patients are involved in the trial and receive their care that you would like to add?