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Supplementary File 1 – Semi-structured interview guide for focus group with patients and caregivers

Introduction

Good afternoon everybody and welcome! Thank you for being here today and for helping us in the creation of our educational booklet on Low Anterior Resection Syndrome, also know as LARS.

Today I will be asking you about your impressions and feedback of the booklet.

My name is Richard Garfinkle – I am a senior resident in General Surgery and have been conducting research with the Colorectal Surgery group for many years.

You were all invited because you've all undergone surgery for rectal cancer and have been identified by your doctors as having experience with bowel dysfunction since your operation. Your doctors also thought you'd be great participants for this focus group, and we appreciate your input.

There are no wrong answers but rather differing points of view.

Please feel free to share your point of view even if it differs from what others have said. Keep in mind that we're just as interested in negative comments as positive comments, and at times the negative comments are the most helpful.

You've probably noticed the microphone. We're tape recording the session because we don't want to miss any of your comments. People often say very helpful things in these discussions and we can't write fast enough to get them all down. We will be on a first name basis today but we won't use any names in our reports. You may be assured of complete confidentiality.

To respect each other's confidentiality, what has been said here will stay here. Is everyone comfortable with that?

In respect of everyone's time, we will try to wrap this up in under an hour. We may go a little over, but not more than 15 minutes. Is everyone okay with that? If you have to leave at any point, not a problem, just let me know when.

Well, let's begin. We've placed name cards on the table in front of you to help us remember each other's names. Let's find out some more about each other by going around the table. Everyone can introduce themselves by name, and in one or two sentences, describe your story with rectal cancer and your treatment.

Given everyone a chance to speak. Then proceed with the following:

Now that everyone has been introduced, we can go on with discussing the LARS booklet.

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General overview

Overall what is your impression of the booklet?

Who had heard about LARS before reading this booklet, and how / from where?

Was LARS or bowel function after surgery discussed with your surgeon?

What did you like about the booklet?

What did you not like about the booklet?

Have you read or found similar booklets like this one in the past, and where did you find them?

Content

Did you like the information that was chosen for the booklet?

Was there any topic about LARS that was discussed in too much detail?

Was there any topic about LARS that was discussed in too little detail, or not discussed at all? How was the overall length of the booklet?

In your experience dealing with LARS, have you learnt any tips and tricks that should be added to the booklet?

Are there important abdominal or bowel symptoms that you've had to deal with that are missing from this booklet?

What new information did you learn from this booklet?

For the caregivers in the room: how can the booklet be made better for caregivers to learn about LARS?

Clinical relevance

Would you have liked to receive a booklet like this before your rectal cancer operation? How would this booklet have better prepared you for life after surgery? Would you like an Internet (online) or mobile-application version of the booklet? Do you see yourself reading over this booklet only before surgery, or would you use it again after surgery?

LARS diaries

Have you used bowel or food diaries before? And who suggested you use one?

How did using a diary help you?

What are your thoughts about the diaries that we've included in the booklet?

Would you use these diaries? And how often?

Would you prefer the diary as an online diary or as an app?

How would you improve the diaries?

Final comments

Do you have any final comments?

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We've come to the end. Thank you everyone for your time and feedback! It is really appreciated and the past hour or so has been very productive. If anyone has any concerns or anything they want taken out of the recording, let me know, it's not a problem. I'll stick around after to talk if you have anything to say.