**Q**uality of Life **A**fter **B**ladder **C**ancer**:**

a Qualitative Interview Study. (Q-ABC - QIS

Participant Information Sheet (Carer)

We would like to invite you to consider taking part in an interview based study relating to your experience as a carer or supporter of someone who has received treatment for bladder cancer.

We are interested in meeting with people who have supported family or friends during either surgery or radiotherapy, even if you no longer perform a “carer” role.

This information sheet explains why the study is being carried out and what it will involve – please take the time to read it carefully and feel free to discuss it with others if you wish. Part one tells you about the purpose of the study and what will happen if you take part. Part two contains more detailed information about the conduct of the study.

If you have any questions the researcher (Dr Sally Appleyard) will be happy to discuss the study further – contact details are at the end of the leaflet.

Thank you for reading this

**Part One**

**What is the Study about?**

This study has been set up to explore the quality of life of patients and their carers following treatment for bladder cancer (surgery or radiotherapy). At present patients and their family and friends may be presented with the choice of surgery or radiotherapy. There is relatively little information available about the impact of these treatments on quality of life. This study is designed to explore how people’s lives are affected after treatment.

**Why have I been invited to take part in the study?**

You supported someone who had surgery or radiotherapy for bladder cancer within the past 2 years.

**Do I have to take part?**

Taking part in the study is entirely voluntary and whether or not you choose to take part will have no influence your relative or friend’s ongoing care. If you do decide to take part in the study you are still free to withdraw from the study at any time without giving a reason. Again, this will have no impact on your relative or friend’s ongoing care.

**What does the Study involve?**

The study involves an informal interview lasting approximately one hour with the researcher: Dr Sally Appleyard, who is trained and experienced in conducting such interviews.

This interview will take place between 1 and 2 years following treatment. The interview will involve discussion of how the cancer and treatment have impacted on your relative or friend’s quality of life, as well as your own, including physical and emotional changes. The discussion will also cover your relative or friend’s experience of deciding between treatments, if they were offered a choice.

The interview can take place at your home or at your local hospital if you prefer. It will be at a time that is convenient for you. The interview will be audio-taped and you will be given the choice of receiving a short report of the findings of the study.

**Will my taking part in the study be kept confidential?**

Yes – all information about you collected during the study will be kept strictly confidential. Further details can be found in part 2 of this information sheet.

**What are the possible disadvantages and risks of taking part?**

The interview will be arranged to try to minimise any inconvenience to you but it will take approximately one hour of your time.

It may be that the interview generates negative thoughts and feelings, this is not the intention of the interview. If you have any concerns during the interview it can be slowed down or stopped.If necessary support will be available following the interview from the research team and local clinical nurse specialist (details at the end of this information sheet).

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**What are the possible benefits of taking part?**

There is no direct benefit to you for taking part, however, some people might feel that having time to discuss their thoughts and feelings is beneficial.

If this study identifies issues that are important to patients and carers which are not routinely discussed in clinic visits or measured in trials this study may help improve the care given to patients in the future, including information provided and support services.

**Does the person who had treatment have to take part?**

No - either the person who had treatment or their carer can take part regardless of whether the other person is – i.e. you do not have to participate as a pair.

What is discussed in each interview will be kept confidential and not revealed to the associated patient or carer.

**Part two**

**What happens if I don’t want to carry on with the study?**

You are free to withdraw from the study at any time without giving a reason. This will have no impact on your relative or friends’ ongoing care.

**What if there is a problem?**

If you have any concerns about any parts of the study you can speak to the researcher who will be happy to meet and discuss your questions. If you remain unhappy and wish to complain formally you can do so through the NHS complaints procedure, each hospital has a patient advice and liaison department (PALS).

**Will my taking part in the study be kept confidential?**

Confidentiality will be regarded at all times. The discussion in the interview will not be shared with the team looking after your relative or friend. If the research team are concerned that your relative or friend are experiencing symptoms or poor quality of life that might be improved with further support they will contact you directly to ask your permission to contact them and then seek their permission to contact a member of their hospital team or GP.

All written and recorded information will be kept securely. The audio-recordings will be destroyed at the end of the study or sooner if you decide to withdraw.

The transcript of your interview and analysis of the interview will be anonymous. Any quotes from your interview used in the analysis and report of the study will be anonymous.

**Involvement of the General Practitioner (GP)**

We will ask your permission to inform your GP that you are involved in the study, they will not receive any information about what is discussed during your interview.

**What happens to the results?**

The results of the study will be used to inform doctors and the wider NHS about the impact of these treatments on quality of life. This will allow more complete information provision for patients contemplating treatment. The results will be presented at conferences and published in peer reviewed journals. No patient –identifying details will be included. The study is part of Dr Sally Appleyard’s MD (similar to a PhD) and will be included in her thesis – no patient identifying details will be included.

**Who is organising the study?**

Brighton and Sussex University Hospitals is sponsoring the study.

**Have patients and the public been involved in designing the study?**

Representatives from the national patient group “Fight Bladder Cancer” and the Sussex Cancer Partnership group have been involved in designing the study.The Jaffa panel (patient and public involvement group) at Brighton and Sussex university hospitals have also reviewed participant information sheet and interview topics.

**Who has reviewed the study?**

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect the interests of patients. This study has been reviewed and given favourable opinion by the South East Coast Brighton & Sussex Research Ethics Committee.

**Who can I contact for more information?**

If you have any questions or would like to discuss this study in more detail then please speak to the research team at your hospital or contact the lead researcher (Sally Appleyard) as below.

**Contact details**

Dr Sally Appleyard CIRU

Tel. 01273 696955 ext 7044 Royal Sussex County Hospital

Email: sally.appleyard@bsuh.nhs.uk Eastern Road

Brighton

BN2 5BE

**What happens now?**

You will be given some time to read think about the study and discuss it with anyone you like. If you have agreed with the person who gave you this information sheet – the researcher will contact you within the next week to answer any questions and see if you are interested in taking part.

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