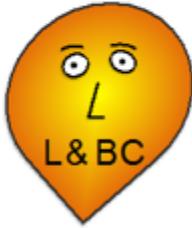


SUMMARY SHEET



Life And Bladder Cancer

The Yorkshire Cancer Research

Bladder Cancer Patient Reported Outcomes Survey

Survey of people newly diagnosed with bladder cancer

You are being invited to take part in a study. This is a short summary of the study. There is also the longer, full information sheet enclosed, if you would like more details.

Before you make up your mind, it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully. Discuss it with relatives and friends if that would help.

What is this study about?

We want to find out what life is like after a diagnosis of bladder cancer. We will do this by asking people who have been diagnosed with bladder cancer to complete some questionnaires at 4 time points after their diagnosis.

All opinions are important. We would like to hear from you, whatever your age, stage of bladder cancer, whether you have symptoms or not and no matter what other medical conditions you may have.

Can I choose whether or not to take part?

Yes, taking part is voluntary and will not affect your medical care. Your medical team will not find out the results of your survey.

If you decide to take part, we will ask you to sign a consent form. You will be given a copy of the consent form to keep. Even if you sign the consent form, you can leave the study at any time without giving a reason. If you decide you do not wish to take part, or you pull out part way through, it will not affect your rights and will not affect your current or future treatment in any way.

You do not have to make your mind up straight away. If you want longer to think it over, a member of the local study team will telephone you after



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2 weeks or send a letter to ask if you have any other questions and whether you want to take part or not.

What will happen if I take part?

We will ask you to complete a questionnaire 4 times; the first is around 3 months after your diagnosis. The rest are at 6, 9 and 12 months after your diagnosis.

Questionnaires can be completed on paper (and posted back in the freepost envelope provided), over the phone, or online (via a secure website). You will be asked how you would like to fill in the questionnaires. When you have consented, you will be sent the first questionnaire by an NHS approved survey provider (by email or by post).

We will ask questions about your general health, your treatment, symptoms and side effects. We will also ask questions about you and your everyday life (e.g. to do with work, your marital status). Some of the questions will be asked in all 4 questionnaires, so we can track how things are changing over the year. The questionnaires will take about 30 minutes to do, but you don't have to answer all the questions in one go. We would like you to answer as many of the questions as possible, even if you don't have any problems – as it is important for us to know this.

Will my taking part in the study be kept confidential?

Yes, your taking part will be kept confidential.

What if there is a problem?

If you want to discuss any concerns about taking part, please telephone the Life And Bladder Cancer study Freephone helpline on 0800 917 1163.

If you have any concerns about your diagnosis and treatment, please speak with your bladder cancer doctor or GP. If you would prefer to speak to someone who is not your bladder cancer doctor or GP, you can telephone *Fight Bladder Cancer* on 01844 351621. *Fight Bladder Cancer* is a bladder cancer charity that will listen to your concerns and offer support and helpful information (Monday – Friday 9:30 – 4:30pm). You can also email them at info@fightbladdercancer.co.uk, fill out an online contact form at <http://fightbladdercancer.co.uk/contact-us> or visit the website <http://fightbladdercancer.co.uk>.

Thank you for reading this information sheet