



The
University
Of
Sheffield.



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Life and Bladder Cancer: The Yorkshire Cancer Research Bladder Cancer Patient Reported Outcomes Survey

Survey of people newly diagnosed with bladder cancer

Additional information about how your personal data is being used in this research study

The University of Sheffield is the sponsor for this study based in England. We will be using information from you and your medical records in order to undertake this study and will act as the joint data controller for this study along with the University of Leeds. This means that we are responsible for looking after your information and using it properly. The University of Sheffield have appointed an NHS approved survey provider, Quality Health Ltd who will keep identifiable information about you for 10 years after the study has finished.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we may keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

You can find out more about how we use your information by referring to your patient information sheet, visiting the study website (lifeandbladdercancer.org) or contacting the study project office on 0114 215 9039. A copy of the study privacy notice is available on the study website

Personal data collected directly from participants e.g. questionnaires

Your local treating NHS hospital will collect information from you and your medical records for this research study in accordance with our instructions.

Your local treating NHS hospital will keep your name, NHS number, date of birth, date of diagnosis, gender and contact details confidential and will not pass this information to University of Sheffield or University of Leeds. Your local treating NHS hospital and Quality Health Ltd will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded for your care, and to oversee the quality of the study. Certain individuals from University of Sheffield and regulatory organisations may look at your medical and research records to check the accuracy of the research study. University of Sheffield and the University of Leeds will only receive information without any identifying information. The people who analyse the information will not be able to identify you

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and will not be able to find out your name, NHS number, date of birth, date of diagnosis, gender and or contact details.

The NHS approved study survey provider, Quality Health Ltd will keep identifiable information about you from this study for 10 years after the study has finished.

Information provided indirectly e.g. being obtained from previously collected medical records

The University of Sheffield and the University of Leeds will collect information about you for this research study from your local treating NHS hospital and Quality Health Ltd. Your local treating NHS hospital and Quality Health Ltd will not provide any identifying information about you to the University of Sheffield and the University of Leeds. Your local treating NHS Hospital will take clinical and treatment data from patient hospital records. This information will be used by your local treating NHS Hospital to complete case report forms, which will then be sent to the research team at the University of Sheffield. These will only contain a unique study ID number and no identifiable data