



The  
University  
Of  
Sheffield.



UNIVERSITY OF LEEDS

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

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

As a university we use personally identifiable information to conduct research to improve health, care and services. As a publicly funded organisation, we have to ensure that it is in the public interest when we use personally-identifiable information from people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use your data in the ways needed to conduct and analyse the research study. 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.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#).

If you wish to raise a complaint on how we have handled your personal data, you can contact our Data Protection Officer who will investigate the matter. If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO).

Our Data Protection Officer is Anne Cutler and you can contact them at [a.cutler@sheffield.ac.uk](mailto:a.cutler@sheffield.ac.uk)

### In the survey of people diagnosed with bladder cancer in the last 10 years (cross sectional survey)

The University of Sheffield and the University of Leeds will collect information about you for this research study from the National Cancer Registration and Analysis Service (NCRAS) and Quality Health Ltd. NCRAS and Quality Health Ltd will not provide any identifying information about you to the University of Sheffield and the University of Leeds. We will use this information as follows:

Participants will be identified by NCRAS, who will create a list of patients. This data will be sent to Quality Health Ltd for the purpose of sending out the surveys. Data provided to Quality Health Ltd (the data processor) is identifiable but will not be made available to the data controllers (University of Sheffield and University of

Leeds). Completed surveys will be returned to Quality Health Ltd, who will clean the data to remove any patient identifiable information.

Survey response data will be shared with NCRAS. This data will be shared for the purpose of NCRAS linking survey response data to patient's disease and treatment information contained within cancer registration records, medical records and NHS databases. NCRAS has access to identifiable data but this will not be made available to the data controllers.

Survey response data and linked information about disease and treatment will be sent to the University of Leeds for analysis. This will be de-identified and will only include the unique study ID number. It will not include identifiable patient information. This means that details such as your name, NHS number and address will be removed.

### **In the survey of people newly diagnosed with bladder cancer (longitudinal survey)**

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.

When you agree to take part in a research study, the information about your health and care may be provided to researchers running other research studies in this organisation and in other organisations. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad. Your information will only be used by organisations and researchers to conduct research in accordance with the [UK Policy Framework for Health and Social Care Research](#).

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of health and care research, and cannot be used to contact you or to affect your care. It will not be used to make decisions about future services available to you, such as insurance.