Privacy Notice for the Life and Bladder Cancer (LABC) study

The LABC study is a quality of life survey of bladder cancer patients in Yorkshire, North Derbyshire, Humber and South Tees.

We are carrying out this research study to find out more about the quality of life for people who have been diagnosed with and treated for bladder cancer and to understand the long term effects of bladder cancer on their lives.

The University of Sheffield and the University of Leeds are running the study and are joint data controllers.

Data Controller: The University of Sheffield, Western Bank, Sheffield S10

Data Protection Officer: Anne Cutler

Data Controller: The University of Leeds, LS2

Data Protection Officer: Adrian Slater

The study sponsor is the University of Sheffield. Their Data Protection Officer is Anne Cutler and you can contact her at a.cutler@sheffield.ac.uk

As universities 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 the 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) as detailed below.

Supervisory Authority:

The Information Commissioner
Wycliffe House
Water Lane
Wilmslow

Cheshire
SK9 5AF

Telephone: 0303 123 1113 or 01625 545745

LABC Study Office:

If you would like to discuss anything relating to the LABC study please contact:

Sarah Bottomley, LABC Project Coordinator

s.e.bottomley@sheffield.ac.uk

Telephone: 0114 215 9039

The legal basis for your processing is:

Section 251 of the Health and Social Care Act 2006 until 24th May 2018.

And then:

Article 6(1) (e): processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller
and
Article 9 (j): processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89 (1) based on Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject from 25th May 2018 when the General Data Protection Regulation (GDPR) comes into effect.

In order to send out the surveys the study needs to access personal data. This privacy notice explains what personal data we are processing and why.

LABC has two complementary sub studies as described below:

1) **Longitudinal study- a survey for people newly diagnosed with bladder cancer**

This study will survey newly diagnosed bladder cancer patients from the Yorkshire, North Derbyshire, Humber and South Tees areas.

Where we collect information about participants
We collect information about participants in two ways:

- When participants give information to us **DIRECTLY**

Participants who have given informed consent to take part in the study may give us information by completing our survey either via post or online. The survey will not ask for personal details such as names and addresses and each survey will include a unique study ID number. Participants will complete their survey online or return it in the post to an NHS approved survey company, Quality Health Ltd, (the data processor). Quality Health Ltd will remove any personal information that may identify participants. This data will then be sent to the University of Leeds for analysis.
As part of the consent process participants will be asked for their name, address, NHS number and email address (for the online option only). These details will be used to send the surveys.

- When participants give information to us I**NDIRECTLY**

For the longitudinal study, recruited patients are required to give their informed consent for the local research teams at recruiting hospitals to complete case report forms that include their clinical and treatment data. This data will be taken from patient hospital records. These case report forms will be sent to the research team at the University of Sheffield. These will only contain a unique study ID number and no identifiable data. Data will be sent securely.

What personal data will be collected and how will it be used

If participants give their informed consent to take part in the study, personal details including name, date of birth, date of diagnosis, gender, NHS number, address, postcode, preferred contact option and email address for the online option (if applicable) will be collected by the local research team at their participating NHS Hospital. Each participant will also be allocated a unique study identification (ID) number.

Participants ID number and identifiable data will be sent securely from recruiting hospitals to the National Cancer Registration and Analysis Service (NCRAS), part of Public Health England (PHE). NCRAS will securely store this information.

NCRAS will transfer this patient identifiable information and the study ID to Quality Health Ltd. Quality Health Ltd will use this information for the purpose of sending surveys to consented participants.

In order to send the surveys, Quality Health Ltd will submit identifiable data (name, postcode, NHS number date of birth, gender) to NHS Digital who will carry out death checks and address checks. NHS Digital carry out these checks so that surveys are sent to the participant's most recent address and so that surveys are not sent to participants who have died. The refined list of patients who are not deceased, along with up-to-date addresses will be provided to Quality Health Ltd.

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).

Participants will return their surveys to Quality Health, either by mail or online. Quality Health Ltd will clean the data received from the survey responses and remove any personal information that may identify you. Survey response data will be sent to the University of Leeds for analysis. This will be de-identified and will be only include the unique study ID number. It will not include identifiable patient information.

How can participants opt out of the study?

Participants who receive a survey but who wish to opt out of the study, and for their information to not be used will be instructed to contact the survey provider, Quality Health Ltd on the Freephone helpline number 0800 917 1163.

Participants can also opt out by contacting the survey provider by email at:

info@quality-health.co.uk

Or writing to the following freepost (no stamp required) address:

Freepost

Quality Health Ltd

Unit 1 Holmewood Business Park

Chesterfield Road, Holmewood,

Chesterfield, Derbyshire S42 5US

Rights available to individuals in respect of the processing

You can leave the study at any time without giving a reason. If you pull out, it will not affect your rights and will not affect your current or future treatment in any way.

We will use the information collected from you up to the time that you pull out of the study, unless you ask for your information to be removed. If you do not want us to use your information, we can remove it for up to 2 weeks following the completion of the latest questionnaire. This has to be limited to 2 weeks as some of the analysis we plan to do includes recently collected data.

If you would like to pull out of the study and for your information to not be used, please telephone the Free phone study helpline on 0800 917 1163.

Data Retention
The NHS approved survey provider, Quality Health Ltd, will destroy your personal details once the study has closed. The survey provider will keep completed paper and online questionnaires for 10 years after the study has closed.

2) Cross sectional study- a survey for people who have been diagnosed with bladder cancer in the last ten years

This study will survey patients diagnosed with bladder cancer in the Yorkshire, North Derbyshire, Humber and South Tees areas in the last 10 years

Where we collect information about participants
We collect information about participants in two ways:

- When participants give information to us **DIRECTLY**

Participants may give us information by completing our survey either via post or online. The survey will not ask for personal details such as names and addresses and each survey will include a unique study ID number. The front page of the survey will ask participants to tick the box if they consent to take part in the survey. When participants complete their survey online or send it back in the post to Quality Health Ltd, this will also be considered as consent to take part in the study. Quality Health Ltd will remove any personal information from the surveys that may identify participants. This data will then be sent to the University of Leeds for analysis.

- When participants give information to us **INDIRECTLY**

Participant data from cancer systems, medical records and NHS databases will be provided to the University of Leeds by The National Cancer Registration and Analysis Service (NCRAS), part of Public Health England (PHE). NCRAS has approvals to work with cancer patient data.

What personal data will be collected and how will it be used

For the cross-sectional study, patients will be identified by NCRAS, who will create a list of patients.

This data will be sent to Quality Health Ltd. Before any surveys are sent out, Quality Health Ltd will send this data to NHS Digital who will carry out death checks, address checks and remove patients who have registered a type 2 objection. The refined list of patients who have not registered a type 2 objection and are not deceased, along with up-to-date addresses will be provided back to Quality Health Ltd. Quality Health Ltd will be provided with patients' names and addresses. This data allows Quality Health Ltd to send 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.

NCRAS take great care to keep the information they hold about patients confidential and, as with other medical records, strict ethical and security safeguards are in place and access is strictly controlled. Information about the National Cancer Registration and Analysis Service including why information about patients and their cancer is recorded, how this information is used, and how, if you wish, you can see your information or have it removed can be found here www.NDRS.nhs.uk.

How can participants opt out of the study?

Patients who have registered a type 2 objection prior to the start date for the work will not be contacted as part of this work. Patients who receive a survey but who wish to opt out of the study, and for their information to not be used will be instructed to contact the survey provider, Quality Health Ltd on the Freephone helpline number 0800 917 1163.

Participants can also opt out by contacting the survey provider by email at:

info@quality-health.co.uk

Or writing to the following freepost (no stamp required) address:

Freepost

Quality Health Ltd

Unit 1 Holmewood Business Park

Chesterfield Road, Holmewood,

Chesterfield, Derbyshire S42 5US

Rights available to individuals in respect of the processing

You can pull out of the study at any time without giving a reason. If you pull out, it will not affect your rights and will not affect your current or future treatments in any way.

If you do not want us to use your information, we can remove it for up to 6 months following the completion of the questionnaire. We cannot remove information that you have provided after this time, as the research team will have started using this information for analysis and reporting.

If you would like to pull out of the study and for your information to not be used, please telephone the FREEPHONE study helpline on 0800 917 1163.

Data Retention

The NHS approved survey provider, Quality Health Ltd, will destroy your personal details once the study has closed. The completed paper and online questionnaires will be stored securely for 10 years after the study has closed.

Reporting plans

The results from both surveys will be made available to patients, their partners/spouses/carers, the funders, NHS, social care, voluntary sector organisations and other researchers through public and professional reporting.

Reported results will not contain any patient identifiable data.