

NPCA Patient Survey: Privacy/Fair Processing Notice

What is the National Prostate Cancer Audit?

The [National Prostate Cancer Audit \(NPCA\)](#) is a collaboration between the Clinical Effectiveness Unit at the Royal College of Surgeons of England (RCS), the British Association of Urological Surgeons (BAUS) and the British Uro-Oncology group (BUG). The NPCA Project Team is based at the RCS.

The aim of the NPCA is to assess the care provided to men diagnosed with prostate cancer in England and Wales and the outcomes it achieves. By auditing the care delivered by cancer services, we can highlight areas where hospitals are doing well, and areas in which the quality of care can be improved. By producing information for all NHS providers of cancer services, it allows these providers to compare themselves with others in England and Wales, and share examples of good practice.

The NPCA also determines the quality of care delivered to NHS patients by capturing the patient perspective through a **NPCA Patient Survey**, a postal questionnaire sent directly to men with prostate cancer.

The NPCA is commissioned by the Healthcare Quality Improvement Partnership (HQIP) on behalf of NHS England and the Welsh Assembly Government, as part of the National Clinical Audit and Patient Outcomes Programme.

What is the NPCA Patient Survey?

The NPCA Patient Survey is designed to determine patients' views of their experience of care and outcomes following diagnosis and treatment. Patients are asked questions about their quality of life, side effects, sexual/urinary/bowel complications, the information they received about their prostate cancer diagnosis and treatment options, and how the decision about their initial treatment was made.

The NPCA Patient Survey is sent to men who underwent radical surgical or radiotherapy treatments, in addition to those men who are being closely monitored for disease progression, 18 months after diagnosis.

What is a privacy notice?

The EU General Data Protection Regulation (GDPR) requires that data controllers provide certain information to people whose information (personal data) they hold and use. A privacy notice is one way of providing this information. This is sometimes referred to as a fair processing notice. A privacy notice should identify who the data controller is and give contact details for its Data Protection Officer. It should also explain the purposes for which personal data are collected and used, how the data are used and disclosed, how long it is kept, and the controller's legal basis for processing.

Our data protection responsibilities

[HQIP](#) is the **Data Controller** (as defined by the Data Protection Act 2008 and all applicable laws which replace or amend it, including the GDPR) with respect to any personal data that will be processed for the conduct of the NPCA Patient Survey. This means that HQIP are responsible for deciding how personal information is used for the Survey, making sure there are appropriate technical and organisational safeguards to protect the data and for upholding the rights of any person whose data is processed.

HQIP has instructed Quality Health Ltd (a specialist survey company) to administer the NPCA Patient Survey as a **Data Processor**. Processors are required to process personal data in accordance with the controller's instructions. HQIP's Interim Data Protection Officer: Sasha.Hewitt@hqip.org.uk

How do we select potential participants?

Potential participants are selected by the NPCA Project Team at the Royal College of Surgeon's Clinical Effectiveness Unit using information that has been collected by the [National Cancer Registration and Analysis Service \(NCRAS\)](#) in England and the [Wales Cancer Network \(WCN\)](#). These organisations are allowed to collect data on patients diagnosed with cancer.

The information provided to the NPCA Project Team is de-personalised - patient identifiable information including name, address, date of birth, address, postcode and NHS number is removed by NCRAS and WCN before they are securely transferred to the NPCA Project Team.

NCRAS and WCN provide clinical information for every man diagnosed with prostate cancer in England (since 2014) and Wales (since 2015) to the NPCA Project Team for analysis. A unique NPCA identifier enables the NPCA Project Team to link with information from other [national datasets](#) about the diagnosis, management and treatment of all men newly diagnosed with prostate cancer including staging, mode of admission, comorbidities, surgical procedure or intervention details, radiotherapy and chemotherapy details, readmissions and complications.

The unique NPCA identifiers of men selected as potential participants of the Patient Survey are securely returned to NCRAS and WCN. The NPCA Project Team will not know the identity of these men.

How do we invite potential participants?

Confidential information (NHS number, patient name, surname, address, postcode and date of birth) for the patients in the NPCA Patient Survey cohort will be securely transferred by NCRAS and WCN to Quality Health Ltd for the purpose of administering the NPCA Patient Survey. Quality Health Ltd will access NHS Digital's *National Data Opt-outs Service* to ensure that patients who have expressed that they do not want their data to be used for secondary purposes as part of the National Opt Out Programme will be excluded.

When sending the details of each eligible man to Quality Health Ltd, their data will be accompanied by the unique NPCA identifier that will allow their survey responses to be linked to health information about the patient's diagnosis and care by the NPCA Project Team at the Royal College of Surgeon's Clinical Effectiveness Unit.

All data is stored and analysed in a secure environment that complies with [NHS Digital's Data Security and Protection Toolkit](#).

Quality Health Ltd will access NHS Digital's *Demographic Batch Service* to carry out mortality checks and retrieve the current patient address for those men in the NPCA Patient Survey cohort. Before a questionnaire is sent out to a patient's home address, a mortality check will be carried out that the patient is alive to minimise the risk that questionnaires are sent to bereaved families. Address checks will be carried out to ensure that the patient address held is still current.

NCRAS, WCN and Quality Health Ltd take their information security responsibilities seriously and apply a number of measures to ensure your information is protected from loss, theft or misuse. Security precautions include appropriate physical security of offices and controlled and limited access to computer systems. Stringent measures have been taken to ensure personal information is securely stored and seen only by the personnel directly involved in the project.

Legal basis for processing personal data to administer the NPCA Patient Survey

Processing personal data (confidential information) requires justification under two legal frameworks: the GDPR/Data Protection Act 2018 and under the common-law duty of confidentiality:

Under GDPR/Data Protection Act 2018, HQIP's basis for lawful processing the *personal data* is 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."*

Some types of personal data, such as health data, are additionally classified as 'special category personal data'. The law considers special category personal data to be more sensitive and gives it more legal protection (for more information see: ICO website: Special Category Data). HQIP's legal basis for processing special category personal data is Article 9(2)(h)– *"processing is necessary for the purposes of preventive or occupational medicine, for the assessment of the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or the management of health or social care systems and services"*

In addition, to be able to contact eligible patients without their consent, we have [obtained special permission](#) to obtain and process personal data under [section 251 of the National Health Act 2006](#) (15_CAG_0143_NPCA Patient Survey). This permission enables NCRAS and WCN to share personal confidential data for patients who are eligible for the patient survey with Quality Health Ltd, so that the NPCA Patient Survey can be administered. More information on section 251 of the National Health Act 2006 is available [here](#).

What happens once I've completed the Survey?

Completed surveys are returned to Quality Health Ltd who clean the response data by removing all patient identifiable information including name, address, date of birth, address, postcode and NHS number. De-personalised response data is securely transferred to the NPCA Project team at the Royal College of Surgeon's Clinical Effectiveness Unit which is responsible for analysing the Patient Survey responses.

What happens to my answers?

The NPCA Project Team link de-personalised answers to the NPCA Patient Survey with de-personalised patient-level, clinical information about disease and treatment on the basis of a unique NPCA identifier for analysis.

The RCS has strict security measures in place to safeguard the use and storage of de-personalised patient-level information, which is handled in accordance with the GDPR. All de-personalised data extracts are stored and analysed in a secure environment that complies with [NHS Digital's Data Security and Protection Toolkit](#).

The NPCA is also careful when publishing information to include graphs or tables that do not allow individuals to be identified. To ensure this, the Audit follows guidelines on publishing statistics issued by the [Office for National Statistics - Review of the Dissemination of Health Statistics: Confidentiality Guidance \(PDF\)](#).

Will my doctor see my answers to this survey?

Your response to the questionnaire will not be shared with your doctor.

Who do we share data with?

When you agree to take part in the NPCA Patient Survey, the information about your health and care may be provided to researchers running other studies in service evaluation and healthcare improvement. These organisations may be universities, NHS organisations or companies involved in health and care research in this country or abroad.

Researchers who want to use data from the NPCA Patient Survey for a research study need to apply to HQIP. These requests undergo a stringent approval process as outlined [here](#). Data will only be shared according to strict governance procedures to ensure compliance with the GDPR and other relevant legislation. As explained earlier, the data that will be shared will not identify you and researchers will not be allowed to combine the data with other information in such a way that it will be possible to identify you.

What if I do not want my clinical patient-level information used by the NPCA?

The [National Cancer Registration and Analysis Service \(NCRAS\)](#) in England and the [Wales Cancer Network](#) are allowed to collect data on patients diagnosed with cancer. Information on how to opt out of data collection is provided [here](#).

How can participants opt out of the NPCA Patient Survey?

Participation is voluntary. Patients consent by returning a completed questionnaire and decline by not returning a questionnaire. Participants are free to withdraw the information they have provided to the NPCA Patient Survey at any time without giving any reason, without their medical care or legal rights being affected. If you wish to withdraw from the survey, please contact Quality Health Ltd, the survey provider, on the FREEPHONE helpline number 0800 783 1775.

Participants can also opt out by contacting the survey provider by email: info@quality-health.co.uk.

Alternatively, participants can opt out by writing to the following freepost (no stamp required) address:

Freepost
QUALITY HEALTH

Reporting plans

The results of the NPCA are published in annual reports which are available on the [NPCA website](#) to provide information regarding the type and extent of prostate cancer and the quality of prostate cancer services and treatment in England and Wales. [Individual provider-level results](#) are available enabling regional and national comparison of performance. [Summaries of the annual reports](#) are prepared for patients and the general public and available on the NPCA website alongside additional information. NPCA results are also communicated in conference presentations and peer-reviewed publications.

How long will the NPCA Patient Survey data be retained?

Quality Health will keep electronic response data and identifiable data (name and address information) separately. Identifiable data will be destroyed within three months of completion of the survey. Quality Health will destroy patient response data one year after the anonymised data has been transferred to the NPCA Project Team for analysis.

The de-personalised answers to the NPCA Patient Survey will be retained by the NPCA Project Team for the duration of the Audit.

Changes to our privacy policy

We keep our privacy policy under regular review and we will always include the latest version on this web page. This privacy policy was last updated on 04.12.19.

Your rights

The GDPR includes a number of rights, although not all of these apply where the legal basis for processing is public task, including the right to erasure and data portability. This privacy policy describes how HQIP will discharge its duties in order to ensure compliance with the rights of data subjects.

You have the right to request access to any personal data that is held by Quality Health Ltd up to three months after completion of the survey when patient identifiable information is deleted. You can withdraw your consent and object to the processing of your personal data or survey answers you provide, at any time before the data is processed for reporting.

You have the right to lodge a complaint with the Information Commissioner's Office (ICO) if you have concerns on how we have processed your personal data. You can find details about how to contact the Information Commissioner's Office [here](#) or by sending an [email](#).

How can I contact the NPCA about this survey and/or my personal data?

If you have any questions about the privacy policy, the information we hold about you or how we use your information please contact the NPCA by [email](#) or write to us at:

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