

National Bariatric Surgical Registry (NBSR) Privacy Notice - Data Protection and Confidentiality

This notice explains how patient's personal information is processed, used, kept safe and details individuals' rights with regards to their personal information contained within the National Bariatric Surgical Registry (NBSR).

What is the NBSR database?

The NBSR database is the database in England and Wales for patients undergoing bariatric surgery for weight loss. The information in the database will be used to assess and improve the quality of services and the outcomes achieved by surgical treatment for obesity. It will also provide comparative information to patients, commissioners and regulators of healthcare professionals.

The system itself is supported by Dendrite Clinical Systems Ltd who act as a Data Processor on behalf of the NBSR.

What information does the NBSR contain?

From 2008 medical staff undertaking bariatric surgery for patients began collecting information for the NBSR. The information includes details about patients, the nature of their medical problems; the details of their surgical treatments and outcome data on how well the patients function before and after their treatment including changes in their weight and medical status.

Since 2018 the information importantly also contains NHS number in order to check the patient against national data regarding readmission. This information is vital to help to establish which surgical treatments result in the best short and long term outcomes. These identifiers are also used by your treating organisations to facilitate local care.

Information that is held within the NBSR has been provided by patient care teams at health organisations that have signed up to participate in the NBSR. This includes all NHS providers undertaking bariatric surgery as well as some private hospitals. Additionally data contained within the registry may be provided by patients directly through outcome surveys that may be completed. For more information on this, please visit the below section.

What happens to the data and who can see it?

The data used in the NBSR is collected by the doctors, nurses and hospital staff treating and managing patients before being entered into the NBSR, although some hospitals enter their data directly into their local system and then upload their data to the NBSR. Once records have been entered into the NBSR they can be reviewed by authorised medical staff using an approved user account with a secure password.

When the data has been entered or uploaded by the hospital or clinician, the software engineers and data analysts at Dendrite Clinical Systems will have access to the data to provide end-user technical support and analysis services (under the direction of the NBSR). The data is held on a secure Tier 3 server by an NHS-approved server host organisation (RedCentric) located in London. Some essential data will be cross checked with your hospitals patient administration system or Hospital Episode Statistics data. Hospital Episode Statistics (HES) is a data warehouse containing details of all admissions, outpatient appointments and A&E attendances at NHS hospitals. Cross referencing ensures that data such as readmissions, complications and further operations on patients undergoing bariatric surgery can be accurately captured.

The information collected is valuable as it allows clinicians to understand the profile of patients undergoing bariatric surgery; the treatments employed and the results that are being achieved by hospitals around the country. The data will be analysed by Dendrite Clinical Systems under the direction of NBSR clinicians to produce regular reports. The reports do not contain the details of individual patients but report results for groups of patients. These results may be broken down by region or hospital, and by other important information that may be related to outcomes such as age, general health problems and which type of treatment was employed.

The reports are likely to be used to help commissioners, providers and doctors understand the outcomes of treatment for bariatric surgery.

The data will not be shared with anyone or used for purposes other than those agreed with the NBSR committee.

What data is collected from patients about their outcomes?

Patients may be contacted at regular intervals by post, phone or email questionnaire to fill in to assess their medical, functional and weight outcomes following surgery.

The information that patients provide in these forms will be available to their treating hospital to monitor their health and the success of their treatment. Participation in filling out these outcome questionnaires is not compulsory. At any point you can inform us that you no longer wish to participate and we will no longer provide you with any questionnaires in the future.

What is the legal basis for the NBSR to process personal data?

Personal data processed within the NBSR relies on the following legal basis:

Public task: the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law.

Special Category data is processed under the following condition:

Health or social care (with a basis in law): (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)

NBSR data is collected for a "medical purpose", as defined in the 2006 National Health Service Act Section 251, for the provision of care and treatment and the management of health and social care services. This includes: Preventative medicine, medical diagnosis and the provision of care and treatment and the management of health and social care services.

The data is collected on patients undergoing bariatric surgery in hospitals that are participating in using the registry with the approval of the Secretary of State under Section 251. This approval is reviewed each year and approval sought for the following year.

Where is data stored and for how long?

The data will be held for an extended period of time - if consent is withdrawn any personal data would be immediately removed.

Security

Information contained within the NBSR is held on a server provided by Dendrite Clinical Systems Ltd or their contracted sub processor (RedCentric). All data remains within the UK and held by a tier three data centre, which is securely backed up each day.

Your rights

Under Data Protection laws, you have rights which allow you to find out what information is held about you, on computer and in certain manual records. This is known as "right of subject access.

If you want to see or receive a copy of your records that are held in the NBSR. please visit this webpage (<https://nbsr2.e-dendrite.com/sar.html>) to fill in your details so that we can ensure that we can accurately identify you and authorise your request.

Under the law, you may also have additional rights in relation to your information. For example:

- You also have the right to request any decisions taken by automated decision making with regards to your information (where applicable);
- The right to rectification of your information is found to be inaccurate (in line with NHS Guidelines);
- The right to restrict processing (where applicable);
- The right to data portability (where applicable);
- You may have the right to erasure of your personal information held by us, in certain circumstances.
- You have the right to withdraw consent at any time, where consent has been given. If you wish to be removed from the NBSR, please contact info@bomss.org

If a patient is removed from the registry, we do not keep any data on such patients, and as such those who do not wish to be included in the registry.

Further information

If you would like to know more about how we use your information or if, for any reason you do not wish to have your information used in any of the ways described in this notice please speak to the bariatric health professionals concerned with your care or contact the NBSR using the details below. Further guidance about data protection can be obtained at www.ico.org.uk. You also have the right to lodge a complaint with the Information Commissioners Office.

Contact information

For general queries, patients may wish to consult with their treating care team. For general NBSR queries you can contact the central team by emailing info@bomss.org