

## NBSR Information for Patients

We need help from patients and members of the public to ensure that bariatric surgery is moving in the right direction, by carrying out national clinical audit. Clinical audit is not new; it is something that many health professionals have done for a long time now as part of everyday practice.

The NBSR is different from many national audits in that it aims to monitor the whole patient operative pathway including complications and long term-follow up outcomes. We think this will make the NBSR even more valuable in terms of identifying and promoting best practice and improving patient care in the future.

The NBSR exists to collect important clinical information about all patients having bariatric surgery in the UK. This includes NHS and private patients. The NBSR was started in January 2009 and up to January 2016 has accumulated more than 50,000 patient records, and has published two large-scale reports of clinical outcomes (2011 and 2014). We are very keen now to involve patients in the development and implementation of Version 2 of the registry. This should ensure that the audit is asking questions that are relevant to the patients who have had bariatric surgery and those having surgery in the future.

We are expanding the NBSR for the annual NHS 'Clinical Outcome Publications' that appears for bariatric surgery on the NBSR website, the British Obesity and Metabolic Surgery Society website and on NHS Choices. We are also developing the NBSR to include patient identifying information, including NHS numbers and names, so that surgeons and bariatric care teams can access previous hospital records if a patient has been operated on elsewhere.

We also plan to develop the registry to track long-term outcomes, like improvement in obesity-related disease and survival, which can be assessed from linkages with other databases such as the GP record. For these research purposes we will be applying for research ethics approval later on. Patients won't have to take part in this research if they don't want to and they will be able to opt out at any time if they do take part.

The NBSR Committee meets three to four times a year with members of the audit team and specialists in our registry software company. We are now seeking a lay member to join as well. If you are interested in being a lay member of the committee please let us know and we will send you an Expression of Interest form.

Thank you for taking the time to read the information for patients below. Please give your feedback using the form at the end of the webpage, [nbsr.co.uk/patient-information](http://nbsr.co.uk/patient-information), where you can also download this information.

## FAQ Information for Patients

### *Background*

National clinical audits can provide an excellent way of improving the patient experience and outcomes. Audits enable hospitals to monitor the standard of care received and record information on treatment. All data collected are subject to strict rules of confidentiality so patients do not need to worry about it getting into the wrong hands. Clinical audit is a continuous process and currently the NBSR helps provide information on:

- Data to reassure patients about the safety of surgery - publishing anonymised mortality data from the NBSR for every surgeon in the NHS yearly as part of the NHS Choices Consultant Outcomes Publications programme
- Service structure – providing information on the number of surgeons in each unit and the number of operations they perform each year, and how completely they record their data
- Obesity-related diseases so that we can demonstrate to commissioners, GPs and other healthcare workers how many of our patients are affected by conditions such as type 2 diabetes, high blood pressure, arthritis and sleep apnoea
- Outcomes after surgery that shows the improvement in the obesity related disease, showing how clinically effective bariatric surgery is for patients and for the NHS

If an audit asks the right questions the data collected can also be used as a research database providing a valuable resource for researchers that will inform best practice in the future. It can answer important questions such as:

- Which operation works best for which patient?
- How can we improve a patient's quality of life?
- Can we assess the risks of a particular operation more accurately?
- Can we identify which patients will get the best results?

### *What is the NBSR and who manages it?*

The NBSR is the National Bariatric Surgery Registry for the United Kingdom and Ireland. It aims to improve the quality of services and the outcomes achieved for patients. The data committee is a group of surgeons, run under the auspices of our national society, the British Obesity and Metabolic Surgery Society (BOMSS), running the registry for the benefit of our members and their patients.

### *What does the NBSR measure?*

The registry currently collects information from all hospitals within the United Kingdom that perform bariatric and metabolic surgery for severe and complex obesity. It is an NHS requirement that all patients having NHS bariatric surgery in the UK have their data entered into the registry. This is due to be extended to all private hospitals as well in the near future. The registry collects information about the obesity related diseases, operations on patients who have bariatric surgery, and their outcomes. The findings will contribute to changes in clinical practice ensuring that patients receive the best care possible and experience an improved quality of life.

### *How are the data processed?*

The hospital trust providing your care will send your information to Dendrite Clinical Systems Ltd electronically using secure data transfer methods.

Dendrite will act as guardians for your encrypted data and will store it securely. They may in the future link the data to other NHS databases held by the Health and Social Care Information Centre and Public Health England. These databases hold patient information relating to operation, hospital stays, and measures of obesity related disease. Your name, date of birth and NHS number would be used to link the NBSR to the NHS databases. The linked information will help us to check whether the NBSR data are accurate. Data linkage will also provide information that will help us to improve our understanding about operation choices and how best these benefit patient outcomes and quality of life.

Once a year Dendrite will combine the information from individual hospitals with data from other parts of the United Kingdom. They will process the data and organise it by region, hospital trust and consultant. They will then remove your name, date of birth, NHS number and any other information that could be used to identify you. Dendrite will transfer a copy of the aggregated data, without personal identifiers, to the NBSR Committee to produce statutory reports such as the NHS Choices Consultant Outcomes Publication. NBSR results at regional, hospital trust and consultant levels will be compared with each other, and also with national standards of care for patients with severe and complex obesity that have been set out by the National Institute for Health and Care Excellence (NICE). Anonymised NBSR and NHS data can also be used to answer important, ethically approved, research study questions that could change clinical practice. If any patient wishes to opt out of their identifiable data being used for research purposes they will have the opportunity to do so.

### *Who will benefit from the NBSR data?*

Stakeholders – staff, patients, carers, managers and the public will use NBSR reports to assess the quality of care provided. They will also be able to see how closely local practice aligns to NICE and BOMSS guidelines. The NBSR Committee will publish regular reports in addition to the Consultant Outcomes Publications that will enable stakeholders to check progress and assess what improvements have been made. New information collected by the NBSR will also help to define, add to and refine existing NICE and NHS quality standards.

The NBSR data may be shared for research purposes within the European Economic Area in a form that will not identify individual patients. The research will always be in line with the overall purpose of the registry aims, for example:

Defining audit standards

Publishing papers in medical journals to provide information about the best standards of care

Providing information for public health

### *How reliable is NBSR data?*

As the NBSR is a large national audit some items are bound to be inaccurate or missing. Linking your data with information in other NHS databases will help us to check whether the data provided by each hospital is complete and accurate.

Once your information has been added to the NBSR only your clinicians will be able to access, check and change it. Dendrite will keep a record of all changes that are made.

### *How do we keep your information safe?*

Data protection and privacy is an important part of the NBSR so no individual patient names can be identified in the published results. The NBSR Committee, BOMSS and Dendrite will make sure the data collected are subject to strict rules of confidentiality as laid down by Acts of Parliament, including the Data Protection Act 1998 and the Health and Social Care Act 2001. National clinical audits have been given permission to use and store patient data in accordance with these strict regulations.

### *How long will we keep your information?*

By collecting a large amount of information, it is easier to identify the most effective operations, which can benefit patients. This can change bariatric surgery so that in future patients will have better outcomes and quality of life after surgery. We will retain the NBSR data for a period of at least 30 years to enable us to collect, assess and report on the long term complications and outcomes of bariatric surgery.

### *Can I opt out of the NBSR?*

National clinical audit is most effective when it has information from as many patients as possible. For NHS funded patients data entry is mandated by national agreements for funding surgery, because the NHS demands that very important information such as mortality and complications for each surgeon are correctly recorded, and reported in the public domain. Only combined data of large groups of patients will ever be published for audit or research, and individual details like NHS number or patient names will never be put into the public domain.

We plan to gain your consent to include your identifiable data. You may opt out from this, and if so your recorded data will not be able to be traced back to you. If you change your mind and want to withdraw consent, please email [info@NBSR.co.uk](mailto:info@NBSR.co.uk) or use the form on the webpage [nbsr.co.uk/patient-information](http://nbsr.co.uk/patient-information) and put "Request to opt-out" in the subject line.

We are also planning to use identifiable patient data for prospective research later on. If you do not want your data used for research you can also opt out from this and it will not affect your treatment in any way. If you wish to find out more about your data currently stored in the NBSR, or want to opt out from the research use (but not from use of the registry for national audit) please complete the website feedback form at [nbsr.co.uk/patient-information](http://nbsr.co.uk/patient-information) and a member of the NBSR data committee will contact you. Alternatively please email [info@NBSR.co.uk](mailto:info@NBSR.co.uk).

Mr Richard Welbourn (Chair), Mr Simon Dexter, Mr Ian Finlay, Mr Marcus Reddy, Mr Peter Sedman, Mr Peter Small, Mr Shaw Somers, Mr Omar Khan, Mr James Hopkins.

NBSR Committee

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