

Patient Information Leaflet



WHAT IS THE BRITISH HERNIA SOCIETY REGISTRY (BHSR)?

The BHSR is a secure database of hernia surgery. It allows us to monitor what operations are being performed and how, including the use of mesh implants. This improves safety by monitoring the results of patients' operations.

Surgeons and hospitals are expected to do this routinely, but a national registry will be far more powerful. Similar databases for cancer, emergency operations and joint replacements in the UK provide accurate and up-to-date information. These have made important discoveries and driven improvements in decision-making, treatment and medical implant technology.

HOW DOES THE BHSR HELP PATIENTS?

The BHSR allows us to:

- Improve patient safety by monitoring how well implants, surgeons and hospitals perform and take action if needed.
 - Compare operations, implants and patient factors (e.g. smoking) that may affect results, to give patients and surgeons as much information as possible, to make the best decisions possible.
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WHAT INFORMATION DO WE COLLECT?

For every hernia operation, we may collect basic information about your operation, any implant used, and your health. This is completely anonymous, unless we have your consent to include your personal details.

Firstly, we ask for your consent to record a few personal details: your name, date of birth, and NHS number. We link this to the information about your operation, which means that if information about you is recorded in the BHSR in the future, (either by you, your surgeon, or from another secure healthcare database) we can connect your records. This allows us to monitor and analyse the results of operations, although your data is hidden from the team doing this.

Secondly, we also ask your consent to record your contact details, and to contact you after your operation. We ask

for your phone number and email address. We do this so we can contact you at 3, 6, and 9 months, and then yearly after surgery, to ask some important questions, only you can answer. We will ask questions about your experience and whether you have had any problems. We arrange for this to be collected by an 'app' or an electronic questionnaire (sent to your phone or email address). This allows us to monitor the long-term outcomes of hernia repairs from the patients' point of view and are known as patient reported outcomes.

WHY DOES THE BHSR NEED MY PERSONAL DETAILS?

Your personal details mean the BHSR can securely link up records about operations, implants, basic health information and your experiences. This means we can see how particular implants, hospitals or surgeons are performing.

DO I HAVE TO GIVE MY CONSENT?

No. If you do not consent we cannot store any identifiable information about your operation or contact you. **Your medical care will be the same whether you give consent or not.** We still record information about your operation, but it is completely anonymous. You cannot be identified and it cannot be linked to any other records. Individual hospitals will store your unsigned consent form as a record.

WHAT DO WE DO WITH YOUR INFORMATION?

The information in the BHSR is analysed to produce reports for surgeons, hospitals and implant manufacturers about what operations are being performed and how. These reports are not about individual patients, rather a summary of operations overall, and you can never be identified from them.

If you consent to us linking your personal details to your record, we can securely link your operation to any information in the future, either entered by you,

your surgeon or imported automatically from another database (such as NHS Digital and NHS Wales Informatics Service). This information includes your experiences, and whether you had any problems or had to come back to hospital. This means we can produce more detailed but anonymous reports about the results of operations (again as a summary, not on an individual basis).

We can also perform research to compare results of operations and implants to guide surgical development and permit us to counsel patients more accurately. Data analysis is anonymised so the identity of patients cannot be identified by the researcher.

We will periodically ask hospitals for information to cross match to our database to ensure our data is accurate and we are not drawing incorrect conclusions. Those who have not consented for their personal details to be included in the registry will not be included.

IS MY INFORMATION SAFE?

Your personal details are completely safe. They are kept confidential at all times in a highly secure database in the UK with very strict rules and secure procedures in line with all data protection laws*. This database is run by a highly experienced registry company (Dendrite Clinical Systems Ltd). Nobody outside the registry team can access your details.

When your information is used for analysis or research, the team doing this cannot see your personal details, and you cannot be identified from any analysis or report. Your surgeon can only view the information that they have entered about you (or another professional, e.g. junior doctor, has entered for them), but not any information you or anyone else has entered.

Your personal details can only be released if required by law.

* The software and data are held on a server in the UK provided by an NHS-approved Tier 3 server host that hold a number of Security and Quality related certifications (including ISO27001, ISO9001, ISO20000 and FACT Content Protection) and is covered by 24x7 manned and CCTV security.

HOW DO I UPDATE MY DETAILS?

If you move away or change email address or mobile number, we ask that you let us know so we can continue to send follow up questions to you intermittently. The information reported by patients is key to measuring outcomes. You can change your details at <https://bhsr.e-dendrite.com>

WHAT IF I CHANGE MY MIND OR WANT TO SEE MY DATA?

You have the right to give or withhold your consent to recording your personal and contact details in the BHSR.

You have the right to see your data. You can do this by completing a patient data management form, which are available at <https://bhsr.e-dendrite.com>

After you have consented, you still have the right to opt out from being contacted for follow-up. We will still keep any information we have, but we will not contact you again. We may still link to other databases, eg NHS databases, to collect long term outcome data. More information is available at <https://bhsr.e-dendrite.com>

You have the right to have your personal, identifiable, details deleted, or all your information deleted. Again, more information is available at <https://bhsr.e-dendrite.com>

HOW TO MAKE A COMPLAINT

If you wish to make a complaint about our collection or use of your personal data, please contact the British Hernia Society (<https://www.britishherniasociety.org/>) in the first instance so that we may seek to resolve your complaint.

You have the right to lodge a complaint with the Information Commissioner's Office (ICO), the statutory body which oversees data protection law in the UK. Please visit the ICO website if you wish to lodge a complaint with the ICO.

The BHS Registry has the duty to ensure your data is processed safely and to notify you if a breach of data security occurs.



British
Hernia
Society

REGISTRY 

For further information:

www.britishherniasociety.org

email: bhsregistry@gmail.com