British Hernia Society
REGISTRY

Frequently Asked Questions for the British Hernia Society Registry

1. WHAT IS THE BRITISH HERNIA SOCIETY REGISTRY (BHSR)?

The BHS Registry is a secure database of hernia surgery that also has patient reported outcome data. It allows us to monitor what operations are being performed and how they are being performed, including the use of mesh implants. By monitoring the results of patients' operations, we can improve safety.

2. WHAT ARE THE AIMS OF THE BHS REGISTRY?

The overall aim of the BHS Registry is to provide the data we need to help improve the management of patients with hernias.

3. HOW IS THE BHS REGISTRY USEFUL TO THE PATIENTS AND PUBLIC?

The BHS Registry will allow us to improve patient safety by monitoring how well implants, surgeons and hospitals perform. It will also allow us to compare operative techniques, implants and patient factors (e.g. smoking) that may affect results. This gives patients and surgeons as much information as possible, to make the best decision possible.

4. WHY WAS THE BHS REGISTRY DEVELOPED?

Currently, the data collection on patients with hernias and hernia operations is poor. By using registries, several other countries have collected a large amount of data which has helped improve outcomes by comparing data and research. In the UK and Ireland, there are registries for other conditions, for example the British Joint Registry collects information about hip and knee replacements. As the BHS, we felt it was very important to see how hernias are managed and to monitor the implants that we use in these operations just as they would for a joint implant.

5. WHO OWNS THE BHS REGISTRY AND DATA?

The British Hernia Society owns the registry and its data but patients can control what types of information are documented about them. Reports on how surgeons or implants are performing will be available to hospitals and to the NHS but this is anonymised and summarised with no identifiable information.

6. HOW WERE PATIENTS INVOLVED IN THE DEVELOPMENT OF THE BHS REGISTRY?

The British Hernia Society and, specifically, our Registry subcommittee, has a patient representative who is well versed in data collection and quality of life issues. They have been instrumental in the registry development and the development of the Patient-Related Outcomes questionnaire, which was designed in conjunction with patients with lived experience of hernia surgery.

7. WHAT IS THE LEGAL BASIS FOR THE BHS REGISTRY?

All databases are required by law to state why they exist. At the BHSR we are collecting and processing patient data on the following legal basis:
Consent: the individual has given clear consent for us to process their personal data for a specific purpose.
More specific data and personal data are classed as 'Special Category data' and a legal basis for collecting this data must exist. At the BHSR we are collecting and processing Special Category data on the following legal basis
Explicit consent: (the patient has given explicit consent)
Health or social care (with a basis in law for a "medical purpose", as defined in the 2006 National Health Service Act Section 251): (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)
Archiving, research and statistics (with a basis in law): (archiving purposes in the public interest, scientific or historical research purposes or statistical purposes).

8. WHAT DATA IS ENTERED IN THE REGISTRY?

For every hernia operation, we collect anonymised basic information, such as if an implant was used and information on general health.

Providing we have patient consent, we collect personal details such as name, date of birth and contact details. We link this to information about the operation, and if information is recorded in the BHS Registry in the future about the same patient, we can connect the records. This allows us to monitor and analyse the results of operations, although data is anonymised to the team doing this.

We also collect data recorded by patients directly called patient-reported outcome measures (PROMS).

Some data, such as a patient being readmitted to hospital, may be obtained by linkage through nationally collected data (NHS databases).

9. HOW ARE PATIENTS FOLLOWED UP BY THE REGISTRY?

Patients are asked to record follow up data at 3, 6, and 9 months, and then yearly after surgery. 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.

10. WHO CAN ACCESS DATA FROM THE REGISTRY ?

The BHS Registry subcommittee can access the data for the purpose of research and improvement. Surgeons can only access the data they put in regarding a patient's operation and no-one else's data. A summarised and anonymised report will be accessible by surgeons and cannot be traced back to individuals. To improve and develop new safer implants, we plan to provide anonymised summarised reports to companies regarding their meshes (implants). Eventually, with enough data, we will be working with NHS procurement to ensure surgeons are all using the safest meshes with the greatest follow-up data.

11. HOW ARE PATIENTS' PERSONAL DATA HANDLED BY THE REGISTRY AND IS IT SAFE?

Personal details are kept confidential at all times and will be kept secure. The data is controlled by the British Hernia Society and secured outside the NHS with up-to-date commercial level security. Very strict rules and secure procedures are in place to ensure the information is kept safe.

Anonymised reports will be released to approved organisations with the aim of improving patient care.

** 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.*

12. CAN A PATIENT VIEW, CHANGE OR REMOVE THEIR BHS REGISTRY DATA?

Patients can view the data held, change their contact details, or withdraw consent via the registry website https://BHSR.e-dendrite.com

13. WHO ELSE THINKS THE BHS REGISTRY IS A GOOD IDEA?

We have the full support of all our governing bodies including the Royal Colleges of Surgeons in England and Ireland. We also have support from the NHS in England and Scotland. The British Hernia Society is one of the largest organisations of surgeons with over 500 members, and they too fully support the development of a registry. Lastly, but not least, we have the support of patient groups who have had hernia repairs. This includes those who have also had poor outcomes from hernia repairs who would like to see an improvement in the management of hernias and the use of meshes.

14. HOW IS THE REGISTRY FUNDED?

Certain aspects, such as development and maintenance of the registry and the website, need funding. Although the registry is strongly supported by both NHS England and Scotland, it is not being funded by the NHS.

To set up the British Hernia Society Registry we received sponsorship from industry, who see the importance of collecting data on their meshes. They do NOT have access to data, and will only receive summarised, anonymised reports from ourselves.

15. WHAT DATA CAN MESH MANUFACTURERS ACCESS?

Mesh manufacturers can request anonymised reports on the outcomes of operations that involve their products only.

16. WILL THE REGISTRY BE KEEPING DETAILS ON WHAT MESH IS USED AND WHAT COMPLICATIONS PEOPLE HAVE?

The registry will collect the data on what mesh is used. We will also look at whether people are readmitted to hospital (due to recurrence of a hernia), and if another operation was needed.

17. IF INDUSTRY HAS HELPED FUND THE SET UP THEN HOW CAN THE REGISTRY BE INDEPENDENT?

Without the industry funding we would not have been able to set up the registry. Whilst they provided the funding, all aspects of the registry have been designed by surgeons and patients, with no input from industry, and, therefore, it is independent.

18. HOW CAN WE TRUST THE DATA THAT IS IN THE REGISTRY?

Entering data into national registries is common practice in the NHS, and you can be assured that the data that is entered by your medical team is correct and complete.

19. I WANT TO FIND OUT MY SURGEON'S OUTCOMES. CAN YOU HELP ME?

As the current use of the registry is voluntary we cannot publish outcomes on individual surgeons.

However, we hope that the registry will become compulsory. If this happens, we expect individual surgeon outcomes to be published similarly to other databases (for example, colorectal cancer, hip and knee replacement surgery).

20. WE WOULD LIKE TO MAKE SOME ENQUIRIES OR OFFER SUPPORT: WHO DO WE CONTACT?

We would be very grateful for your support. The best way to contact us is via our email: registry@britishherniasociety.org

21. I AM A PATIENT AND I HAVE OTHER QUESTIONS ABOUT THE BHS REGISTRY: WHO CAN HELP ME?

You can ask further questions, or request more information by emailing registry@britishherniasociety.org

We will reply as quickly and with as much information as possible.

22. WHO IS ON THE BRITISH HERNIA SOCIETY'S REGISTRY SUB-COMMITTEE?

Please click the following link to find out about our Registry sub-committee.
https://www.britishherniasociety.org/british-hernia-society-sub-committees

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For further information:

www.britishherniasociety.org
email: registry@britishherniasociety.org