

UK Hand Registry Patient Information

What is the UK Hand Registry (UKHR)?

This is a database of information about hand conditions collected across the UK. This will help us to find out which treatments work best by observing outcomes as measured from questionnaires and monitoring of complications – unexpected problems. It was set up, is owned and is run by the British Society for Surgery of the Hand (BSSH), the UK's national hand surgery organisation.

What data is collected?

- a) Personal details are needed in order to link you to your treatment and the outcome. The personal information stored includes name, gender, date of birth, NHS number, and email address.
- b) In addition, we store information about your general health, diagnosis, treatment and your answers to the questionnaires (which is classed as sensitive personal information under the General Data Protection Regulation, GDPR).

Data are entered into the registry by a member of the team involved in your care.

Do I have to participate?

No, your consent is entirely voluntary and if you prefer not to participate, your medical care will be delivered in the normal way. Your personal details in particular cannot be kept without your consent.

What would I be asked to do?

You are asked to complete questionnaires before and after treatment. This is why your email address is important as we will send links to these questionnaires when they are due.

If I do participate, what are my rights?

You are entitled to:

- a) Withdraw consent at any time
- b) Request access to your data
- c) Request correction
- d) Request erasure
- e) Request restriction of processing
- f) Request the transfer of your personal data.

Further information on all these rights can be found on the Information Commissioner's Office (ICO) website: www.ico.org.uk.

If you wish to exercise any of the rights set out above, you can contact us either:

By emailing customer.support@amplitude-clinical.com.

Or, by writing to the British Society for Surgery of the Hand at 35-43 Lincoln's Inn Fields, London WC2A 3PE.

Or, by telephoning the British Society for Surgery of the Hand on 020 7831 5162.

Conditions regarding requests:

- a) Time limit to respond
We try to respond to all legitimate requests within one month. Occasionally it may take us longer than a month if your request is particularly complex or you have made a number of requests. In this case, we will notify you and keep you updated.
- b) Fee
You will not have to pay a fee to access your personal data (or to exercise any of the other rights). However, we may charge a reasonable fee if your request is clearly unfounded, repetitive or excessive. Alternatively, we may refuse to comply with your request in these circumstances.

Who is the data controller?

The data controller organisation (see www.ico.org.uk) for your personal data in the registry will be the British Society for Surgery of the Hand (and not the NHS).

We have appointed a data protection officer (DPO) who is responsible for overseeing questions in relation to this consent form. If you have any questions about this consent form, including any requests to exercise your legal rights, please contact the DPO using the details set out below:

Email: Helen.roberts@bssh.ac.uk
Postal Address: British Society for Surgery of the Hand,
35-43 Lincoln's Inn Fields, London WC2A 3PE
Telephone Number: 020 7831 5162

Data Retention:

Details of retention periods for different aspects of your personal data are available in our retention policy which you can request from us by contacting us using the contact details above. Is my data stored securely? Your personal details are treated as confidential and will be stored safely. We have put in place appropriate security measures to prevent your personal data from being accidentally lost, used or accessed in an unauthorised way, altered or disclosed. Your personal details will not be available outside BSSH and its secure IT provider, with these exceptions:

- (1) BSSH may approve a specific research project related to your diagnosis or treatment. The majority of this research uses only anonymised information that means it is impossible to identify individuals. From time to time researchers may wish to gather further information. In these cases we would seek your approval prior to disclosing your contact details. You would be free to decline and again this would not affect your care.
- (2) We may in future consider linking to other healthcare information resources (including Hospital Episode Statistics and other orthopaedic registries). Linking this data allows us to collect information on other aspects of your health, e.g. if you ever have further surgery or develop health problems. We do this to improve our ability to monitor patient safety and patient outcomes, and so that people and organisations involved in improving surgery can better understand and develop improved or more cost-effective medical treatments. In order to obtain any linked data about you, we would provide your operation and personal details to the body responsible for these other datasets so that they can match with records they hold – this may be NHS Digital (e.g. for HES) or the relevant Data Controller (for other musculoskeletal registries).
- (3) Your treating health care professional and his/her clinical team can also access and analyse your data to check they are individually giving good care. In addition, your registry data can be accessed in the future by other medical professionals who are involved in your medical care.
- (4) Transfer of identifiable data outside of the European Economic Area is not permitted. Anonymised data (your identifying details removed) may be released to approved organisations.

How will my data be processed?

We process the data which participating patients provide to improve our understanding of hand problems and of their treatment, thus helping us provide future patients with the best care. BSSH is responsible for all acts of processing. We retrieve and analyse your data so that we can compare large numbers of patients, usually removing anything that can identify you as an individual. Such analysis may have to be performed by a specialised third party, in which case they will be bound by the same high security standards and legal contract, whether identifying details had to be included or not.

You will not be identifiable within the results of any analyses which are shared, and any transfer of data will be encrypted. All studies using data from the Registry are recorded on the BSSH website.

Children: Monitoring the outcome of surgical procedures in children is as important as it is for adults. It is the child's parents or guardian who is asked to consent for data to be collected.

Where can I find out more information?

The BSSH website (<http://www.bssh.ac.uk>) contains more information including details of any studies and any information obtained through analysis of the Registry data. If you want to see what data is stored on you, please write as detailed below.

Contact Details:

Visit our website: <http://www.ukhr.net>

Send an email to: customer.support@amplitude-clinical.com

If you would like to contact the ICO, the UK supervisory authority for data protection issues, the details are as follows:

Address: Wycliffe House, Water Lane, Wilmslow, Cheshire, SK9 5AF

Telephone: 01625 545 745

Email: international.team@ico.org.uk

Website: www.ICO.org.uk