Bone and Joint Infection Registry (BAJIR) Privacy Notice - Data Protection and Confidentiality

What is the BAJIR database?

The BAJIR database is the UK Bone and Joint Infection Registry. It is designed to collect data on all patients with bone and joint infections in the UK. The information in the database will be used to assess and improve the quality of services and the outcomes achieved by bone and joint infection treatments across the NHS. It will also provide comparative information to patients, commissioners and regulators of healthcare professionals.

What information does it contain?

From 2018 medical staff treating patients with a new diagnosis of a bone or joint infection began collecting information on the BAJIR registry. The information includes details about the patient, the nature of the bone or joint infection, the results of the relevant investigations performed, antibiotic and surgical treatments, outcome data on how well the patient is functioning before and after their treatment.

The information importantly also contains the local hospital and NHS number in order to check the patient against national data regarding re-operation and survival. This information is vital to help to establish which treatments result in the best outcomes for patients with bone and joint infections.

What data do you collect from patients about their outcomes?

Patients are contacted at 6 months, 1 year and then at yearly intervals by post with a questionnaire to fill in to assess their degree of pain and symptoms following their treatment for infection. 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. From the information collected on these questionnaires, anonymised data will be used for the purposes of understanding bone and joint infection better. 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 BAJIR database?

BAJIR 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.

The data is collected on patients with a new diagnosis of a bone or joint infection 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. For patients entered into the registry we have 18 months to get their written permission to continue holding the data. After that all data about patients who haven't given consent will be fully anonymised.

Who manages the BAJIR database?

The BAJIR database is managed by a steering committee, who are a group of healthcare professionals that specialise in this field in conjunction with Northumbria Healthcare NHS Foundation Trust, who provide a home for the registry and control the data.

What happens to the data and who can see it?

The data are collected by the doctors, nurses, and hospital staff treating and managing the patient. Hospital computers are used to collect the information, which is collated, checked and approved before being uploaded to the BAJIR database. Once the records have been loaded, they can be reviewed by authorised medical staff using an approved user account with a secure password.

When the data has been uploaded by the hospital or clinician, the software engineers and data analysts at Dendrite Clinical Systems will have access to data on a secure server in Dendrite's offices. Some essential data will be cross checked with your hospitals patient administration system or HES data to ensure that we record all further operations on the same infected bone and joint, and to ensure we have medical status correctly recorded. Hospital Episode Statistics (HES) is a data warehouse containing details of all admissions, outpatient appointments and A&E attendances at NHS hospitals.

The software engineers at Dendrite will produce an annual report under the guidance of the BAJIR clinicians.

The information collected is valuable as it allows clinicians to understand the nature and incidence of bone and joint infections, the profile of patients, 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 guidance of BAJIR clinicians to produce BAJIR annual reports. The reports do not contain the details of individual patients or their infection. They 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 bone and joint infections.

The data will not be shared with anyone, or used for purposes other than those agreed with the BAJIR steering committee. The data will be held indefinitely even when a patient is no longer undergoing treatment for their bone or joint infection as late recurrence is a common problem for these types of infections.

BAJIR Database Server

The server is hosted on the NHS network (N3) within a data centre in London, by Piksel. This is a tier four data centre which meets the highest levels of building security.

The service delivery and information governance provided complies with ISO 20000 & ISO 9001 accreditation and the security structure is aligned alongside ISO27001. The security arrangements are internally audited approximately every three months and externally audited every six months.

All servers have firewall and anti-virus software installed which is configured to use real-time scanning.

Backup Resilience

The data is securely backed-up each day. All backed up data stored is compressed, de-duplicated and encrypted within a secure off-site vault.

There are two backup vaults, the primary one is hosted locally and is then backed up to a secure secondary off-site vault hosted within a separate datacentre located at Heathrow.

Dendrite Security

Dendrite Clinical Systems is assessed against NHS Information Governance standards, which includes both physical and organisational security measures. Dendrite's toolkit assessment score is available on the IG Toolkit website (https://www.igt.hscic.gov.uk/Home.aspx).

The computer software program created by Dendrite that holds the BAJIR data has been independently tested to ensure that it is not vulnerable to unauthorised access, or internal breaches of security.

Can I ask to see the data that the BAJIR database holds about me?

Requests to see what data is held on the BAJIR database about you may be made through the BAJIR website via the subject access request form.

Can I ask to be removed from the BAJIR registry?

Requests to be removed from the BAJIR database can be directed to

nhc-tr.bajir@nhs.net

If a patient is removed from the registry, we are not permitted to keep any data on such patients, and as such those who do not wish to be included in the registry. Thus, if a patient were to re-present to a hospital with another episode of a bone or joint infection it is feasible that they may be re-added to the database and later informed of this.

Further information

Queries should be directed to the BAJIR team at - nhc-tr.bajir@nhs.net