

Bone and Joint Infection Registry (BAJIR)

*Issued by Information Governance (Northumbria Healthcare NHS Foundation Trust),
Last reviewed March 2021*

This notice explains how patient's personal information is processed, used, kept safe and details individuals' rights with regards to their personal information contained within the Bone and Joint Infection Registry (BAJIR).

The BAJIR is designed to collect data on all patients with bone and joint infections in the UK, for organisations that have signed up to its use. 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.

Northumbria Healthcare NHS Foundation Trust provide the registry for other Healthcare providers and act as the Data Controller for all personal information it contains for the purpose details in this notice. This means that Northumbria are responsible for how your information is used within the registry. Northumbria is registered with the Information Commissioners Office, our registration number is: Z691260X. You can also find more information as to how we process personal information by visiting: <https://www.northumbria.nhs.uk/about-us/privacy-policy/>. Organisations treating patients remain responsible for their locally held records and will each have their own privacy notice. Please consult with these directly for how individual organisations process patient data. The BAJIR is managed by a steering committee, who are a group of healthcare professionals that specialise in this field in conjunction with Northumbria Healthcare.

In order to provide the BAJIR, the system itself is provided by Dendrite Clinical Systems Ltd who act as a Data Processor on behalf of Northumbria. AS a processor Northumbria Healthcare NHS Foundation Trust has undertaken all relevant due diligence and have appropriate governance in place such as contracts.

What information does the BAJIR contain?

From 2018, medical staff treating patients with a new diagnosis of a bone or joint infection began collecting information for the BAJIR. The information includes details about patients, 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. These identifiers are also used by your treating organisations to facilitate local care, it is also used to check for any National Data Opt Outs that have been applied.

Information that is held within the BAJIR has been provided by patients care teams at Health organisations that have signed up to participate in the BAJIR. For more information on if your treating organisations has signed up to participate, please consult with your treating orthopedic team or visit their privacy notice. Additionally data contained within the registry may be provided by patients directly, through outcome surveys that may be completed. For more information on this, please visit the below section: what information is collected from patients on their outcomes.

What happens to the data and who can see it?

The data used in the BAJIR is collected by the doctors, nurses and hospital staff treating and managing patients before being uploaded to the BAJIR. Once records have been uploaded, they can be reviewed by authorized 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 Hospital Episode Statistics data to ensure that all further operations on the same infected bone and joint, and to ensure we have the 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 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.

What data is collected 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 to process personal data?

Personal data processed within the BAJIR relies on the following legal basis:

Public task: the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law.

Special Category data is processed under the following condition:

Health or social care (with a basis in law): (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)

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. This includes: Preventative medicine, medical diagnosis and 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.

Where is data stored and for how long?

The data will be held for an extended period of time 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. Personal data will be retained for up to 18 months within the BAJIR where consent has not

been gained. If consent has been given and data has not been anonymised it will be held for a period of 20 years. If consent is withdrawn any personal data would be immediately removed.

Security

Information contained within the BAJIR is held on a server provided by Dendrite Clinical Systems Ltd or their contracted sub processor. All data remains within the UK and held by a tier four data centre, which is securely backed up each day.

Your rights

Under Data Protection laws, you have rights which allow you to find out what information is held about you, on computer and in certain manual records. This is known as "right of subject access.

If you want to see or receive a copy of your records that are held in the BAJIR speak to a member of your treating health team who will be able to help you or we have a handy request form on our website that can be used. In certain circumstances access to your records may be limited, for example, if it is felt to be in your best interest or for the protection of others.

Under the law, you may also have additional rights in relation to your information. For example:

- You also have the right to request any decisions taken by automated decision making with regards to your information (where applicable);
- The right to rectification of your information is found to be inaccurate (in line with NHS Guidelines);
- The right to restrict processing (where applicable);
- The right to data portability (where applicable);
- You may have the right to erasure of your personal information held by us, in certain circumstances.
- You have the right to withdraw consent at any time, where consent has been given. If you wish to be removed from the BAJIR please contact nhc-tr.bajir@nhs.net

If a patient is removed from the registry, we do not 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

If you would like to know more about how we use your information or if, for any reason you do not wish to have your information used in any of the ways described in this notice please speak to the orthopedic health professionals concerned with your care or contact the BAJIR using the details below. If you do not feel comfortable doing this you can also find out more by contacting the Information Governance Department or the Northumbria's designated Data Protection Officer using the below contact information. Further guidance about data protection can be obtained at www.ico.org.uk. You also have the right to lodge a complaint with the Information Commissioners Office.

Contact information

For general queries, patients may wish to consult with their treating care team. For general BAJIR queries you can contact the central team by emailing: nhc-tr.bajir@nhs.net

For specific queries regarding this Privacy Notice you can contact the IG team at Northumbria at the following:

Information Governance team	Data Protection Officer Tracey Best
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3rd Floor
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