



## **Keele's National MSK Audit and Research Database: Privacy Statement**

Living with musculoskeletal conditions can be hard and affect you in many ways. By answering some questions about your health and wellbeing, your musculoskeletal healthcare team can get a better understanding of how you are feeling and coping.

This data is collected by your Healthcare Provider using an online platform to help collect this information and share it with your musculoskeletal team.

The online system collects information to support routine holistic care for patients with musculoskeletal conditions.

This aims to improve the care provided to people by helping musculoskeletal teams understand symptom burden and disease severity. Your healthcare provider uses the data gathered to inform individual patient care, and together with Keele University, to additionally conduct research, audit, and service evaluation. Keele University, the British Society of Rheumatology (BSR), and your healthcare provider are joint data controllers for the information provided.

### ***Sources of information***

Patients are registered on the online platform by their musculoskeletal service administrator or clinician. Information about symptoms, wellbeing and health are submitted online by the patient. If data are used for research purposes, linkage with other NHS databases may occur. Further information about data linkage is available in the research database protocol.

Data are gathered by patients and clinicians via a secure web-based platform. The information is held on a secure server.

Security and confidentiality are maintained through use of restricted access with passwords and security agreements. All individuals who access personal identifiable data are your healthcare provider employees, who access the information for the purposes of clinical care. Where data are used for research and clinical audit, they are pseudonymised and users are unable to identify patients from the information at their disposal.

### ***What will we do with the information you provide to us?***

All the information provided will only be used for the purpose for which you provided it, or to fulfil business, legal or regulatory requirements if needed.

Keele University, BSR, and your electronic survey provider will not share any information provided to us to any third parties for marketing purposes.

Information is held in secure data centres in the EEA which comply with the Data Protection Act (2018) and the General Data Protection Regulation (2018).

All data are held on a restricted server. Staff at healthcare provider sites can access data for their site only. Staff at Keele University and within the West Midlands Secure Data Environment team are responsible for processing the data to create a pseudonymised dataset for research.

Data may be used to monitor the delivery of Keele's National MSK Audit, Research Database, and service evaluation. Aggregated data may be used to publish research at various levels (e.g. by patient group or pain site).

Where data are requested for research purposes, an application is made and approved via Keele's National MSK Audit and Research Database team.

### ***What information are we collecting?***

Keele's National MSK Audit and Research Database does not collect more information than is needed to fulfil the requirements of the programme and we will not retain it longer than is necessary.

The information we ask for is used either to maintain a record of your care or to contact you, provide information to support and inform clinical care, or for Keele-approved research purposes. We process:

1. Demographic data including age and gender.
2. Care data including diagnosis and treatment.
3. Routine patient reported outcomes such as the musculoskeletal health questionnaire (MSK-HQ).
4. Routine patient reported experience measures.

### ***Use of data processors***

Data processors are third parties who process data for us. We have contracts in place with our data processors. This means they cannot do anything with the information unless we have instructed them to do it.

Our data processors will not share any information with any organisation other than us. They will hold it securely and retain it for the period we instruct.

The data processors we use are:

- Provider of the British Society of Rheumatology (BSR) electronic patient reported outcome measure (ePROMs) platform (Net Solving)

- Other Providers of online data collection platforms commissioned by musculoskeletal healthcare providers to capture patient survey data
- Academic partner for curation of the pseudonymised data Keele University (National Musculoskeletal Audit and Research Database).
- West Midlands Secure Data Environment (WMSDE) commissioned by Keele University to securely store/host the Research Database.

### ***How long is the data retained for?***

Information added to patient's clinical records is retained in line with the Records Management Code of Practice for Health and Social Care (2016).

### ***Patient's Clinical Care***

All health and social care providers are subject to a statutory duty to process information about a patient for their clinical care. This includes medical diagnosis, the provision of health care or treatment, performance against national targets, local clinical audit and service improvement. Keele University therefore applies for following lawful basis for processing personal data:

Article 6(1)(e) – Necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller.

In addition, as this National MSK Audit and Research Database processes special category data (such as health data), and therefore must process this data under an additional legal basis. Keele University applies the following legal bases for processing this data:

Article 9(2)(h) – Necessary for the purposes of preventative or occupational medicine, for assessing the working capacity of the employee, medical diagnosis, the provision of health or social care or treatment or management of health or social care systems and services on the basis of Union or Member State law or a contract with a health professional.

And

Article 9(2)(i) – Necessary for reasons of public interest in the area of public health, such as protecting against serious cross- border threats to health or ensuring high standards of healthcare and of medicinal products or medical devices.

Keele's National MSK Audit and Research Database

For any research conducted using Keele's MSK Research Database data, applications are reviewed by Keele's National MSK Audit and Research Database Management Team and are processed under the following legal basis:

Article 6(1)(a) - the data subject has given consent to the processing of his or her personal data for one or more specific purposes;

And

Article 9(2)(a) – the data subject has given explicit consent to the processing of those personal data for one or more specified purposes, except where Union or Member State law provide that the prohibition referred to in paragraph 1 may not be lifted by the data subject;

Data from patients who have not explicitly consented to the research database within the online data collection portal will not be processed/shared with Keele University for any research purposes.

### **Confidentiality**

All information received via Keele's National MSK Audit and Research Database is treated as confidential. Identifiable information is only processed for the purpose of informing individual clinical care and treatment by the healthcare provider. All other information is processed in a pseudonymised format, initially retaining NHS number, postcode, and date of birth, until data are linked within the secure data environment at which point a new dataset is developed where individual patients are then only identifiable using coded patient lists which are held separately to the dataset within the secure data environment.

The Keele National MSK Audit and Research Database team, clinicians, or researchers will not publish information which can enable individuals to be identified, nor allow third parties to access the data.

The confidentiality and security of information is maintained in the following ways:

- In all publications, the statistical information is reviewed to ensure the risk of identification is minimised, and where necessary small numbers are suppressed.
- All publications include aggregated data at a relevant level.

### Your Rights

Under the Data Protection Act 2018 and the General Data Protection Regulation (GDPR) 2018 you have rights as an individual which you can exercise in relation to the information we hold about you.

Rights for individuals are:

- The right to be informed.
- The right of access.
- The right to rectification.
- The right to erasure.
- The right to restrict processing.
- The right to data portability.
- The right to object.
- Rights in relation to automated decision making and profiling.

For more information on your rights as an individual, visit [Information Commissioner's Office \(ICO\)](#)

### ***What if I do not want my information used?***

As a patient, you can choose not to provide data to the National MSK Audit and Research Database. Please tell your healthcare professional that you do not want to take part.

If you would not like your data to be used for research purposes, please let your healthcare professional know. You can also choose to not have any of your confidential patient information used in research and planning via the NHS opt-out service (<https://www.nhs.uk/your-nhs-data-matters/>).

### ***Complaints or queries***

Keele University and the BSR take data protection and privacy requirements seriously. If you have any concerns, questions or wish to make a complaint you can contact us using the information at the bottom of this notice.

You can also complain to the Information Commissioners Office directly:

Information Commissioners Office  
Wycliffe House  
Waterlane  
Wilmslow, Cheshire SK9 5AF  
0303 123 1113  
<http://ico.org.uk>

### Changes to this Notice

We keep our privacy notices regularly under review. This privacy notice was last updated in February 2023.

### Contact Us

Keele University's Data Protection Officer can be contacted at: [dpo@keele.ac.uk](mailto:dpo@keele.ac.uk).

The BSR's data protection officer is Caroline Wilson, and can be contacted on [cwilson@rheumatology.org.uk](mailto:cwilson@rheumatology.org.uk)

