Fracture Liaison Service Database (FLS-DB)

Information for Patients
V13, October 2021
Fracture Liaison Service Database (FLS-DB) fair processing statement

Why is this team collecting my information?
The NHS aims to provide you with the best possible care. Clinical audit is an excellent way of improving patient care. Audits monitor the standard of care received by patients. They look at the care provided and ask questions about it:

- What should we be doing?
- Are we doing it?
- How can we improve?

What is the Fracture Liaison Service Database (FLS-DB)?
Breaking a bone after a fall is a common injury. Caring for patients with these broken bones or fractures and preventing future fractures is an important part of the work of the NHS. This hospital takes part in the FLS-DB, which has been set up to improve the care of patients who are at risk of a fragility fracture or osteoporosis.

A ‘fragility’ fracture is a broken bone that happens after a fall from a standing height or less. Fragility fractures often affect the larger bones of the body such as the back, hip or wrist. Bones are strong and usually don’t break from a simple fall, but as we get older our bones become weaker. Osteoporosis and other bone diseases can increase this effect of age, and further weaken bones. This means that even a low-impact fall from a standing height can cause a broken bone.

Patients who have suffered a fragility fracture are at higher risk of breaking another bone; either the same bone again or another bone in the body. Fracture liaison services (FLSs) are teams of nurses, doctors, therapists and administrative staff who treat people (usually aged 50 and over) with fractures to reduce the chance of experiencing another broken bone. This is called secondary fracture prevention (ie preventing the second fracture).

The FLS-DB is a national clinical audit which gathers information about fracture care, treatment and referrals and measures trust performance against national and professional standards and provides regular feedback to health professionals. This information enables individual hospitals to review their performance against national standards and focus on areas where they can make improvements to patient care.

Why do we need to audit FLSs?
Not all areas of the country have an FLS. This means some patients may be missing out on preventative care. Also, FLSs vary in size and what they do, and we need to understand which types of FLS work best.

The first step in creating consistency and providing the best possible care to all patients is to identify what care patients are currently receiving. This is why the FLS-DB is so important. It will help the NHS to understand which areas of the country have an FLS, which areas do not
have an FLS and how successful each FLS is at preventing secondary fractures. This information can then be used to improve the quality and coverage of secondary fracture prevention care. The information collected will help to:

- Identify differences in quality of care and provision of services.
- Highlight areas of good quality care and areas for improvement.
- Make recommendations to healthcare providers on the provision of services and best practice.
- Identify if hospitals are following national and professional guidelines.

Who runs the FLS-DB?
The data controller, who has overall responsibility for the collection, storage and processing of personal identifiable information is joint across the Healthcare Quality Improvement Partnership (HQIP) and NHS England. However, HQIP and NHS England will not be processing any of the data.

The FLS-DB is managed by the Royal College of Physicians (RCP) on behalf of HQIP and NHS England as part of the Falls & Fragility Fracture Audit Programme (FFFAP). This is a multidisciplinary national clinical audit which is being carried out in partnership with a number of organisations:

- British Orthopaedic Association
- British Geriatrics Society
- Royal Osteoporosis Society
- Public Health England

The University of Bristol will be analysing the data.

What does it mean to be a part of the FLS-DB?
Being part of the FLS-DB does not mean that you will be given different care or have your treatment options limited. The FLS-DB will just collect the details of what type of care you receive in order to understand how the FLS in your area identifies patients, investigates their individual circumstances, provides information to you and refers you to treatment if necessary. By collecting this information, the FLS-DB can help the NHS understand how care is being implemented across the country and make sure that all patients are getting the best possible care.

What personal information do you collect?
The FLS-DB will collect information about the care you are given by an FLS. In order to monitor standards of care we need to collect the following personal information: NHS number (a unique number), date of birth and postcode.

There are very strict rules surrounding the use of personal data. The FLS-DB has section 251 approval by the Secretary of State for Health, who imposes very tight conditions on what information can be processed and by whom. This means we can set aside the common law duty of confidentiality in order that identifiable patient information can be passed on without individuals’ consent.

Why do you need this personal information?
To know whether an FLS has successfully prevented you from suffering a second fragility fracture we need to be able to look at your care over a period of time and possibly across different geographical locations. If you did suffer a second fracture, it might not happen for months or years after your first fracture. You might have moved house, or you might be on holiday in a different area of the country.

Collecting this information allows us to link to other national data sets which provide further information about patient care and outcomes of care. For example, if you started treatment at one FLS and then moved to an area that did not have an FLS, we could still identify any treatment you received in your new location and find out how successful your fracture prevention treatment was. If we did not collect confidential information, we would not get accurate information on the quality of your care.

What other information about my care do you collect?

- Your injury - whether you have had a fracture and what type of fracture it was.
- Your treatment – what scans and tests you were given and whether treatment (for example, bone protection medication) was initiated or any other recommendations were made (for example, a referral to strength and balance classes).
- Follow up – whether you continued treatment and whether you have had any further fractures or falls.

Where does my confidential information go?

We have a legal duty to protect your information and maintain confidentiality. Your information will be held safely on a secure computer database by our experienced IT team at Crown Informatics, who follow best practice in data protection and security. The data collected are subject to strict rules about confidentiality including those of the General Data Protection Regulation (2018), the Data Protection Act (1998), the Health and Social Care Act (2001) and to the recommendations of the Caldicott Report (1997).

How long will we hold your data for?

It will be held for the duration of the audit. Should the audit come to an end, it will be held for a further five years after that. Staff at Crown Informatics are all fully trained in information governance and will only see personal details for database administration and must follow strict confidentiality rules.

How will my confidential information be used?

Data is supplied to the University of Bristol for analysis, but this will be done so that no individual patient can be identified. Reports produced by the audit will not contain NHS numbers or any other information that could be used to identify anyone. You can view our reports on our website.

We sometimes get requests from hospitals, universities, and academic or healthcare organisations who want to carry out research using the data that we collect. We always ensure that researchers that we agree to share data with have appropriate legal approvals in place to share data. Sometimes researchers require data to be linked to other datasets; this is done by NHS Digital as described above and the researchers don’t receive information that could be used to identify you as an individual.

Can I access my information?
Yes. The FLS-DB only collects information that your health care providers collect whilst treating you. The easiest way for you to see this information is to ask the people treating you.

**How the NHS and care services use your information**

The Royal College of Physicians is one of many organisations working in the health and care system to improve care for patients and the public.

Whenever you use a health or care service, such as attending Accident & Emergency or using Community Care services, important information about you is collected in a patient record for that service. Collecting this information helps to ensure you get the best possible care and treatment.

The information collected about you when you use these services can also be used and provided to other organisations for purposes beyond your individual care, for instance to help with:

- improving the quality and standards of care provided
- research into the development of new treatments
- preventing illness and diseases
- monitoring safety
- planning services

This may only take place when there is a clear legal basis to use this information. All these uses help to provide better health and care for you, your family and future generations. Confidential patient information about your health and care is only used like this where allowed by law.

Most of the time, anonymised data is used for research and planning so that you cannot be identified in which case your confidential patient information isn’t needed.

You have a choice about whether you want your confidential patient information to be used in this way. If you are happy with this use of information you do not need to do anything. If you do choose to opt out your confidential patient information will still be used to support your individual care.

To find out more or to register your choice to opt out, please visit [www.nhs.uk/your-nhs-data-matters](http://www.nhs.uk/your-nhs-data-matters). On this web page you will:

- See what is meant by confidential patient information
- Find examples of when confidential patient information is used for individual care and examples of when it is used for purposes beyond individual care
- Find out more about the benefits of sharing data
- Understand more about who uses the data
- Find out how your data is protected
- Be able to access the system to view, set or change your opt-out setting
• Find the contact telephone number if you want to know any more or to set/change your opt-out by phone
• See the situations where the opt-out will not apply

You can also find out more about how patient information is used at:
https://www.hra.nhs.uk/information-about-patients/ (which covers health and care research); and
https://understandingpatientdata.org.uk/what-you-need-know (which covers how and why patient information is used, the safeguards and how decisions are made)

You can change your mind about your choice at any time.

Data being used or shared for purposes beyond individual care does not include your data being shared with insurance companies or used for marketing purposes and data would only be used in this way with your specific agreement.

Saying ‘no thanks’
In England, patients who have chosen to opt-out of their confidential data being used for purposes other than their own care and treatment (Type-1/Type-2 opt-outs and the incoming National Data Opt-out Programme) will not be included in this audit. Wales do not operate a national opt-out programme, but patients are still able to object to being included in individual audits, such as this one, under GDPR.

National clinical audit works best when it includes information from as many patients as possible. If you do not want your information to be used, then please tell the people who are treating you. Your doctor or nurse will be able to note that you do not want to participate, and your data will not be used.

If a patient thinks their information has been submitted to the audit and they would prefer to have it removed, they should contact the hospital that treated them or the audit team. In England, patients who have chosen to opt-out of their confidential data being used for purposes other than their own care and treatment (National Data Opt-out Programme) will not be included in this audit. Scotland and Wales do not operate a national opt-out programme, but patients are still able to object to being included in individual audits, such as this one, under GDPR.

Not taking part in the audit will not affect your treatment in any way.

If you are happy for your data to be used for the audit, but not to be shared with researchers, when appropriate legal approvals have been met, you can specifically opt out of your data being used by researchers by contacting us: ffp@rcp.ac.uk.

Right to complain to a supervisory body

If a patient thinks that their information is being used inappropriately, they have the right to complain to the Information Commissioners Office (ICO).

Raising concerns
If want to arrange for your data to be removed, updated or corrected please call, email or write to:

Crown Informatics, Ltd.
enq@crowninformatics.com
01777 709009

If you would like to know more about how we use your information or if you are concerned that your personal information has not been handled properly please contact us. We aim to respond in a reasonable time (normally 28 days).

Further information and contact details
Falls and Fragility Fracture Audit Programme
London, NW14LE
FLSDB@rcp.ac.uk

HQIP
Phone: 020 7997 7370