Who is managing this research?

The Clinical Trials Research Unit (CTRU) manages the BLISS project. We are part of the **Leeds Institute of Clinical Trial Research** at the **University of Leeds**. If you would like to know more about us or about clinical trial research in general, please visit our website https://www.leeds.ac.uk/lictr.

The BLISS project is funded by Blood Cancer UK, to whom we are very grateful.

The project and its lead researchers have been approved by the UK Health Research Authority Research Ethics Committee (REC).

Any questions?

You can email the BLISS team directly: ctru-bliss@leeds.ac.uk

Keeping your data safe

We want you to understand how your personal data is used and protected in the BLISS project. Your privacy matters to us, and we will treat all your information with care. You can withdraw consent to use your data in this project at any time.

You can read the BLISS Data Privacy Notice by visiting our website: https://ctru.leeds.ac.uk/bliss or scanning this QR code.

UNIVERSITY OF LEEDS

BLISS
Blood cancer Long-term follow-up using Integrated healthcare SystemS data

Patient information for a data linkage project called BLISS.
(Short for: *Blood cancer clinical trials Long term follow-up using Integrated health SystemS data.)*

Did you take part in any of these clinical trials?

- Myeloma X
- Myeloma XI
- MUKOne
- MUKThree
- MUKFour
- MUK Five
- MUKSix
- MUKSeven
- MUKEight
- MUKTwelve

If so, you might like to learn more about this project.

You can let us know If you don't want your information to be used in this way.

A quick overview:

- When patients take part in a clinical trial, NHS staff collect data using forms and databases.
- This takes time and money, so sometimes we can only follow up patients for a limited time.
- We are going to use Healthcare Systems Data to follow up patients for longer, to understand how well treatments work in the long-term.
- **You will not need to do anything at all to take part in the BLISS project**. We will collect your data straight from the NHS and you will not need any extra appointments.
- You can opt out of the BLISS project any time.

What is Healthcare Systems Data?

The NHS collects data about patients as part of normal day-to-day running of healthcare services (e.g. hospital appointments and admissions and the reasons for these).

Some of this is coded and made available to researchers through a central process. This is called ‘Healthcare Systems Data’.



About the BLISS project

We think that using Healthcare Systems Data could be a great way to make more use of information that is already being collected.

But first, it is important to check that the data is suitable for use in clinical trials. This work has not been done before for blood cancer clinical trials, so the **BLISS project** will test how reliable and useful the data is.

We will combine the data we already have about you from your clinical trial with new Healthcare Systems Data. We will then use this combined data to support long-term follow-up.

The sort of information we are looking to include:

- whether you are still alive
- if you are diagnosed with another cancer
- what other treatments you receive
- if you are admitted to hospital for infections, bone fractures or heart disease

Permission to use your data

The clinical trials listed on page 1 started before the BLISS project was set up. That means we did not ask for consent for linkage to data held by national data providers (such as NHS England).

We have permission from the Health Research Authority, on the advice of the Confidentiality Advisory Group (CAG), to obtain follow-up information. We will share a limited amount of your personal data (NHS Number, date of birth and sex) with NHS England to obtain linked Healthcare Systems Data.

You can find out more about CAG here (or scan the QR code): https://www.hra.nhs.uk/about-us/committees-and-services/confidentiality-advisory-group/.

This linkage will be undertaken with ‘Section 251’ of the NHS Act 2006 support from the Health Research Authority on advice from the CAG. The national data opt out will be respected.

How to opt out of the BLISS project

Participants may opt out of this follow-up project at any time by contacting Leeds CTRU. A family member or carer can also do this for you if needed.

For more information on the project and how to opt-out, please visit the BLISS website at https://ctru.leeds.ac.uk/bliss or via this QR code.

You can also email the BLISS team directly: ctru-bliss@leeds.ac.uk