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

Blood cancer clinical trials Long term follow-up using Integrated health SystemS data (BLISS)

Patient information for data linkage study

Did you take part in any of these clinical trials?

- **Myeloma X**
- **Myeloma XI**
- **MUKOne**
- **MUKThree**
- **MUKFour**
- **MUKFive**
- **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

When patients take part in a clinical trial, NHS staff collect data using individual 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 and to use this data to understand how well treatments work in the long-term.

BLISS Project Aims

It is important to check that healthcare systems data is suitable for clinical trials. This work has not been done before for blood cancer clinical trials, so we are testing it with the BLISS project.

Healthcare Systems Data will be linked to existing myeloma clinical trial data in the BLISS database.

We will use linked data to assess outcomes and check the validity and usefulness of using healthcare system data to monitor clinical trial outcomes. Outcomes will include whether patients are still alive, if they have been diagnosed with another cancer, what treatments they have had and if they have been admitted to hospital for infections, bone fractures or heart disease.

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'.

How Will it Affect Me?

You will not need to do anything to take part in the BLISS project.

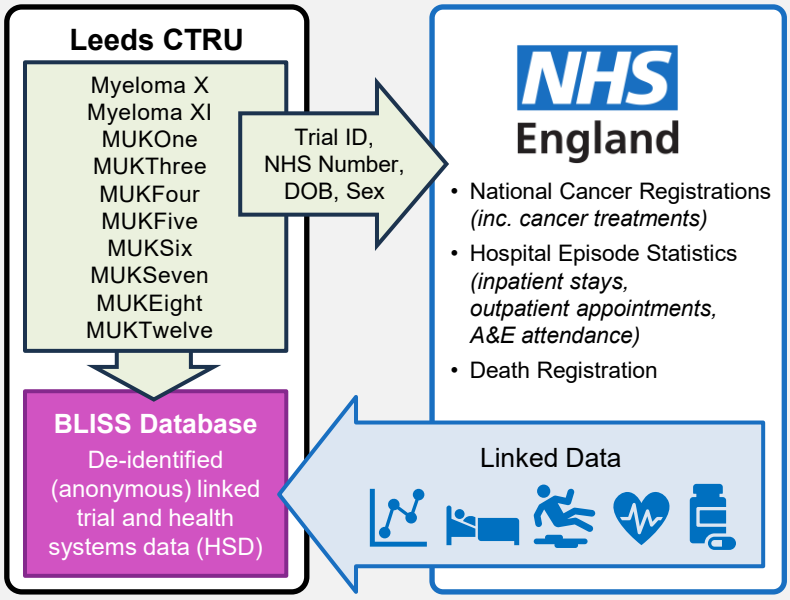
We will collect your data straight from NHS data providers and you will not need any extra appointments.

Data Linkage

At the time of recruitment for the trials listed 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. This involves sharing a limited amount of personal data (NHS Number, date of birth and sex) with NHS England to obtain linked Healthcare Systems Data.

You can find out more about the CAG from 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 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 the QR code.
You can also contact the BLISS team directly at ctru-bliss@leeds.ac.uk

ctru University of Leeds
Blood cancer UK
UNIVERSITY OF LEEDS

BLISS IRAS ID: 343775 Poster version 3.0_260317