MyeCare

A prospective, real-world registry of acute myeloid leukaemia patients in the United Kingdom

The following pharmaceutical companies and charities provided sponsorship and contributed funding to the DIDACT Foundation in support of MyeCare. These organisations have had no involvement in the governance or outputs from MyeCare: Anthony Nolan, Cure Leukaemia, Daiichi-Sankyo, Jazz Pharmaceuticals, Leukaemia UK, Servier.

Version 1.0 – 6th August 2026

Registry Vision & Strategic Objectives

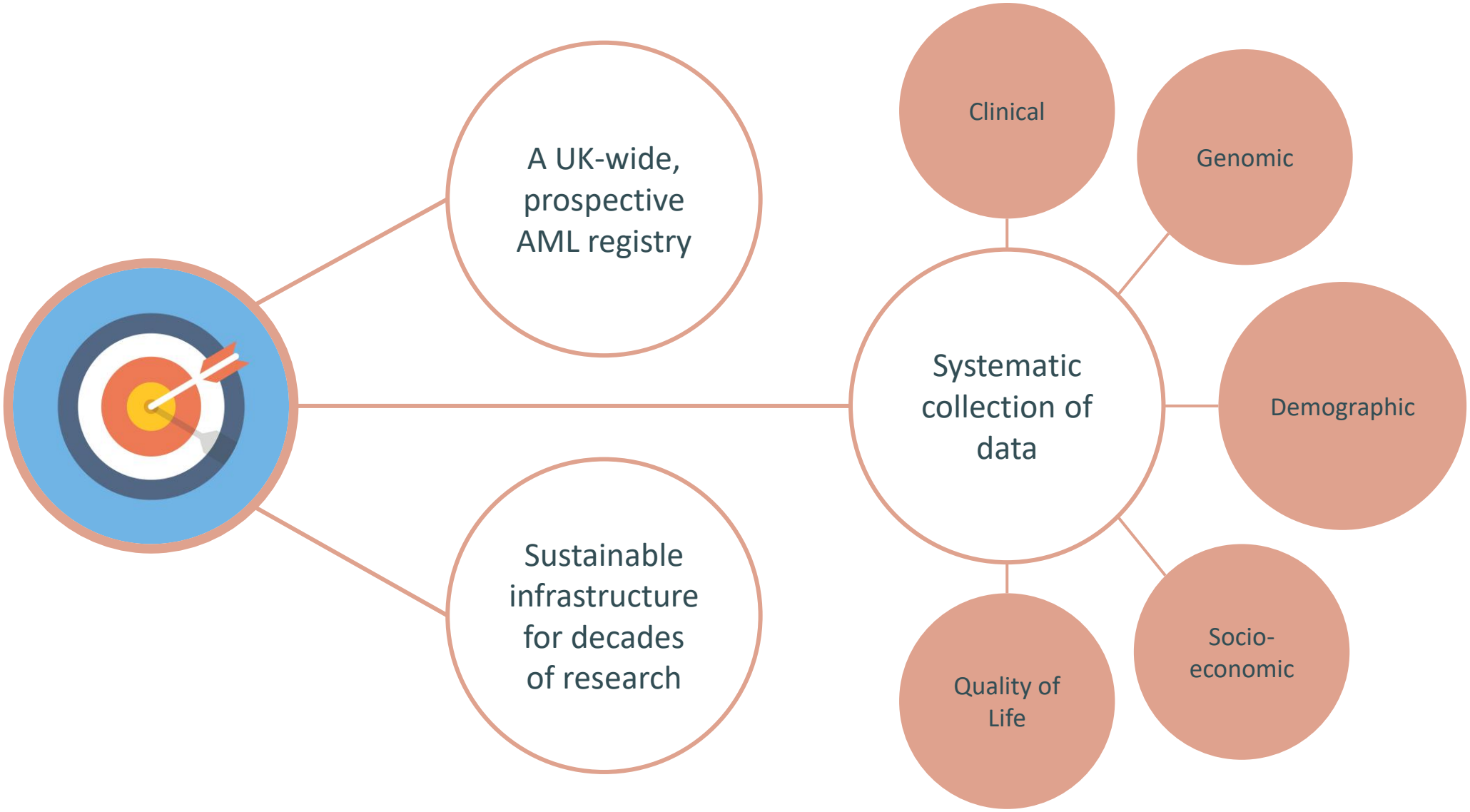
Current AML Treatment Challenges

- Despite advances, most patients still die from resistant disease (<50% 5-year survival)
- Allogeneic stem cell transplantation (allo-SCT) is the only curative therapy for many, but access is uneven, influenced by ethnicity and socio-economic status, with barriers not fully quantified
- Emerging evidence suggests distinct mutational patterns in adult AML across ethnic groups, potentially affecting outcomes
- There is an urgent need for new drug, transplant, and cellular therapies, though treatment toxicity remains a major challenge
- Challenges exist in designing and delivering timely prospective trials, highlighting increasing importance of real-world data (RWD)

The Unmet Need - What's Needed?

- Better understanding of disease biology and how ethnicity, demographics, and biology influence outcomes
- Whilst randomised clinical trials remain the gold standard, there is increasing recognition of the potential of RWD, as trials can be costly, time-consuming, and don't capture the full AML patient spectrum
- Combining RWD with comprehensive genomic sequencing to enable:
    - Development of more personalised, effective therapies through global pharma collaboration
    - Better insights into factors affecting quality of life and healthcare use.

The MyeCare Registry: Vision



Aims of the Registry

1. To develop a repository for data on adult AML patients in the UK, with the aim of improving the outcomes of patients with AML
2. To provide a robust framework of real-world demographic, diagnostic and clinical data, linked with whole genome sequencing (WGS) data for future cross sectional and longitudinal research in AML
3. To provide access to guidance and expertise for clinicians treating AML, via the Registry community, encouraging standardisation and equity in patient care
4. To understand equity of access to transplant and transplant outcomes according to ethnicity and socio-economic status

Strategic Objectives of the Registry

1. Improve understanding of AML outcomes across diverse patient populations
2. Enable integrated clinical and genomic research at scale
3. Support equity and standardisation of care, including transplant access
4. Create a trusted data platform to inform policy, commissioning, and innovation

What Makes MyeCare Unique



Prospective, real-world design



Clinically matched whole genome sequencing (WGS)

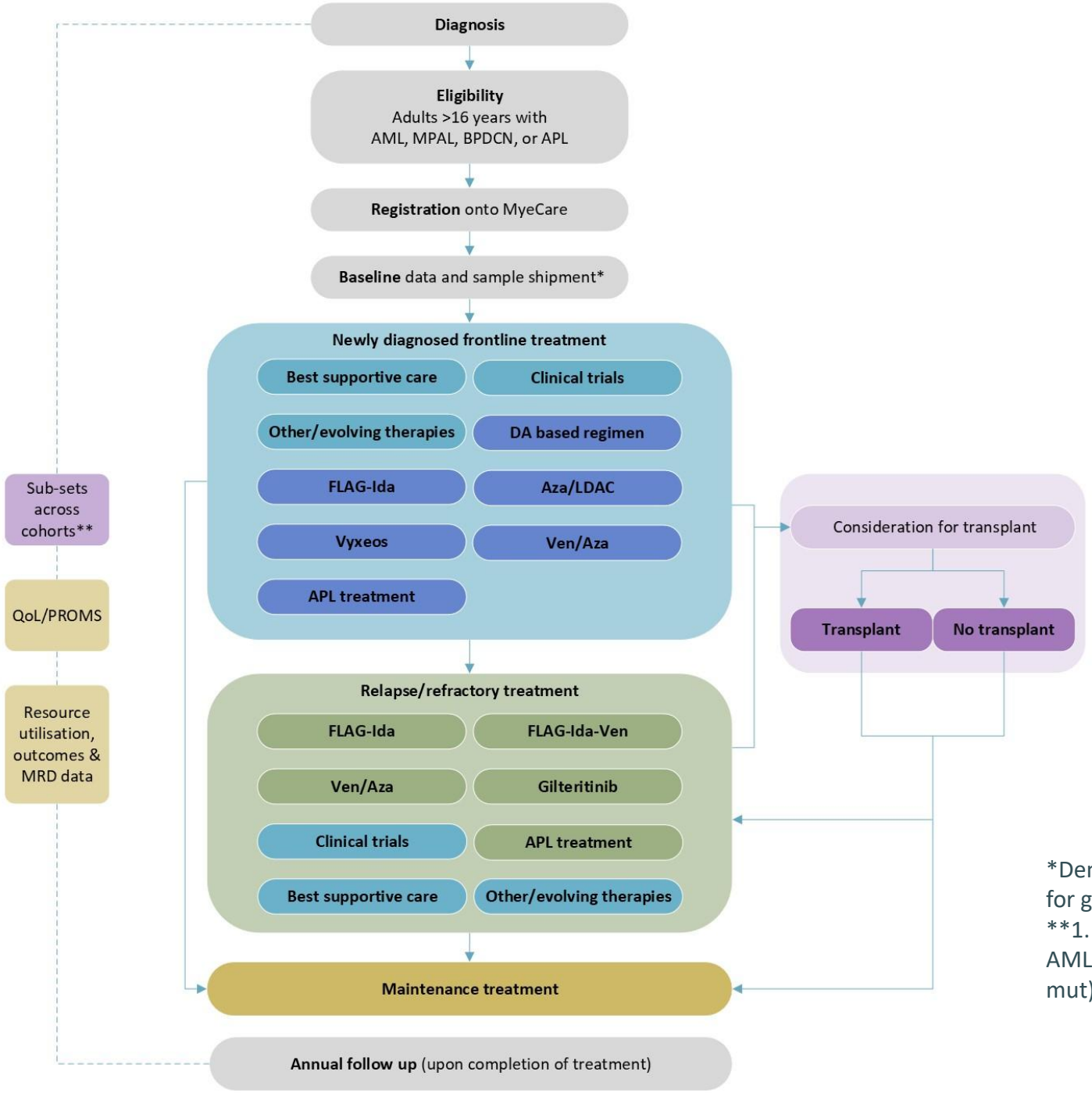


Large, ethnically diverse UK population



Integration with chemotherapy and transplant datasets

MyeCare Schema



*Demographics, patient data, disease biology (ELN2022), samples for genetic testing.
**1. Therapy-related AML (tAML); 2. Germline predisposition to AML; 3. Genetic AML subsets (CBF, FLT3 mut, IDH1/2 mut, sAML mut); 4. CHIP

Whole Genome Sequencing

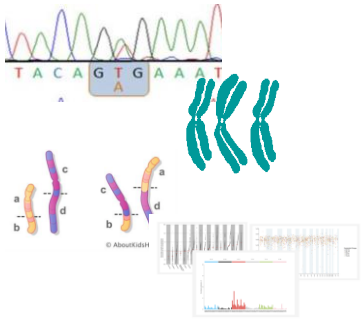
Whole Genome Sequencing (WGS)

What is whole genome sequencing?



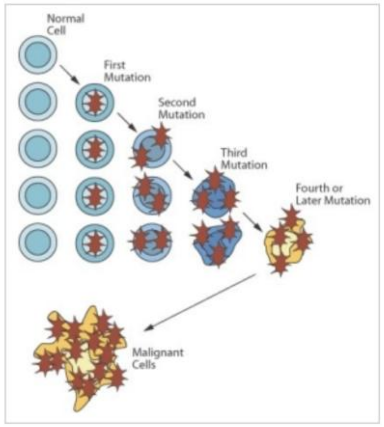
Does what it says on the tin: determines the order of the bases A / T / C / G in all the DNA in a cell(s)

What 'mutations' can WGS detect?



- Small variants & indels
- Copy number variants
- Structural variants
- Mutational burden & signature

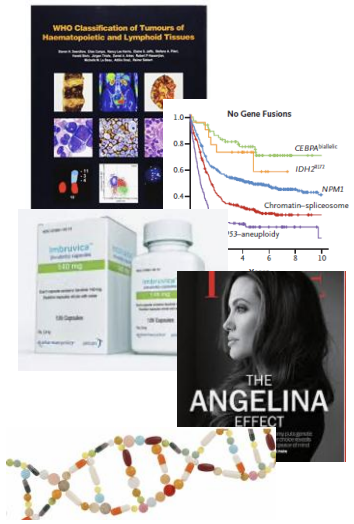
Why is that relevant to AML?



AML like other cancers can be considered to be an 'acquired' genetic disease: DNA changes 'mutations' which occur in blood cells during your lifetime can cause leukaemia

https://stanfordhealthcare.org/medical-treatments/c/cancer-risk-assessment-genetic-testing-counseling/about-this-treatment/types.html

How is this relevant to the MyeCare Registry?

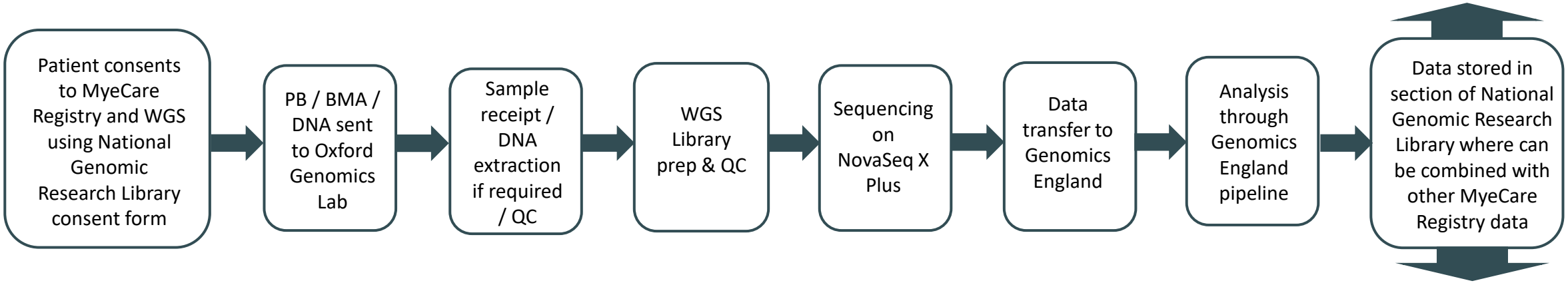


- Better diagnostic subgrouping
- Identification of prognostic genomic factors including in different therapies
- Identification of potential therapeutic targets
- Identification of genetic predisposition or pharmacogenomic factors

N Engl J Med. 2016; 374:2209

WGS – What Are We Doing?

HaemOnc Network of Excellence doing comparison of WGS with Standard of Care (SOC) genomic testing (data collected by MyeCare Registry) to demonstrate the evidence that WGS is a suitable replacement for much SOC testing and support NHS commissioning of testing



WGS data is available in the National Genomic Research Library for all MyeCare Registry purposes as per previous slide

WGS Data Sharing

- **Genomics England Limited (GEL) Patient Information Sheet (PIS)/Informed Consent Form (ICF) covers:**
  - Storage of de-identified genomic and health data in the NGRL
  - Use of limited identifiers by GEL to support secure data linkage
  - Access to de-identified data by approved researchers only
- **MyeCare Registry PIS/ICF consent covers:**
  - Deposit of Registry clinical data into the NGRL
  - Controlled access to Registry data in the NGRL by Sponsor-approved researchers

All data access is governed and ethically approved. More information on the NGRL can be found here

Registry Summary & Progress

Registry Summary

Design	Description
Patient identification	Potential participants will be identified either following referral from a General Practitioner (GP) or multi-disciplinary team (MDT) meeting at a linked hospital, for treatment of suspected or proven AML, APL, MPAL or BPDCN.
Collection methods	Routine clinical information, including demographic, diagnostic, genomic, treatment, transplant, outcome and follow-up data will be inputted by sites into a central Registry database.
QoL/PROMS	QoL/PROMS data completed by participants either on paper (and inputted by sites) or electronically direct into the Registry database
WGS	Separate consent to GEL's NGRL. Samples sent to OUH Regional Genetics Laboratories for sequencing; data then stored by GEL. Clinical Registry data then linked with GEL WGS data.
Research projects and data access	Data sharing will be conducted in accordance with the MyeCare Registry Data Access Policy.

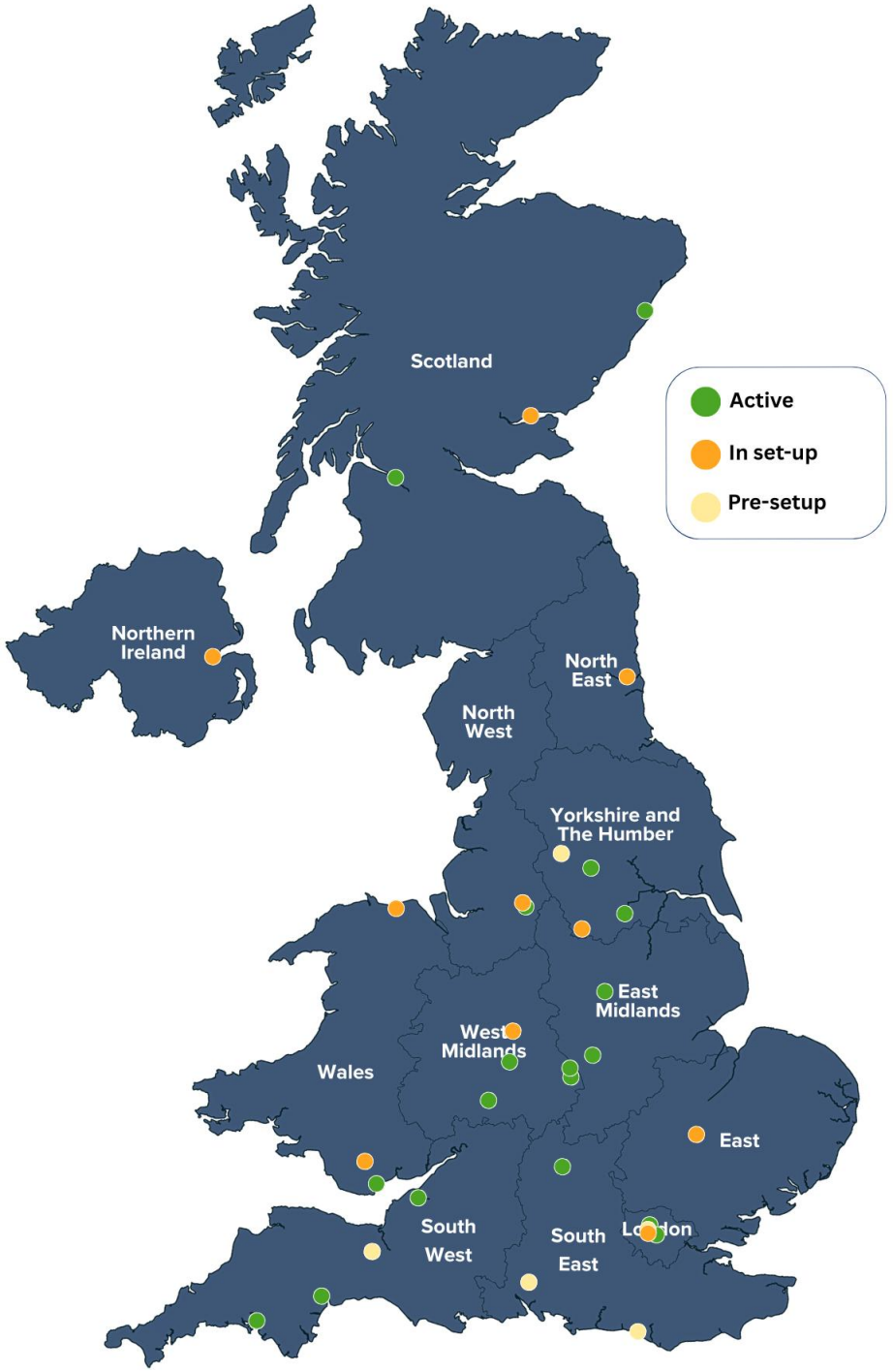
MyeCare Registry Progress

Target recruitment: 800 participants/year

Target number of sites: 30+ leukaemia treatment and transplant centres in the UK

Number of participants recruited	178 (as of 6th August 2026)
Number of sites open	18 (as of 6th August 2026)
First site activated	21st July 2025
First participant registered	22nd July 2025
Recruitment duration	This is an ongoing Registry, with no foreseen end date
Follow-up duration	Annually, for up to 5 years from diagnosis

Map of Sites


Active
In set-up
Pre-setup
Scotland
Northern Ireland
North East
North West
Yorkshire and The Humber
East Midlands
West Midlands
Wales
East
South West
South East
London

Recruitment Progress



Registry Team

Core Registry Team

Sponsor/data controller: DIDACT Foundation

Chief Investigator: Dr Priyanka Mehta

Accelerating Clinical Trials Ltd (ACT) Team (Registry site and project management):

- Paul Sherrington, Chief Executive Officer
- Anna Hockaday, Chief Clinical Operations Director
- Malak Alsawady, Registry Project Manager
- Catherine Stadon, Site Engagement Specialist

Site queries: reg-aml-001sites@act4patients.com

ACT website: www.act4patients.com

Wider Registry Team

Dendrite Clinical Systems:

- Database platform provider

Oxford University Hospitals (OUH) Regional Genetics Laboratories:

- Processing of whole genome sequencing (WGS) samples

Genomics England Limited (GEL):

- Storage of WGS data in the National Genomics Research Library (NGRL) and linkage to MyeCare clinical data

Governance

Steering Committee

Chairs

- Professor Charles Craddock, Professor of Haemato-oncology, University of Warwick, Academic Director Centre for Clinical Haematology, Chair UK AML Research Network
- Dr Priyanka Mehta, Consultant Haematologist, Bristol Haematology and Oncology Centre

Purpose

- ✓To support the delivery of the UK MyeCare Registry and,
- ✓To advise the Registry's Sponsor relating to its progress.
- ✓The Committee will also play an important role in the review, and approval of applications for access to Registry data and linked whole genome sequencing (WGS) data

Registry Management Group

Purpose: To oversee day to day Registry management; review risks and issues. Includes Sponsor/Data Controller representative.

Constitution:

- Professor Charles Craddock – Chair of the Registry Steering Committee
- Dr Priyanka Mehta – Chief Investigator
- Dr Paul Robinson – CEO of DIDACT Foundation
- Dr Paul Sherrington – CEO of ACT
- Anna Hockaday - Chief Clinical Operations Director
- Malak Alsawady – Registry Project Manager

Funding and Sponsorship

- Set-up grants received from: AbbVie, Astellas, Jazz Pharmaceuticals, Servier and Hartley Taylor
- Sponsors:
  - Contracts in place: Anthony Nolan, Cure Leukaemia, Daiichi-Sankyo, Jazz Pharmaceuticals, Leukaemia UK, Servier.
  - Initial sponsorship agreements provide funding for 1 to 2 years. Renewals are reviewed and considered on an ongoing basis.
  - Funders receive 6-monthly summary reports; further data requests will follow the Data Access Policy process

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Research Projects and Data Access Requests

- Data sharing will be conducted in accordance with the MyeCare Registry Data Access Policy.
  - The data access request process is overseen by the MyeCare Registry Steering Committee.
- Types of research to be supported include but are not limited to:
  - **Academic** requests (research, publications)
  - **Sponsor activities** (clinical trial sponsorship), including requests from MyeCare Registry Steering Committee or UK AML Research Network members
  - **NHS** commissioning data or research requests from other trusts
  - **Industry** requests (research, market access)
  - Collation with **other databases** to support meta-analysis
- Requests may include access to MyeCare Registry data and additional linked WGS data held by Genomics England.

For any site queries, please email reg-aml-001sites@act4patients.com

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