Increasing Access to Blood Cancer Trials in Northern Ireland

An Executive Summary of a Stakeholder Event

A Stakeholder event, held on 10th June 2026, brought patients, carers, HSC professionals, researchers and colleagues from cancer charities together to hear and reflect on data and findings from the "Increasing Access to Blood Cancer Trials in Northern Ireland" project. Stakeholder discussions highlighted significant challenges in accessing blood cancer clinical trials and related care in Northern Ireland (NI), alongside opportunities to improve patient experience, equity, and system efficiency.

A dominant theme was **inequity of access**, with several patients required to travel to Great Britain (GB) for trials and specialist treatments. This creates substantial **financial, emotional, and logistical burdens** for patients and families, highlighting unmet needs. Participants emphasised the importance of **holistic and practical patient support**, — especially for those travelling or undergoing prolonged treatment. A recurring suggestion was the introduction of a **dedicated liaison/navigation role** to support patients across the pathway.

There is a clear need to **increase local clinical trial capacity in NI**, particularly through investment in workforce (notably pharmacy, research staff, and clinical academics and strategic trial portfolio development.

Operational challenges within services were identified, including **long clinic waits, pharmacy delays, and limited access to dietetic support, particularly for hospital inpatients**. These affect patient experience. Improvements in communication, digital tools, pre-assessment models, and environment were also suggested.

There is also a need to improve **data collection (including equality data), awareness of trials, and communication with patients**, particularly to address misconceptions (e.g. fear of placebo) and ensure inclusive participation across all communities.

Finally, **system coordination and pathways**, especially for patients presenting outside specialist centres or in emergency settings, require improvement to ensure safe, timely, and appropriate care.

Suggested Action Points from Discussion Groups at Stakeholder Event

1. Improve Access to Trials in NI

- Expand local clinical trial availability to reduce reliance on GB referrals
- Develop a **strategic trial portfolio** aligned with population needs and rare diseases
- Strengthen relationships with sponsors and promote NI as a trial site
- Increase **protected research time** for consultants and staff
- Develop **clinical academic roles**
- **Monitor equity of access** to haematology clinical trials
- **Advocate for mandatory completion of patient characteristics in Encompass**
- **Monitor number of patients in Paediatrics and Adults attending for clinical trials out with NI**
- Remove lack of **access to** above standard of care **PET scans in trials (SPPG)**
- **Rapid escalation of access to advanced therapies** to bring NI in line with GB as this is impacting haematological, oncological and non-malignant clinical care in Northern Ireland
- Support for bid to introduce a **paediatric ECMC on the island of Ireland**

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2. Address Workforce and Resource Gaps

- Urgently invest in **pharmacy workforce**, including dedicated trial pharmacists
- Increase staffing in research teams and allied health professions (AHPs)
- Increase dedicated research capacity for medical staff
- Secure funding for clinical trial infrastructure and delivery
- Reframe pharmacy as a **core enabler of trials**, not a bottleneck

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3. Reduce Patient Burden (Travel & Costs)

- Conduct a **comprehensive assessment of financial toxicity** for patients travelling to GB
- Improve and tailor financial support packages
- Engage with sponsors and charities to enhance support
- Establish a **dedicated liaison role** to:
    - Support patients travelling for treatment
    - Coordinate care across regions
    - Link with Clinical Nurse Specialists (CNS)
    - Provide emotional and practical support

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4. Strengthen Patient & Carer Support

- Create a **centralised information resource**:
    - Travel guidance
    - Accommodation
    - Peer support
    - Practical tips for carers
- Improve emotional support, particularly for children, AYA, and long-term patients
- Work with charities to co-design support

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5. Improve Experience for Patients Attending Clinic or Hospital

- Review clinic day to ensure maximum efficiency and reduce length of day
- Improve access to dietetic support and suitable menu for hospital in-patients
- Review digital tools to support communication with patients during clinic visits e.g. pharmacy

6. Increase Trial Awareness

- Review and improve public information on clinical trials
- Review and improve clinical trials information and awareness with wider healthcare community
- Share trial outcomes with participants