Leukaemia & Lymphoma NI Policy and Advocacy Group:

Bringing together the voices of patients, families, clinicians and researchers

6 POLICY PRIORITIES TO IMPROVE OUTCOMES FOR LOCAL PEOPLE

1 EQUAL ACCESS TO THERAPIES

Patients should not have to travel to GB to access treatment when the immune system is so vulnerable. Families should not be separated during the most traumatic time.

2 MORE CLINICAL TRIALS IN HAEMATOLOGY

Patients living in Northern Ireland do not get equal access to clinical trials and the new treatments they make available. Clinical trials are vital to improve outcomes for patients.

3 EQUAL GOVERNMENT SUPPORT

NIHR/DHSC funding for AMRC member charities funding medical research only available in England. AMRC charities in Northern Ireland should receive similar funding support on an equitable basis.

4 EARLIER DIAGNOSIS

Delays in diagnosis are common in blood cancers due to the vague symptoms that patients experience. These delays lead to poorer outcomes and must be addressed through action to raise awareness.

5 EQUAL PRIORITY FOR BLOOD CANCERS

Blood cancer research has led to better treatments and survival rates across many types of cancer. Haematology clinical trials, research investment and the needs of patients should be given equal consideration alongside solid tumours.

6 SUPPORT HAEMATOLOGY WORKFORCE

Haematology workforce challenges in NI are leading to additional pressure on existing staff. Action is required to introduce new ways to improve job satisfaction and encourage job retention.

LOCAL POLICY PRIORITIES FOR BLOOD CANCER & REDUCING INEQUITY IN NI

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PRIORITY 1: Local Delivery of CAR-T and other cellular therapies

Commitment in Dept of Health Cancer Strategy to monitor viability of proving CAR-T locally

Current arrangement of accessing treatment in GB not equitable:

*Travel to GB increases risk of infection
*Travel to GB separates families at worst possible time
*Patients prevented from receiving treatment if not well enough to travel
*Financial impact: cost of travel and extra time for carer away from work

c. 6 weeks in GB at point of treatment

Evidence of need and potential impact:

*Widely accepted that CAR-T can be delivered in existing transplant centres, as treatment has evolved
*NHS England is encouraging Autologous Stem Cell Transplant (ASCT) Centres to pursue accreditation for CAR-T to increase capacity - the existing accredited ASCT service at Belfast City Hospital provides a strong foundation for local CAR-T delivery
*Workforce retention concerns if cutting edge therapies not delivered locally
*Research centres need local delivery of cellular therapies to progress research into CAR-T & other cutting edge treatments into clinical trials
*Potential UK Government investment into advanced therapies cannot be fully realised in Northern Ireland due to absence of local treatment delivery

Call to Action: NI Assembly, Local Government, Department of Health and Health & Social Care Trusts

1. Urgent review of barriers to CAR-T delivery in Northern Ireland and publish clear roadmap to local commissioning
2. Commit to phased implementation at Belfast City Hospital to assess the feasibility of delivering the treatment locally using the current infrastructure
3. Support service improvement project to identify ways to reduce challenges and inequalities in the current system until local delivery is achieved
4. Engage with DHSC to understand changes to CAR-T centres to increase capacity in England, in preparation for myeloma treatment approval

LLNI will continue to work with patients, clinicians, health departments and other charities to advocate for **urgent CAR-T in Northern Ireland**

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PRIORITY 2: Improve Access to Haematology Clinical Trials

Commitment in both DoH Cancer Strategy and Cancer Research Framework to increase number of patients taking part in clinical trials

Current clinical trial opportunities not equitable to other areas the UK:

*Currently 8 open haematology clinical trials in NI however in areas of GB with similar population numbers, Glasgow has 27 trials and Manchester 68

*10-15 years ago, every patient in NI diagnosed with leukaemia was enrolled in a clinical trial: currently 1 adult trial open with 1 patient enrolled

*The recently opened ALL paediatric trial took almost 6 years to become available to patients in Northern Ireland

*Some patients travel to GB to access trials, leading to emotional, physical and financial stress for both patients and family members

Evidence of need and potential impact:

*60% reduction in patients enrolled in haematology clinical trials since the Covid pandemic, falling from an average of 84 patients per year to just 33

*Research-active hospitals achieve better outcomes as patients enrolled in trials have access to new treatments or combinations not routinely available

*Trial patients gain access to latest treatments funded by a pharmaceutical or charity sponsor, with cost savings for DoH on standard-of-care treatments

*Clinical research in NI is essential to develop and retain skilled researchers and clinicians, and help to drive economic growth

*A number of haematology trials are currently waiting to open in NI; additional investment would have immediate impact for clinical trial delivery

Call to Action: NI Assembly, Local Government, Department of Health and Health & Social Care Trusts

1. Drive forward clinical trials in Northern Ireland to attract investment from ATTC, similar to recent investment in Wales
2. Ensure implementation of clinical trials advisory group as per Cancer Research Strategic Framework
3. Instigate service improvement to enable access to PET scans above the current standard-of-care, as scans are an essential part of clinical trial delivery
4. Commit a dedicated budget to building and sustaining the workforce needed to advance clinical trials

LLNI will continue to raise charity funds for translational research & work with NI Cancer Trials Network to support **local trial delivery**

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PRIORITY 3: Equitable access to government research investment

Commitment in Cancer Research Framework to create research capacity and enhance research culture

Current inequity in government funding for blood cancer research:

*In June 2026, the National Institute of Health Research announced £37m funding for medical research charities to invest in early career research. This funding was only open to charities in England and not available to charities supporting research in other areas of the UK

*LLNI invested £665k in local blood cancer research in 2024/25 - during this financial year the charity received no government or charitable grants

Evidence of need and potential impact:

*Surgical treatment options for blood cancers are limited, therefore research innovation is crucial for reducing mortality and improving outcomes

*NI missing out on potential UK government investment into progressing advanced therapies as therapies such as CAR-T are not delivered in NI

*Cancer Research Strategic Framework Priority 1 & 2 aims to increase access to research and create research capacity, requiring dedicated investment

*Blood cancer research offers hope to patients & families for new treatments, more treatment options or kinder treatments

*The first use of multi-drug combinations were used to treat childhood ALL

*Blood cancer research led to the development of CAR-T, with research now showing promising results for some solid tumours and auto immune diseases

Call to Action: NI Assembly, Local Government, Department of Health and Health & Social Care Trusts

1. Commit £1.2m funding to medical research charities in Northern Ireland on equitable basis to England, to support local medical research in NI
2. Commit to a package of matched funding to boost funds raised by the generous Northern Ireland public through the work of LLNI
3. Place equal value on both medical research and patient support charities, by contributing to core and support costs for both vital areas
4. Recognise Cancer Research as an investment, not a Cost

LLNI will continue to drive public donations and fundraising activities to enable continued **charity investment in local blood cancer research**

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PRIORITY 4: Champion earlier diagnosis of blood cancer to improve outcomes

DoH Cancer Strategy commits to reducing patients diagnosed in emergency setting - currently 30% of blood cancer diagnosis

Why early diagnosis is critical in blood cancer:

*First point of intervention for most cancers is through prevention and screening, but currently no known methods relevant to blood cancers
*Diagnosis of blood cancer is challenging due to vague symptoms that can be attributed to other, more likely causes
*Many blood cancers can progress rapidly - acute leukaemias can cause life-threatening complications within days or weeks if not diagnosed quickly

Evidence of need and potential impact:

*Around one third of people with blood cancer visit their GP three or more times before receiving a diagnosis, compared to 7% in breast cancer
*30% of blood cancer patients are diagnosed in an emergency setting, in contrast to only 3% of breast cancers and 7% in prostate cancers
* Half of the UK population cannot name one symptom of blood cancer
*Current cancer waiting time metrics in Northern Ireland begin at the point of urgent GP referral - for blood cancers, delays primarily occur before urgent GP referral to haematology for diagnostic investigation
*Early diagnosis improves outcomes, helps prevent irreversible disease-related complications, reduces stress and uncertainty for patients, and eases pressure on the health system

Call to Action: NI Assembly, Local Government, Department of Health and Health & Social Care Trusts

1. Commit to PHA awareness programme to highlight need for awareness & early diagnosis due to limited prevention, screening and surgical treatments
2. Commit to including research, public awareness and education for blood cancer in any cancer strategy and programme for government
3. Develop blood cancer specific measures to include pre-diagnosis delays, to more effectively monitor delays experienced by blood cancer patients

LLNI will support research into innovative solutions to encourage early diagnosis and work in partnership with UK charities to ensure GP education initiatives reflect the needs and realities of Northern Ireland

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PRIORITY 5: Blood Cancers have equal priority to other types of cancer

Many Cancer Strategy actions are framed around the pathways and experiences more associated with solid tumours

Why blood cancers cannot be considered in the same way as other cancers

*With blood cancer, the cancer attacks the immune system, therefore the patient's immune system is weakened by both the disease and the treatment
*Patients with acute blood cancers, who are at the highest risk of serious infection, are currently treated in facilities that are not designed to meet the needs of severely immunocompromised patients
*Many blood cancers remain incurable, but patients can live full and productive lives with active monitoring or maintenance treatment

Evidence of need and potential impact:

*Current haematology services in Belfast City Hospital are delivered in an environment that is not suitable for modern haematology care
*Blood cancer patients spend more time in hospital than many other cancer groups, making access to appropriate facilities particularly important
*DoH Cancer Strategy commits to providing palliative care to all patients with non-curative cancer, which does not align with chronic blood cancers
*A Comprehensive Cancer Centre must have haematology needs at its core, both children and adults, as many current standard-of-care treatments were initially developed for blood cancer treatments e.g. chemotherapy, combination treatment for childhood ALL, CAR-T, genomic testing

Call to Action: NI Assembly, Local Government, Department of Health and Health & Social Care Trusts

1. Drive forward with urgency the new haematology ward in Belfast City Hospital to improve patient outcomes and facilitate clinical research
2. Ensure official statistics, including NICR cancer data and DoH metrics are expressed as a combined figure for all blood cancers
3. Consider needs of patients with non-curative blood cancer, who can live long and well following diagnosis and treatment
4. Incorporate needs of people living with non-curative cancer in development of the 'Right to be Forgotten' legislation

LLNI will raise awareness of the **distinctive nature of blood cancers** and the importance of research in driving progress for all cancers

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PRIORITY 6: Support Haematology Workforce Sustainability

Commitment in DoH Cancer Strategy to fully implement the Haematology Stabilisation Plan

Workforce pressures impacting haematology services and staff:

*Modern blood cancer treatments have improved outcomes but often need intensive monitoring, management of side effects and supportive care

*Adolescent and Young Adult support requires a specialist skill set, including psychosocial support and the educational & developmental needs

*Paediatric haematology relies on highly specialised staffing to deliver complex treatment and ongoing support for children and their parents

Evidence of need and potential impact:

*Cancer Research Strategic Framework commits to a review to identify skills gaps in clinical research and provide actions to ensure staff have access to relevant training

*Each Health & Social Care Trust must ensure that cancer trials and studies are promoted across their services and that the whole clinical team is supported and facilitated to participate in cancer research

*Blood cancer is the UK's fifth most common cancer but the third biggest cancer killer. Enabling the clinical and academic workforce to dedicate protected time to all phases of research is essential to accelerating innovation, improving survival and delivering better outcomes for patients

Call to Action: NI Assembly, Local Government, Department of Health and Health & Social Care Trusts

1. Commit to reintroducing dedicated research time for haematology staff in the clinical setting to drive and encourage clinical based research
2. Commit to engaging with the current workforce to understand service pressures and implement measures to improve staff retention and workforce sustainability
3. Drive forward the implementation of the Adolescent and Young Adult Regional Standards to ensure young people have access to a specialist multidisciplinary team and age-appropriate cancer care

LLNI will lead **research education sessions** for clinical staff to improve understanding of current research and progress towards clinical impact

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Working Together on Ten Immediate Priorities

Practical steps that would make a real difference for patients and families before the next Assembly Elections

Actions Deliverable Within This Mandate:

1. Review barriers to CAR-T delivery in NI and publish a clear roadmap to local commissioning
2. Support a service improvement project to help reduce challenges and inequalities in the current system, until local delivery of CAR-T is achieved
3. Change current processes to enable access to PET scans to be accessed above the current standard-of-care
4. Publish an urgent update on the progress of the new haematology ward in Belfast City Hospital and a timeline for implementation
5. Implement an interim solution to ensure timely access to essential post-transplant vaccinations while a long-term commissioning arrangement is agreed through the GP contract, in line with the approach in England
6. Extend the current UK Government's Children's Cancer Travel Grant to Northern Ireland where families face higher travel costs compared to GB
7. Attend LLNI's Blood Cancer Roundtable event Open Day at the Johnston Cancer Research Centre to hear directly from patients, families, researchers and clinicians about the key challenges facing blood cancer care and research in Northern Ireland
8. Introduce combined reporting of blood cancers within official cancer statistics to better reflect the overall impact, burden and outcomes of blood cancer in Northern Ireland
9. Arrange an urgent meeting with relevant Policy Teams in DoH and LLNI to discuss key priorities and potential solutions, both short and long term
10. Facilitate a Health Committee visit to LLNI and the Johnston Cancer Research Centre to hear directly from patients, clinicians and researchers about the opportunities and challenges facing blood cancer research in Northern Ireland

LLNI will continue to work with government, Department of Health, patients, clinicians, and other charities to advocate for **drive change**