Welsh Affairs Committee -

Cross-border healthcare arrangements for England and Wales

About Blood Cancer UK –
We're a community dedicated to beating blood cancer by funding research, supporting those affected, and campaigning for change. Together, we've invested over £500 million in blood cancer research, transforming treatments and saving lives. We research, we support, we care. Because we know what it takes.

Blood cancer, including leukaemia, lymphoma, myeloma and myeloproliferative neoplasms (MPN) and myelodysplastic syndromes (MDS), is the fifth most common cancer and third biggest cancer killer in Wales – with 11,000 people living with or in remission from the disease, and more than 600 deaths annually.

Introduction –
Blood Cancer UK welcomes the opportunity to contribute to this inquiry on cross-border healthcare between England and Wales. Our evidence draws on insight from the ***UK Blood Cancer Action Plan (2024)***, our ongoing policy and clinical engagement work, and a targeted survey of 26 healthcare professionals (HCPs) from across the UK - including consultant haematologists, clinical nurse specialists and clinical researchers, responsible for delivering blood cancer care.

As highlighted in our Action Plan, equitable access to treatments and clinical trials remains a critical determinant of survival and quality of life for people with blood cancer. With blood cancer care becoming highly specialised, and advanced therapies – such as CAR-T – requiring delivery in a limited number of tertiary centres or regional teaching hospitals, cross-border care between Wales and England is essential.

Advanced blood cancer treatments such as CAR-T therapy and allogeneic stem cell transplants (ASCT) place significant demands on specialist services and patients. These treatments require complex care environments, including strict infection control, single-room isolation facilities, intensive monitoring, and highly trained disciplinary teams.

Patients undergoing these therapies are often profoundly immunosuppressed and may require prolonged inpatient stays in tertiary centres, sometimes for several weeks or months, followed by extended periods of follow-up care. This creates substantial capacity pressures within specialist centres, particularly in relation to bed availability, workforce constraints, and on their ability to accept out-of-area referrals in a timely manner.

Despite the importance to patients of having equitable access to treatments, existing cross-border arrangements are not fit for purpose for modern specialist blood cancer care. Barriers risk widening inequalities, particularly for members of rural and geographically isolated communities with blood cancer. Therefore, ensuring that cross-border referral pathways across England and Wales function effectively is an important part of improving outcomes for people living with blood cancer.

1. What are the most pressing issues for those accessing cross-border healthcare, whether through a GP, hospital, or specialist care?

1.1 Reliance on cross-border care for specialist treatments –
Blood cancer care is becoming increasingly specialised, with therapies such as CAR-T, stem cell transplants and bispecific antibodies delivered in a small number of tertiary centres across the UK. With just one specialist centre in Wales (Cardiff), a structural reliance on cross-border care has been established, with patients particularly dependent on services available at English centres.

Healthcare professionals report that capacity and infrastructure limitations in Wales mean that many patients cannot access NICE-approved treatments locally and must cross the border:

"[Patients] *sometimes need to be referred to English centres to receive specialist therapies due to capacity/infrastructure in Wales. Locally, they cannot access many NICE approved treatments and initially would be referred to Cardiff."* – Consultant Haematologist, South Wales

Even in Wales, infrastructure and workforce limitations mean that access to specialist treatments is highly centralised and constrained – with the most advanced blood cancer therapies and trials predominately delivered in Cardiff. This creates a multi-step pathway (e.g. local centre > Cardiff > Specialist centre in England) which leads to delays:

"Cardiff is the only site able to deliver some of these [treatments] *and we don't have the space or workforce to do this for the whole of Wales".* – Consultant Haematologist, South Wales

As a result, cross-border referral is often not a matter of choice but necessity. This reflects wider system pressures identified in recent reports about NHS capacity challenges in Wales and reinforces concerns that the existing cross-border arrangements – set out under the England-Wales Statement of Values and Principles – are not well suited to highly specialised cancer pathways.

1.2 Complexity and lack of clarity in referral pathways

A consistent finding across our survey of healthcare professionals was that referral pathways between England and Wales are complex, inconsistent and poorly understood. Despite the existence of some formal arrangements, clinicians reported a high degree of uncertainty and administrative burden. Approval delays to exceptional requests for funding by clinicians to local health boards contribute to this.

"[The pathway is] ***Not clear to me – but would usually refer to Cardiff prior to needing referral to England…I don't feel confident regarding referral pathways for these out of hours emergencies."*** – Consultant Haematologist, South Wales

"I'm not particularly aware of any pathways. Leukaemia patients have historically travelled outside of Wales to access CAR-T, and paediatric patients continue travel outside Wales to access ASCT." – Consultant Haematologist, South Wales

"Restricted – we have to refer inside Wales first, unless on the border, then complete paperwork stating exceptional circumstances on why we have to go outside Wales, which is often very timely to complete." – Clinical Nurse Specialist, West Wales

Where existing pathways do exist and function effectively (e.g. between North Wales and Manchester), these appear to be dependent on the individual knowledge of healthcare professionals or networks. More common themes from our survey respondents included confusion around responsibilities, communication gaps, and the additional burden placed on them when navigating cross-border systems.

This inconsistency was also reflected in some of the responses we received from staff working at centres in England, who regularly treat people with blood cancer from Wales who have been referred for specialist treatment:

"We get cross border referrals from consultants for cell therapy trials running in London without local health board approval being sought first by the referring team. We then have to explain that local health board approval needs to be given before we can see the patient here." – Clinical Nurse Specialist, London

The lack of a single, clearly defined cross-border pathway may result in delayed treatment initiation, a rise in clinician uncertainty (particularly when the need for care is urgent), and the inefficient use of specialist capacity. For time-sensitive conditions, such as acute blood cancers, these delays can be hugely significant.

1.3 Travel burden and financial barriers

For some blood cancer patients – particularly those living in more rural and deprived areas – travelling from Wales to England for treatment poses significant logistical and financial challenges. Clinicians report:

"Travel is a big issue, also no support for carers/loved ones. CAR-T patients are now frequently sent to Bristol as Cardiff is full, adding up to 2 hours to a 2.5 hour journey." – Clinical Nurse Specialist, West Wales

"Distance, local levels of poverty, poor transport links. We have patients who live in West Wales who are referred to central Manchester." – Clinical Nurse Specialist, North Wales

The financial challenge of travelling out of area for treatment is felt particularly hard by people living with blood cancer – with treatments like CAR-T requiring significant extended stays in hospital. While reimbursement schemes exist on a local and regional basis, many of these frequently require patients to pay for travel, accommodation, and food up front:

For financial support with travel/food etc, we allow patients to be reimbursed via the health board (claimed back from commissioners) as patients should not be "out of pocket" for having to travel to access CAR-T further from home. However, this does still require patients to pay the money up front and be reimbursed which not everyone can afford to do." – Clinical Nurse Specialist, South Wales

Critically, these barriers have shown to influence the treatment decisions taken by patients. In the *UK Blood Cancer Action Plan*, we highlighted how – because of costs, unreasonable travel demands, and the impact on family or work – patients will sometimes choose or be offered less optimal treatment closer to home:

"The most common issue is that the patient declines referral out of area as they do not wish to travel and they opt for whatever treatment is available closer to home." – Consultant Haematologist, South Wales

The existing arrangements have caused a clear inequity among blood cancer patients in Wales, where many who are clinically eligible are being excluded. Active steps must be taken to formalise the referral process and address these financial barriers.

1.4 Gaps in patient support

Support for patients undergoing treatment outside of Wales is inconsistent and often insufficient. While some shared care arrangements exist, there is no consistent, structured model of support and referring teams are particularly reliant on the resource available at specialist treatment centres.

"Patients accessing CAR-T in England would still be under care of referring team so receive medical input. Psychological support depends on treating centre." – Clinical Nurse Specialist, South Wales

This evidence also demonstrates the negative impact of cross-border referrals on the continuity of care available to patients – which is hampered by workforce constraints locally and at specialist centres. This increases the burden on patients or their families and can negatively affect experience and outcomes.

1.5 Barriers in accessing cross-border clinical trials

Radiotherapy and surgery are rarely used in blood cancer treatment, with chemotherapy, stem cell transplants, and immunotherapies often the only options. For patients, acceptance into a clinical trial can offer vital access to new drugs and sometimes be their only option. Despite this clinical need, access to trials in England for patients in Wales is limited due to a lack of awareness, poor availability, complicated eligibility criteria and practical, financial and social barriers.

"Lack of awareness of trials available and patients often unwilling to travel to participate." – Consultant Haematologist, South Wales

"I get the sense [access to trials] is not brilliant. I believe there was an issue with a patient who couldn't access CAR-T trial in London due to her address being registered in Wales." – Haematology Fellow, London

Wales also has a lower participation rate for clinical trials than England[1]. Healthcare professionals outlined challenges with trial awareness and the inequity in access to the resource needed for setting up academic or non-commercial trials, compared with commercially funded studies funded by pharmaceutical companies:

"I don't think **[cross-border referral pathways]** ***are effective. I am mainly aware of trials running in Wales."*** – Consultant Haematologist, South Wales

"No [barriers] for commercial studies where travelling and accommodation expenses are generally paid. Cost for non-commercial studies would generally be prohibitive though." – Consultant Haematologist, South Wales

While guidance by Health & Care Research Wales states that the costs associated with cross-border referrals to participate in clinical trials should be met by the trial site, we've heard anecdotally that the experience of patients and clinicians is quite different – particularly for non-commercial clinical trials.

These points reflect wider challenges facing blood cancer patients who are interested in participating in trials across the UK. The concentration of research at large centres in England means cross-border access is essential, but existing mechanisms must be

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[1] Health and Care Research Wales, Wales Cancer Network, & Wales Cancer Research Centre. *Moving Forward: A Cancer Research Strategy for Wales.* https://walescancerresearchcentre.org/wp-content/uploads/CReSt-English-FINAL.pdf (2022)

improved to support this. While recent policy developments, such as the Rare Cancers Act, aim to improve trial identification and awareness, they do not address the practical barriers associated with cross-border access.

2. How can the use of data and digitalisation improve the experience of patients using cross-border healthcare and the information available to clinicians? What changes need to be made to ensure cross-border compatibility?

Treatments for people with blood cancer can span across primary care, local and specialist services, and co-ordination is often challenging. Both patients and healthcare professionals have shared frustrations about delays and interruptions to treatment or access to clinical trials because of communication failures between services. The poor level of interoperability is a key barrier to patient care, particularly for those moving between NHS England and NHS Wales on a regular basis and is leading to service inefficiencies. There is also no national standard for the exchange of cross-border information.

It is vital that interoperable IT systems are co-designed and integrated across the NHS in England and NHS Wales. As part of this process, the blood cancer workforce must be involved in the commissioning, set up and roll out of these tools. Without this, we will repeat situations where tools such as electronic patient record software are set up by non-clinical staff and therefore do not meet the needs of the clinical workforce – especially those who are referring patients out of area for treatment.

Patients and staff have also expressed concerns about the lack of access to key clinical data for researchers, including test results and genomic profiling. Similarly, the lack of a single, cross-nation repository of ongoing research is having a negative impact on patient and clinician awareness of clinical trials. The UK Government must work with industry partners, charities and NHS staff to establish a clinical trial directory. We’re also calling on the Welsh Government to improve the existing cancer data infrastructure.

3. How will recently announced reforms, including the abolition of NHS England and the UK Government's 10 Year Health Plan, impact on cross-border healthcare?

It’s not yet known how the abolition of NHS England and the publication of the 10 Year Health Plan will impact cross-border healthcare for people living with blood cancer. These reforms could present opportunities to make improvements, including redesigning cross-border systems to reflect current specialised treatment requests, introducing network-based care models and aligning commissioning or access pathways to treatments across England and Wales.

However, reforms also pose potential risks to the blood cancer community, including:

- A further divergence between pathways in England and Wales if reforms are not aligned or agreed in collaboration
- The continued lack of clarity around accountability for cross-border care
- Failure to address the structural issues which underpin many of the challenges with cross-border care, including workforce shortages, funding decisions, and data sharing

The ambitions set out in the National Cancer Plan and wider health reforms are encouraging, particularly the emphasis on improving coordination of care and patient experience across the system. The proposed development of a Single Patient Record has the potential to transform cross-border care by enabling clinicians in England and Wales to access consistent, real-time patient information. If implemented effectively across both nations, this could reduce delays, improve clinical decision-making, and support seamless care for patients moving between services.

We also welcome the UK Government's recent commitment to introduce a dedicated funding pot to cover travel costs for children and young people undergoing cancer treatment. This is a positive step to recognising the financial burden associated with accessing specialist care, often across borders.

The recent publication of the Rare Cancers Act does go some way to improving outcomes by ensuring more data is shared about clinical trials across the UK. Clause 3 of the Act will ensure patient data from cancer registries across the UK is shared with the 'Be Part of Research' Registry – with a new tailored service for rare cancers, collating all UK patient data in a single, accessible, registry. However, this does not address the practical barriers in accessing cross-border trials such as travel, local funding approvals, and capacity restraints at specialist centres.

Both current and future reforms must prioritise equitable access to specialist care and innovation, including for patients who rely on cross-border services between England and Wales.

4. Is Welsh language provision sufficient in cross-border healthcare?

While this was not a primary focus of our evidence collection, we recognise that patients travelling between England and Wales may face barriers in accessing care or treatments due to language barriers. Similarly, language needs may not be consistently communicated and implemented across systems. Given the importance of clear communication in complex blood cancer care, it is important that Welsh language provisions are embedded within cross-border pathways.

Blood Cancer UK already produces health information for patients and healthcare professionals in Welsh. We have also developed a referral support service, where healthcare professionals can actively refer people to the charity after diagnosis which is available in 170+ languages. Depending on need, patients or loved ones will receive support through a seven-week email journey or a phone call with our expert nurses.

Despite the service being in its scale-up phase, we've encountered local and information governance challenges when trying to introduce this service in Wales. By improving roll-out, newly diagnosed people in Wales would have better access to reliable information about blood cancer in Welsh. We're calling for the next Welsh Government to create national incentives for Health Boards to establish charity partnerships like this.

5. What is the experience of patients in England and Wales who are reliant on the use of healthcare services on the other side of the border?

As outlined above, the experience of blood cancer patients when accessing cross-border healthcare is mixed. Some of the themes raised with us include:

- Cross-border barriers are directly affecting patient treatment choices – with some declining optimal options due to travel burden while others are not referred due to perceived barriers
- They're causing a negative impact on their quality of life – travel, separation from families, inconsistent psychological support and the financial strain significantly affect patient wellbeing
- Fragmented and burdensome experiences – delays due to administrative complexity and fragmented care between local and specialist centres
- Widening health inequalities – cross-border care disproportionality affects rural populations, lower-income patients, and those with a limited support network

Some of these issues were also raised by members of the blood cancer community in response to a survey we used when feeding into the National Cancer Plan in 2025:

"My mother has been treated at the haematology units of a district general hospital and a large city university hospital. The quality of care has been markedly different. Both units have had staffing shortages during the four years since her diagnosis, and these have led to slower or disrupted care." – Carer of someone living with blood cancer, Wales

"Pathways should be constantly updated to provide the best care for that patient." – Carer of someone living with blood cancer, Wales

"My husband was diagnosed with Post Transplant Lymphoma; Burkitt's Lymphoma - He had his transplant in England and was NOT checked up on enough, leading to this ultra rare and deadly disease." – Carer of someone living with blood cancer, Wales

“Although various clinical trials have been running since her diagnosis, my mum has been repeatedly told she ‘lives in the wrong place to be eligible’.” – Carer of someone living with blood cancer, Wales

6. What lessons can be learned from other cross-border health arrangements?

Evidence from across the UK highlights that cross-border healthcare can function effectively for people living with blood cancer where systems are formalised, transparent, and adequately resourced. However, this is not consistently the case for all health boards in Wales.

A repeat finding from our healthcare professional network was that cross-border systems work best when referral pathways are clearly defined, widely understood, and routinely used. For example, pathways between Northern Ireland and specialist centres in England, and between North Wales and Manchester, demonstrate the benefits of clarity and consistency:

“[We have] *very clear and good referral/communication pathways* [between North Wales and Manchester].*”* – Clinical Nurse Specialist, North Wales

“No hindrance at our end. NHS boards in Scotland, Wales and NI appear to be reasonably quick once we get involved but I cannot comment on the first steps in the pathway.” – Consultant Haematologist, Newcastle

Other UK arrangements demonstrate that formalised commissioning structures and pre-agreed funding routes are critical to enabling timely access. For example, Scotland’s and Northern Ireland’s out-of-area referral systems provide more structured national frameworks for accessing specialist services and agreeing funding arrangements.

Strong clinician-to-clinician relationships and formal coordination mechanisms are consistently identified as key enablers to effective cross-border care. However, this is often informal and relies on individual effort rather than system design. Formal communication structures must be embedded into cross-border models.

“Clinicians in NI have established excellent working relationships with haematologists in quaternary centres[2]. We are keen to ensure patients* [in NI] *are afforded opportunities to participate…however travel is a barrier.” – Consultant Haematologist, Belfast

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[2] Quaternary care represents the fourth level of healthcare, extending beyond tertiary care to address extremely complex or rare medical conditions. These hospitals are equipped to perform highly specialised surgeries, experimental procedures, and advanced diagnostic techniques.

Finally, experiences from the across the UK highlight that patient support (e.g. financial reimbursement, holistic care, psychological support) is often the weakest component of cross-border care, despite being critical to access and outcomes. Even in more established arrangements, support is inconsistent and financial barriers persist. Cross-border pathways must include comprehensive, standardised patient support including financial, logistical, and psychological elements.

Conclusion –

In summary, cross-border healthcare between England and Wales will continue to be an essential part of modern blood cancer care. However, as outlined above, existing arrangements are not fit for purpose for the increasingly specialised treatment pathways. These currently rely on individual clinical knowledge and informal agreements between centres.

Without reform, patients with blood cancer in Wales will continue to face:

- Limited local access to specialist treatments
- Complex and unclear referral pathways
- Significant travel and financial burdens
- Barriers to clinical trials and innovation

To address these challenges, we recommend that the Committee calls on the UK and Welsh Governments, NHS England and NHS Wales to:

- Develop a streamlined, cross-border referral pathway, with defined responsibilities around reimbursement and approval processes, embedded support for patients, and clear timelines for urgent cases
- Address the financial and practical barriers preventing patients from accessing cross-border treatments and trials by:
  - Expanding and coordinating existing travel and accommodation support schemes currently available across Wales and England
  - Removing ‘up-front’ payment requirements where possible
  - Establishing a clear entitlement for carer support where prolonged travel or accommodation is required
- Introduce interoperable digital systems and better data sharing for out of area referrals
- End the current blood cancer workforce crisis by engaging with NHS Wales’ haematology workforce to address challenges with capacity and knowledge of cross-border referral pathways
- Facilitate greater cross-border participation in commercial and non-commercial clinical trials with improved communication of open trials across nations

This inquiry provides a critical opportunity to develop a modern, coordinated, and patient-centred cross-border healthcare system, ensuring that everyone affected by blood cancer can access the treatment and care they need, regardless of where they live.