A Service Evaluation of Patient Experiences of Clinical Trials in Blood Cancer

Independent Service Evaluation conducted and authored by Professor Olinda Santin, School of Nursing and Midwifery Queen's University Belfast

Professor Olinda Santin

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Overview

A qualitative methodology was adopted, using focus groups with patients and caregivers recruited from the Belfast Health and Social Care Trust (BHSCT) haematology service. The interview schedule was developed collaboratively in partnership with Olinda Santin (OS), members of the clinical team, and patient representatives to ensure relevance and sensitivity to participant experiences.

Eligible patients and caregivers were invited to take part and were offered the choice of participating either online or face-to-face. In total, three focus groups were conducted: one via Microsoft Teams and two held in person within the BHSCT.

All focus groups were audio-recorded with consent and subsequently transcribed. The data were thematically analysed by Professor Santin, and the findings were synthesised into this report.

Overall, participants reported very high levels of satisfaction with the haematology service, strongly influenced by the professionalism, openness, and compassion of staff. Trust, reassurance, and emotional security were consistently highlighted, with nurses and consultants playing a central role in delivering personalised, attentive care within a well-coordinated and collegial team environment.

Clinical trials were broadly viewed as a positive and valued component of care, offering access to additional treatment options and generating hope, particularly when standard therapies were limited. Participants emphasised the importance of clear communication, early and appropriate introduction of trial information, and strong emotional support throughout decision-making and participation. Trial involvement was generally experienced as low burden and reassuring especially when delivered close to home; significant challenges were reported for those required to travel, including financial strain, logistical complexity, and emotional and practical burden on families.

Across all discussions, participants highlighted opportunities to further strengthen care through improved communication and feedback on trial outcomes, enhanced practical and nutritional support, better coordination across services, and reduced waiting times.

Overall, while experiences were overwhelmingly positive, the findings point to clear areas for service development to better support patients and caregivers throughout treatment and clinical trial pathways.

Main Findings

This report presents the findings from three focus groups involving 17 patients and 16 caregivers, exploring experiences of the haematology service and clinical trials. The results are organised into the following key areas: overall experiences of the haematology service and staff; patient and caregiver perceptions of research and clinical trials as part of the haematology service; clinical trial recruitment experiences; experiences of participating in clinical trials; and service improvement recommendations. The sections that follow provide a detailed account of these findings.

1. Overall experiences of the Haematology Service and Staff

All participants discussed a high level of satisfaction with the haematology service. This positivity was mainly attributed to the perception of the professionalism and service provided by the staff. Participants consistently described overwhelmingly positive interactions with haematology staff, particularly consultants and trial nurses, highlighting relational qualities that fostered trust, reassurance, and a sense of being in capable hands. Participants highlighted the collegiality of the team and how the team respects each other and this ensured a feeling of trust in patients and family members.

"when a group of people work well together and respect each other... you can really see there is a good spirit within the haematology team,".

"she would make a point of coming down and seeing us... say hello and chat."

Haematology staff were described as open and willing to discuss issues, even in situations of uncertainty. This transparency built confidence among patients and caregivers that “no stone was left unturned,” reinforcing perceptions of optimal care. A key strength was staff’s ability to form meaningful, individualised connections, despite patients’ awareness of high workloads. Although the Haematology department was perceived as busy, participants consistently highlighted that staff particularly nurses always made time to engage in conversation. Nurses were often described as having “special gifts” that made patients and caregivers feel important; for example, they were noted to recognise individuals in crowded settings, greet them, and address them by name. The delivery of the current helpline was highly praised as ensuring patients and families were informed and supported . In most cases, with the exception of one participant, individuals reported seeing the same health professionals over time, which supported continuity of care. Staff attentiveness and proactivity were described as going “a long way” in fostering emotional security, regardless of clinical outcomes.

> "availability of the nurses, the trial nurses... if you have any concerns, you just pick up the phone and you get through... straight away,"

Key messages on Haematology Service and Staff

- All participants expressed high satisfaction due to staff's professionalism, openness, and transparency that built strong trust even amid uncertainty.
- Observable collegiality and mutual respect created a "good spirit" reassuring patients of coordinated, high quality care.
- Nurses formed meaningful connections remembering names, making time to chat, providing continuity despite heavy workloads.

2. Patient and Caregivers perceptions regarding research and clinical trials being part of the Haematology Service

Participants generally viewed clinical trials and research as an important component of the haematology service. They described research as offering additional treatment options, particularly when options for standard therapy was limited or associated with significant side effects. Overall participants discussed that being offered clinical trials or being involved in research felt it could provide potentially better outcomes for the patients. A key importance of this integration within the service was the opportunity to provide evidence that will help other patients or family members with similar issues in the future while also benefiting future service users. Participants felt that research helps contribute to longer-term service development and improved treatment options. Several participants expressed trust in clinical staff to recommend trials appropriately and valued the opportunity to contribute to the development of new treatments. Although some were surprised to learn that trials were available within the service, this was not presented as a negative view; rather, the main concern was that for some people the opportunity should have been introduced earlier. Overall, participants perceived clinical trials and research as a positive and valuable part of haematology care, helping people feel that they had somewhere to go when standard treatment options were limited.

Key messages :

- Patients and caregivers are happy that research and clinical trials are offered as part of the haematology service.
- Patients and caregivers felt that research should be part of haematology because it advances knowledge and treatment.
- Patient and caregivers felt that trials should be available within the haematology service and discussed early.
- Patient and Caregivers discussed the perception that trials can offer better or less harmful treatment options.
- Patients felt that participation helps future patients and future planning.

3. Clinical Trial Recruitment Experiences of patients and caregivers

Participants described being informed about clinical trials during routine consultations, often soon after diagnosis or when treatment options were being discussed. Trial information was typically introduced by the consultant in a way that felt natural and integrated into the standard treatment pathway. This was usually supported by written materials and followed by further explanations from specialist nurses or trial nurses.

While participants appreciated receiving information, several found the volume of written material overwhelming and emphasised the importance of reassurance and clear, plain-language explanations. The presence of a named nurse or trusted member of the care team was viewed as particularly valuable in answering questions, reducing anxiety, and supporting understanding. Patients and families expressed a need for reassurance regarding potential side effects, safety, and what participation in a trial would involve. In this context, the research nurse was often seen as a key figure in facilitating understanding and providing emotional support.

Overall, participants felt that trial information was generally introduced appropriately; however, they highlighted that its delivery should be calm, personalised, and responsive to the emotional state of patients and their families. Participation in a clinical trial was widely perceived as a highly personal decision. Although some families reported initial concerns about their loved one being treated as a “guinea pig,” they ultimately recognised that the choice to participate is deeply individual and context-dependent.

'Why should my relative be a Guinea pig' but if someone wants to be part of something…. The patient is the core to this. If the patient is happy – would be allowed. We had the choice'

'We would go back to our mum - it's your choice, and she would have got comfort. It's very personal and sensitive'.

'A large part of it is a good relationship with your consultant. At the end of the day, I put my trust in her. She has your best interests at heart. I was offered the trial drug right from the start. Positive idea of trials, you're offered the best and then the best of treatment going ahead'

Key messages

- Trials were introduced naturally by consultants during routine appointments as standard care options viewed as positive.
- Patients and caregivers do need information on what to expect, written materials were seen as beneficial but often felt overwhelming .
- Emotional reassurance that was provided from nurses was essential alongside factual explanations in plain language to ease anxieties and worries
- Decisions on participating in trials rested on personal choice, patients often wanted to give something back to other patients and caregivers and rested on strong trust in clinicians and nurses as experts.

4. Experiences of Clinical Trials

The majority of discussion centred around common experiences when on trials . Overall, benefits centred on treatment advancement and reassurance, while challenges disproportionately affected families which had to travel outside of Northern Ireland, highlighting needs for better travel support, and general psychosocial support particularly for caregivers .

Positive Experiences

Participants described clinical trial participation as a predominantly positive experience, largely due to perceptions of enhanced treatment options and increased emotional reassurance. Trial involvement was associated with access to promising therapies, which were often perceived as less toxic than standard treatments.

Being offered participation in a clinical trial was frequently equated with a sense of hope, particularly in relation to the potential for long-term organ protection compared to standard care.

For patients and families who participated in trials or treatment delivered at or close to home, the practical demands were described as minimal. These typically included additional blood tests or the completion of diaries, and were not perceived as burdensome. Instead, trial participation during treatment phases was seen to provide an added layer of reassurance without significantly increasing strain.

Trials were also viewed as offering reduced-toxicity treatment options, with some participants noting the potential to avoid the more “notorious” side effects of chemotherapy. Additional monitoring, tests, and regular communication with clinical teams contributed to a sense of safety, hope, and security in the context of uncertain outcomes.

"Extra reassurance… with the very unknown outcome"; made standard care "more bearable"

Key messages

- Clinical trial participation was viewed as a largely positive experience by patients and families.
- Being offered a trial was often interpreted as a source of hope, particularly for long-term outcomes and potentially less toxic treatments.
- Participation close to or at home was seen as low burden, with minimal additional demands.
- Extra monitoring and contact with clinical teams provided reassurance, safety, and emotional support.
- Trials helped make standard treatment feel more manageable and less overwhelming.

Challenges with participating in a Clinical trials away from home

For participants who were required to travel for clinical trials or treatment, challenges were notably intensified, with significant logistical and family-related burdens emerging, often amplified by distance from treatment centres. Even among those receiving treatment locally in Northern Ireland, long protocol-driven hospital days and extended waits for pharmacy were described as highly demanding, contributing to the perception that trial participation could be more challenging than standard care. Hospital car parking , particularly in the Royal Victoria site was described as highly stressful and adding to the burden of participation.

When travelling to England for treatment, a minority of families were given charitable support, which provided assistance with booking and arranging flights or accommodation, which was described as transformative. These supports provided practical resources including laundry facilities, and a sense of community that enabled home comforts, supported family coping, and reduced pressure on individual caregivers. However, most participants did not have access to such support. In these cases, caregivers reported significant isolation and burden as they managed major life disruption, accommodation and travel arrangements, and financial pressures while caring for an unwell patient away from home.

Being in an unfamiliar city without established support networks further compounded emotional strain. Caregivers also described the practical and physical challenges of travelling with a seriously ill person, particularly through airports and public transport, often without assistance. Overall, travel for treatment was experienced as especially burdensome for caregivers, amplifying both logistical and emotional demands and shaping how clinical trial participation was experienced.

For participants who were required to travel for treatment, financial costs were described as a significant challenge. Families reported substantial out-of-pocket expenses, with some noting costs of up to £10,000 due to accommodation and travel in high-cost locations such as London, while others highlighted the strain of repeated smaller expenses, including £800 taxi fares. Although some costs were reimbursable, the requirement to pay upfront created considerable financial pressure. In several cases, this placed families at risk of financial hardship, particularly where they did not have immediate access to funds to cover expenses prior to reimbursement.

‘’Not everyone could afford the £9000 paid up front. King's College picked up on the issue of having to stay. They got us a good house so mum could rest and recover and made it pleasant. For six weeks’’

Key Service Improvement Recommendations Results

Participants expressed high overall satisfaction with the haematology service's delivery of clinical trials and , with many stating no major changes were needed and emphasizing the effectiveness of current practices. Reflecting appreciation for compassionate care, clear explanations, and successful treatment outcomes. However, a few targeted improvements emerged, centring on communication, practical support, and patient-centred adaptations during trials.

- **Treatments provided closer to home**

For participants who travelled to England for treatment or clinical trials, a key recommendation was the increased availability of treatment and trial access closer to home. This was seen as a way to reduce the range of logistical, financial, and emotional burdens experienced by families. Participants emphasised the importance of continuity of care within familiar services, highlighting that patients were more comfortable and placed greater trust in their local consultant team. Being treated away from this established relationship was described as removing an important "safety net," with families noting that patients were taken out of their comfort zone when care was delivered in unfamiliar settings. This disruption to continuity was perceived as a significant disadvantage of receiving treatment away from home.

- **Feedback and Progress Updates**

A prominent suggestion from participants was the need for improved feedback on trial progress and individual outcomes, enabling them to feel more connected to the research process. Families expressed a strong desire for updates on study findings, including information on relapse rates or emerging comparative results between treatments, even where such data might be preliminary or subject to limitations. Many participants highlighted the absence of follow-up after trial completion, noting that they would value ongoing communication sometimes years later regarding the outcomes of trials. Continuous post-trial summaries were viewed as an important means of maintaining engagement, providing closure, and recognising the contribution of patients and families to research.

"feedback on the progress of the trial itself,"

"what did they find out from it"

- **Ongoing Reassurance and Monitoring**

Participants valued the frequent monitoring associated with clinical trial participation; however, they also expressed a need for more proactive and structured reassurance throughout the trial process. This included routine check-ins that went beyond clinical assessments to explore how participants were coping, particularly in relation to practical and psychological impacts of participation. Patients and caregivers need support and guidance on how to manage travel, children , pets etc when participating in trials. Participants highlighted the importance of opportunities to ask questions about their experience and to receive clear reassurance regarding side effects and treatment effects. In addition, they emphasised the value of being actively signposted to appropriate sources of support when needed for practical issues .

- **Improved Nutritional support**

A number of participants highlighted a gap in nutritional support during treatment and clinical trial participation, recommending the provision of “diet-specific” options tailored to the effects of therapy, including taste changes and swallowing difficulties. Hospital meal provision was frequently described as inadequate, with some participants reporting that they were unable to tolerate or swallow the available food. In response, some relied on nutritional supplement drinks; however, participants emphasised the need for more proactive, treatment-adapted menus to prevent deterioration in nutritional intake. This was seen as particularly important given that treatment-related side effects often significantly reduce appetite and the ability to eat, increasing the risk of malnutrition.

"I ate what you get in the hospital... couldn't swallow a lot of it; it was too dry."

- **Improved co-ordination/communication with wider health and social care**

Despite generally positive experiences within haematology services, families often had to interact with other health and social care departments, which was sometimes challenging. In particular, Accident and Emergency (A&E) departments were described as difficult environments due to limited staff awareness of complex haematology treatments and the heightened infection risk faced by immunocompromised patients in crowded clinical settings. Participants reported feeling the need to repeatedly explain their family members condition and treatment requirements in acute care contexts. To address this, they suggested the development of a patient-held card or other form of documentation to communicate key clinical information more effectively when accessing non-specialist services.

- **Efficiency and waiting times**

Participants suggested that improved waiting times within clinic settings could significantly enhance the patient experience. They described long treatment days characterised by extended waits for blood tests, delays associated with samples being sent to different hospitals, and leaving hospital late at night only to return again the following day. These processes were experienced as challenging on multiple levels, both physically and emotionally. Pharmacy delays were a particularly common source of frustration, with patients reporting waiting several hours for medications and, in some cases, needing to travel long distances back to the hospital to collect them. Overall, these delays were seen as a key area for improvement and one that participants felt should be prioritised within service delivery.

'In Tuesday and Wednesday, then finished treatment, often bloods at 4.30 and bloods had to go to RVH and sometimes leaving at 9:00 at night and having to come back the next day'

Agree it's a long day. Drive from xxxxxx and it's a long day. The trial nurses are trying to chivvy pharmacy along, can't fault them.

Big frustration. I'm sure everybody would…. even a normal cream (takes a long time from pharmacy), it's not just about the chemo.

You have your review logged, just waiting. I would rather go home and get it the next morning. The time was stretching too much.

- Improved family support

Participation in clinical trials and treatment was particularly challenging for families, especially those required to travel long distances. Participants highlighted a need for greater support for caregivers, particularly in relation to the practical demands of travel, accommodation, and the coordination of caring responsibilities. These logistical pressures were often experienced alongside the emotional demands of supporting an unwell family member, indicating a need for more structured and accessible forms of family support throughout the treatment and trial process.

To travel for trials you have to be fit . both of you, we were on our own