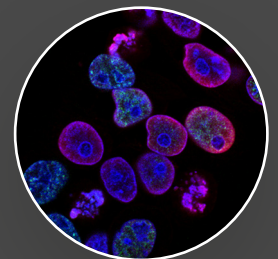




SANGUINE STAKEHOLDER FORUM REPORT

'Uniting forces: addressing
needs in blood cancer care'



Executive summary

Hematological malignancies account for a substantial share of cancer cases worldwide. In Europe alone, around 300,000 cases are diagnosed every year, significantly contributing to cancer-related illness and death. Hematological malignancies, encompassing cancers such as leukaemia, lymphoma, and multiple myeloma, represent a significant health concern within the European Union (EU).

The SANGUINE project is pioneering novel approaches to the early detection of these blood cancers. The development of the HemaChip, a state-of-the-art cancer early diagnosis tool, will enable quick, minimally invasive, cost-effective, and highly sensitive tests that will improve treatment outcomes.

While working on the early diagnosis tool, SANGUINE is also engaging diverse stakeholders from hospitals, non-governmental organisations (NGOs), research institutes, small and medium-sized enterprises (SMEs), and policymakers. To ensure its holistic approach, SANGUINE invites stakeholders to foster discussion on the latest developments in blood cancer care and what is needed to improve early detection, diagnosis, and treatment.

As part of this project, the European Cancer Organisation hosted the Stakeholder Forum online event 'Uniting Forces: Addressing Needs in Blood Cancer Care' on Friday 11 October, to discuss technological innovations, best practices and public policies to improve the treatment of blood-related diseases.



**Funded by
the European Union**



SANGUINE is a Horizon EU-funded project focused on advancing the field of hematological malignancies by developing a state-of-the-art blood test that enables early detection of these cancers, leading to improved treatment outcomes and enhanced quality of life for patients.



The project is dedicated to improving cancer care through the development of an innovative blood test for haematological malignancies. The test intends to detect specific biomarkers in the blood allowing early diagnosis and better outcomes for patients. By providing validated tools and software, the project aims to revolutionise the early diagnosis of blood cancers and have a positive impact on the lives of patients and their loved ones across Europe. The project objective includes:

- Developing a Revolutionary Blood Test: Create an advanced blood test for early detection of hematological malignancies, leveraging cutting-edge technologies and interdisciplinary expertise.
- Integrating STEM and SSH: Combine science, technology, engineering, and mathematics (STEM) with Social Sciences and Humanities (SSH) to ensure inclusivity, ethical rigour, and patient-centred approaches in cancer diagnostics.
- Fostering Stakeholder Collaboration: Engage patients, caregivers, health professionals, and policymakers to promote ethical implementation, regulatory alignment, and effective dissemination of project outcomes.

SANGUINE is also part of the so-called 'Prevention and Early Detection (Screening) Cancer Mission Cluster' that received funding from the European Commission through the Horizon Europe programme, aiming to develop better long-term cancer control strategies towards prevention, screening and early detection of cancer. There is a combined effort of all projects to extend the reach and impact of each other's research.



What makes blood cancers difficult to diagnose?

The Stakeholder Forum kicked off with an overview of blood cancer by Professor John Gribben. A key message conveyed was that blood cancers, compared to many other cancers, provides special complexities in respect to detection and diagnosis overall.



Supporting this, Professor Gribben referred to the latest WHO Classifications which indicate that there are approximately 128 subtypes of lymphoma (81 B-cell, 40 T-cell and 7 dendritic subtypes included, 21 of which have been added since the 4th edition) and 109 subtypes of myeloid tumours.

Blood cancers are difficult to diagnose because of their non-specific and heterogeneous symptoms. Further to this, the process of detection and diagnosis usually involves multiple consultations and appointments that further prolong the diagnostic pathway.

In relation to different types of blood cancer, there are a wide variety of symptoms. This can include fever, pallor/change of skin, fatigue or tiredness, non-shimmering rash, behavioural changes, and body pains (particularly in the bones/joints and back). By their nature, such symptoms individually are not necessarily easily attributable to a tumour per se and are therefore, all-too-often, not taken due account of.

One third of cases are diagnosed through emergency admission to hospital and these cases have a worse survival (40% at 3 years) than those presented by other routes (77% at 3 years). Accordingly, the role of the general practitioner (GPs) is important in better recognising such symptoms and the patient's condition, and referring their investigation correspondingly.

What emerges from this brief overview is that new technologies and practices that offer opportunities to **improve the early detection of blood cancers, if proven, offer the promise of considerable positive impact on the quality of life and survival of blood cancer patients.**

Improving early detection: a patient centred approach

Bringing together 11 partners from clinical and non-clinical backgrounds, SANGUINE is a Horizon Europe funded project that commenced in 2023. Professor Yuval Ebenstein from the Coordination Team of Tel-Aviv University shared the primary objectives of the project, which include:



- To **discover the biomarkers** that uniquely identify hematological conditions.
- To validate the discovery platform, the **Hemachip**, as a **diagnostic tool for various blood cancers**.
- To evaluate the **early detection capability** and sensitivity of the Hemachip.

On the one hand, together with clinical partners, SANGUINE is working on innovative technology that can detect specific biomarkers in the blood, enabling early diagnosis and better outcomes for patients.

On the other hand, non-clinical partners are working together to improve medical decision-making and meet the needs of medical professionals and patients for effective implementation.

In particular, **PredictBy aims to better understand the factors that drive and hinder participation in blood testing for early detection of blood cancer**. Key objectives to increase the willingness of individuals to participate in the SANGUINE test for early detection of blood cancers include:

- developing a co-creation process to develop a communication package to increase testing rates.
- Bringing forward a dual communication strategy: personalised messages for patients and health care professionals (HCPs).

The European Cancer Organisation (ECO) supports PredictBy's work in ensuring a patient-centred approach and considering all stakeholder perspectives to identify the relevant factors to be addressed.

In particular, there are three stakeholder engagement activities where PredictBy and ECO work together:

- Focus groups to validate relevant factors regarding participation in early diagnosis programmes and identify preferred communication and information channels.
- Bilateral interviews to validate (1) the factors identified by the focus groups and (2) the content developed for the communication package.
- and to test the communication models developed with an online panel.

Stakeholder perspective – HARMONY Big Data Platform



Among the purposes of the stakeholder forum was to help foster connections between SANGUINE and other EU supported projects with focus on blood cancers.

Jesús María Hernández-Rivas, Professor in Hematology & Senior Hematologist, Medical University of Salamanca presented the case study project of the HARMONY Big Data Platform.

The HARMONY Big Data Platform for hematological malignancies, is a secure and innovative research data ecosystem that aims to provide a big data-based and cutting-edge analytical services.

Anonymous patient datasets at the Big Data Platform are securely collected, complying with all legal and ethical requirements, harmonised and then analysed. Currently, there are more than 179,000 datasets of blood cancer patients and 115,000 records are currently available. The platform also offers data exploration tools.

The HARMONY Alliance is composed of the success of two projects HARMONY and HARMONY PLUS, both funded by the European Innovative Medicines Initiative (IMI, now IHI). Once concluded, thanks to the strong commitment of the partners and the inclusion of different stakeholders, the HARMONY Alliance continued its work as a non-profit collaborative research foundation.

More information about the HARMONY project is available [here](#).

Stakeholder perspective – 'Myeloma diagnosis across Europe' report

A second stakeholder perspective was provided by Silene ten Seldam, Patient Evidence Research Assistant at Myeloma Patients Europe who provided a presentation on the Myeloma Diagnosis Across Europe Report, published in 2022 which address the experiences of Europeans myeloma patients and their perspectives towards European hematologists.



As the report emphasised, early diagnosis of myeloma has been shown to minimise disease complications and improve the quality of life. Yet, existing literature on myeloma and testimonials from patients highlight that many patients experience delays, often due to non-specific symptoms, lack of myeloma awareness in primary care or other causes.

Unfortunately, key findings in the report emphasised:

- **Approximately 51% of patients waited 3 or more months after the onset of symptoms before seeking medical help.**
- **Approximately 24% of patients waited 5 months or more to get a diagnosis.**
- **In contrast, 13% of haematologists stated it took their patients 5 months or more to get a diagnosis.**
- **Most patients saw up to 3 different specialists (e.g. primary care, renal, orthopaedics) before receiving a diagnosis; however, 21% of patients saw more than 3, and more importantly:**
 - Approximately 34% of patients stated that their diagnosis was delayed.
 - 25% of clinicians described the timing of diagnosis in their country as delayed.

The full report is available [here](#).

Stakeholder perspective – The Joint Accreditation Committee ISCT–Europe & EBMT (JACIE)

A final case study project was presented by **Eugenia Trigosso Arjona**, Nurse Coordinator, La Fe Hospital & Co-Chair, SIOPE Nursing Working Group.

JACIE is a collaborative initiative established by the **International Society for Cell & Gene Therapy (ISCT)** and the **European Society for Blood and Marrow Transplantation (EBMT)**. It serves as the primary accreditation body in Europe for organizations involved in hematopoietic stem cell transplantation (HSCT) and cellular therapy.

JACIE's mission is to improve the quality of patient care and laboratory performance in HSCT and cellular therapy by promoting the adoption of high standards and best practices.

This accreditation is particularly important for hematological malignancies due to the complex and high-risk nature of the treatments involved, such as hematopoietic stem cell transplantation (HSCT) and cellular therapies.

JACIE accreditation plays an important role in advancing the quality and consistency of care for patients with hematological malignancies. By setting and enforcing rigorous standards, it ensures that patients receive the safest, most effective, and state-of-the-art treatments, ultimately improving outcomes and enhancing their quality of life.

More information about JACIE is available [here](#).

In conclusion, stakeholders recommend between others:

- the need for a more empathetic and patient-oriented approach in primary care settings.
- patients highlighted the emotional burden of feeling unheard and the relief that only came with an accurate diagnosis, despite its severity.
- Improving clinical pathways by fostering a culture in which patients feel validated, understood and supported throughout the healthcare pathway.
- Developing a multidisciplinary approach including hematologist, oncologist, radiologist and palliative care expert.

Improving quality of cancer care for haematological malignancies: the essential requirements of quality cancer care

Recognising the unique care challenges associated with haematological malignancies, Professor John Gribben highlighted a recent collaborative initiative between the European Cancer Organisation and European Hematology Association. This effort aimed to identify and define the essential requirements needed to deliver high quality cancer care in haematological cancers.

The Essential Requirements for Quality Cancer Care papers are organisational specifications developed by European experts across oncology disciplines. They are designed to provide oncology teams, patients, policymakers and managers with an overview of the key elements required within any healthcare system to ensure high-quality care throughout the patient journey. Focused on the European context, these consensus-based documents outline the critical elements and best practices needed to deliver high-quality, multidisciplinary care for specific tumour types, including haematological malignancies.

In order to support the creation of an Essential Requirements for Quality Cancer Care: Haematological Malignancies, an expert panel of co-authors was convened, comprising representatives from healthcare professional organisations and patient advocates, to examine the key requirements for delivering high-quality cancer care in haematological malignancies. The result was the development of the European Cancer Organisation Essential Requirements for Quality Cancer Care: Haematological Malignancies.

This document outlines the organisational framework and actions necessary to ensure top-quality care for patients with haematological malignancies. The aim, therefore, of this joint initiative is to enable timely diagnosis and improve outcomes through some good practices.

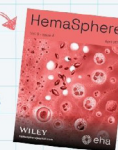
How many boxes does your hospital tick?

- ☒ fast, easy access to accurate diagnostic tests
- ☒ established pathways for referral to specialist centres
- ☐ centralised services
- ☒ monitoring patient well-being
- ☐ treatment strategies agreed by a multidisciplinary team
- ☐ involving patients and their families at all stages of decision-making

Essential Requirements for Quality Cancer Care Hematological malignancies



eha

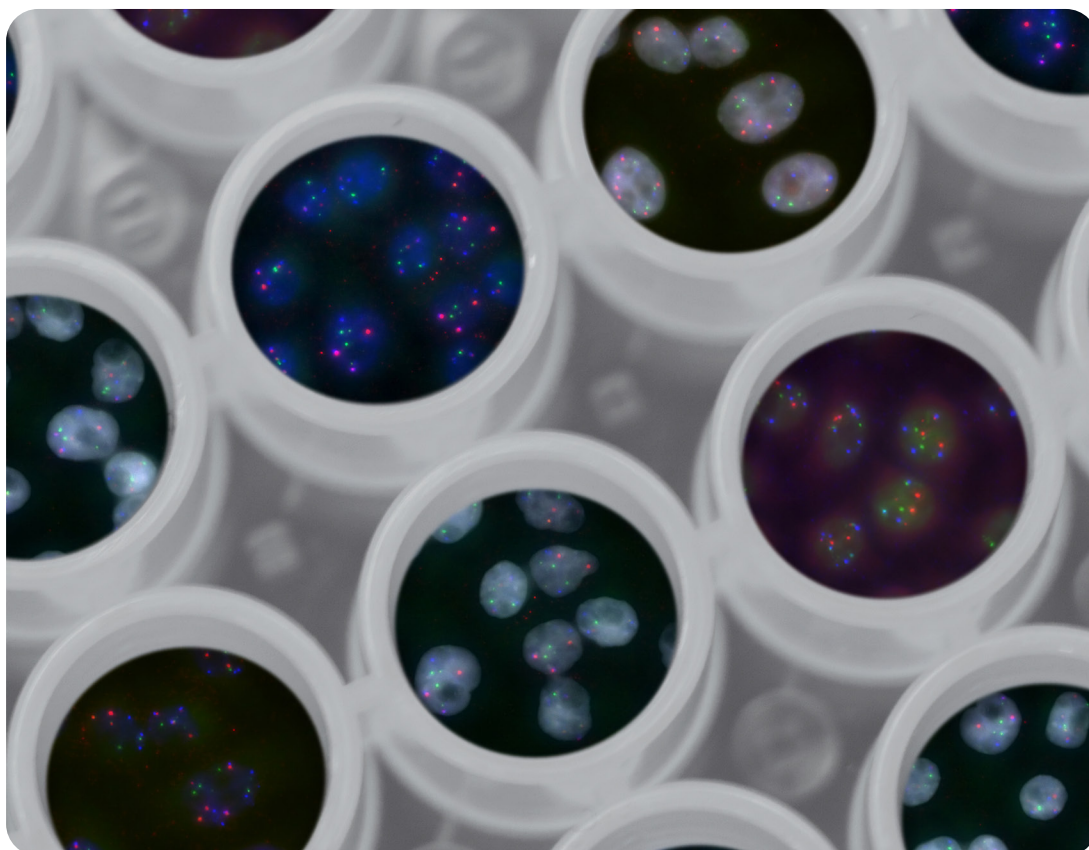


The ERQCC panel aims to establish a standard that is both ambitious and realistically feasible for most countries. Recommendations include:

- **a centralised approach for the management of haematological cancers, with large centres with specialised resources for molecular diagnostics, complex treatments (such as acute leukaemia, stem cell transplants and CAR-T), and multidisciplinary support.**
- **This model also makes it possible to provide input to smaller centres, integrate psychosocial support, and increase access to clinical trials.**

Although the ERQCC expert group is fully aware that it is not possible to propose a one-size-fits-all system and factual limits, these recommendations aim to establish a realistic quality standard attainable by all countries

The Essential Requirements for Quality Cancer Care: Hematological Malignancies were published subsequent to the SANGUINE stakeholder forum and are available for view (open access) [here](#).



Europe's Beating Cancer Plan and the EU Cancer Mission: public policies to improve treatment of blood-related diseases in Europe

Session 3 of the Stakeholder Forum focused on situating the Sanguine project within the broader framework of EU health policy, including the Europe's Beating Cancer Plan and the EU Cancer Mission. While these initiatives have advanced important areas of cancer research, blood cancers have not been sufficiently visible in policy or funding priorities.

Speakers repeatedly underlined the value of EU-funded projects in driving innovation and collaboration in haematology. However, it was noted that the rapid growth in initiatives have come with some sense of fragmentation, where greater coordination could be welcomed. There were also concerns raised about the potential of results and promise from projects being risked if sustainability of funding is not in place.



Experts, including SANGUINE Coordinator and speakers, raised the fact that without sustainable framework to link them together, and resources to secure long-term impact risk of avoidable duplication is present.

In particular, Robin Doeswijk, head of European Affairs at the European Haematology Association (EHA), recommended the '*clustering*' of EU-funded projects to be more thematic and regular, bringing together different initiatives on haematological malignancies under a common framework.

Alongside these structural concerns, the conversation also turned to patient-centred issues, with survivorship standing out as a critical gap in current policy. This was raised in particular by Doctor Francoise Meunier and Professor John Gribben. Haematological malignancies are often diseases of young people, and while many are curable, survivors face discrimination and unmet needs in long-term care.

The Right to be Forgotten¹ was singled out as an essential measure to protect survivors across Europe from difficulties in accessing insurance, loans, or employment, said Dr. Meunier.

Equally important is the need for appropriate medical follow-up. Several participants expressed concern that survivorship care is increasingly shifted to primary care physicians who may lack the necessary expertise, raising doubts about the quality of support survivors receive.

Adolescents and young adults were also mentioned as a priority population who deserve targeted attention, both in terms of research focus and in the design of survivorship programs.

The session identified both the opportunities and the challenges in advancing blood cancer care at the European level. Recommendations emerging from the session include:

- Ensure sustainability of research projects through mechanisms for continuation funding, structured clustering, and central coordination across EU initiatives.
- Improve survivorship policies by including survivorship care in specialised haematology settings and implementing the *Right to be Forgotten* across all EU member states.
- Address the needs of adolescents and young adults (AYA) through dedicated research, public policies, and tailored survivorship programs.

¹ The 'Right to Be Forgotten' is a legal provision addressing the issue of financial discrimination issue and designed to protect cancer survivors. It refers to the rights of cancer survivors to resume a 'normal' lifestyle without encountering discrimination based on their past cancer diagnosis, after they have been declared cured. More on: <https://endingdiscrimination-cancersurvivors.eu/financial-discrimination-against-cancer-survivors/>

Main findings and recommendations

The SANGUINE Stakeholder Forum made clear that addressing the specific needs of blood cancer patients requires tailored, cross-sector policy attention — particularly in the areas of early detection, quality standards, data-driven innovation, and patient-centred communication.

On the basis of these discussions and the evidence presented in this report, the European Cancer Organisation makes the following policy recommendations to national governments, EU institutions, and the broader health policy community:

1. A New Policy Mindset on Early Detection: Beyond Traditional Screening

Blood cancers rarely fit into conventional screening paradigms. Unlike breast or colorectal cancer, they lack a clear population-wide screening mechanism. Yet this must not be mistaken for a lack of early detection potential.

- Moving towards, a **risk-adapted early detection model**, prioritising the development of diagnostic pathways tailored to symptom clusters and high-risk groups. This requires investment in **diagnostic infrastructure**, including multidisciplinary rapid diagnostic centres and tools for front-line clinicians.
- Furthermore, innovation in non-invasive technologies—such as liquid biopsies or biomarker-based devices like HemaChip—should be strategically supported through EU funding mechanisms.

2. From Guidelines to Guarantees: Embedding Quality Standards into Systems

The Essential Requirements for Quality Cancer Care (ERQCC) in Haematological Malignancies represent a consensus framework that can guide Member States toward more equitable, effective care delivery. But without national adoption and policymaking these standards remain more an aspiration.

- **Member States should support for integrating ERQCC indicators into cancer control strategies**, accreditation systems, and health system performance monitoring. This includes ensuring access to essential components such as **molecular diagnostics**, **CAR-T cell therapies**, and **psychosocial care**.

3. Making the Invisible Visible: Reframing Awareness and Communication

Haematological cancers often go undetected not because the signs are absent, but because they are unrecognised or misunderstood—by patients and professionals alike. The psychological toll of feeling unheard, misdiagnosed, or left in diagnostic limbo was strongly echoed at the Forum.

- To close this gap, **public health communication should become patient-informed, psychologically attuned.** Tools like the PredictBy behavioural science model showcased under SANGUINE offer replicable frameworks for engaging both the public and providers.
- EU institutions should invest in the **co-creation of targeted awareness campaigns**, involving patients and clinicians, to translate complexity into clarity—and suspicion into timely investigation.

4. Putting Blood Cancer on the Policy Map: From Margins to Mainstream

While solid tumours have often led the policy conversation in cancer, haematological malignancies have remained less visible—despite their clinical and research complexity.

- EU and national governments should ensure that **blood cancer is fully integrated into future cancer strategies**—whether in the follow-up to Europe's Beating Cancer Plan, the EU Cancer Mission, or national research and control plans. This includes:
 - convening **regular multi-stakeholder policy dialogues.**
 - issuing **targeted funding calls**, ensuring **representation of haematological cancers** in governance and priority-setting mechanisms.

Conclusions

The first SANGUINE Stakeholder Forum brought together experts, patients and project co-ordinators to bring attention to the need for further research into improving the early diagnosis of blood cancers.

Besides sharing the project's mission and some of the activities already performed by the consortium members, such as those done in cooperation between PredictBy and ECO, this initiative also involved experts and healthcare professionals working outside SANGUINE demonstrating how important it is to offer moments of discussion and reflection on blood cancers that are difficult to prevent and have unfortunately a very high mortality rate.

A key part of this discussion was to bring the needs and demands of patients and survivors to the centre, following the principle of 'patient centricity' framed in Europe's Beating Cancer Plan and cancer initiatives and activities.

Acknowledgment

This report summaries the key presentations, contributions and discussion shared at the first SANGUINE Stakeholder Forum '*Uniting Forces: Addressing Needs in Blood Cancer Care*' organised on 11 October 2024 by the European Cancer Organisation together with the project consortium.

ECO is the Work Package (WP) leader of the Dissemination, Communication, Exploitation and Stakeholder Engagement Work Package. In particular, ECO is responsible to ensure patients and stakeholders are involved in the development, implementation, and dissemination of the SANGUINE project; and facilitate the coordination and their participation in networking and joint activities with other EU-funded projects concerning innovative screening and early detection.

Authors

- Riccardo Moschetti, Senior Policy Officer
- Clémentine Rialland, EU Projects Officer

Speakers

- John Gribben, Barts Cancer Institute, Queen Mary University of London. Past President European Hematology Association
- Yuval Ebenstein, Professor, Department of Chemical Physics, School of Chemistry, Tel Aviv University
- Frank Folkvord, Co-founder, PredictBy
- Jesús María Hernández-Rivas, Professor in Haematology & Senior Haematologist, Medical University of Salamanca
- Silene ten Seldam, Patient Evidence Research Assistant, Myeloma Patients Europe
- Eugenia Trigoso Arjona, Nurse Coordinator, La Fe Hospital
- Solomon Alexis, Patient Advocate, Myeloma Patients Europe

Contributors

- Richard Price, Head of Policy, European Cancer Organisation
- Agnese Konusevska, Head of Communication, European Cancer Organisation
- Norbert Couespel, Policy Research & EU Projects Manager
- Otilia Colceriu, Communication Officer, European Cancer Organisation
- Zoë Parker, Policy Research and EU Projects Assistant, European Cancer Organisation

Suggested citation

Moschetti R, Rialland C, (2025). *Uniting Forces: Addressing Needs in Blood Cancer Care*; European Cancer Organisation; Brussels.



SANGUINE



**Funded by
the European Union**

Funded by the European Union – Horizon Europe – Grant Agreement n. 101097026.

Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the European Union. Neither the European Union nor the granting authority can be held responsible for them.

sanguine-project.eu