ALAN
Acute Leukaemia Advocates Network

ACUTE LEUKEMIA ADVOCATES NETWORK

GLOBAL SUMMIT 2025

Executive Summary

The ALAN Global Summit 2025, held in Madrid, brought together the global acute leukemia advocacy community in a way that highlighted both the urgency of the challenges ahead and the maturity of the movement that has grown around this disease. Over three days, the summit explored the intersection of rapidly evolving scientific landscapes, diverse health system realities, and the lived experiences of patients and caregivers. Participants collectively acknowledged that acute leukemia poses distinctive obstacles: compressed diagnostic timelines, limited opportunities for shared decision-making, profound emotional distress, and disparities in access to treatment that vary sharply by geography. These complexities require advocacy strategies that are informed, adaptable, and grounded in evidence rather than intuition alone.

Central to the summit was the shift toward a more structured, data-driven form of advocacy. Attendees discussed global patient experience surveys, preference studies, and real-world evidence that increasingly shape policy dialogues and research agendas. The emphasis on evidence-based approaches marked a clear evolution from traditional storytelling models, underscoring a movement that is now recognized as a legitimate contributor to scientific and regulatory conversations. Presentations throughout the summit demonstrated how patient-generated data can illuminate unmet needs, challenge assumptions, and provide a basis for accountability in healthcare systems.

At the same time, the summit highlighted the persistent tension between knowledge generation and knowledge utilization. While significant amounts of data now exist, the challenge lies in ensuring that these insights are effectively translated into meaningful change - whether in clinical guidelines, national policies, or market access pathways. Several sessions revealed a gap between research outputs and practical implementation, calling attention to the need for stronger coordination, clearer communication, and shared frameworks for measuring impact across organizations.

Workshops offered a candid space for examining structural and organizational barriers. Participants raised concerns about limited staffing, underdeveloped digital infrastructure, fragmented patient pathways, and the difficulty of maintaining engagement in regions where acute leukemia patient populations are small or transient. Discussions also exposed stark contrasts across health systems - ranging from tax-funded models to environments heavily dependent on out-of-pocket payments. These conversations underscored the importance of tailoring advocacy tools and strategies to local conditions while maintaining a global perspective.

Ultimately, the summit reaffirmed that sustained progress in acute leukemia advocacy depends on partnership, transparency, and continuous learning. The final message was one of collective responsibility: no single organization, specialist group, or health system can meet the needs of acute leukemia patients alone. Advocacy must remain both ambitious and realistic - grounded in data, strengthened by community insight, and guided by a vision of equitable access to high-quality care worldwide. The summit served not only as a review of past achievements but as a strategic roadmap for the work that lies ahead.

Call to Action

These are the 10 most critical advocacy imperatives (synthesised across the entire summit), i.e., the actions the conference repeatedly told patient advocates, organisations, and systems they *must* take.

1. Use evidence, not only stories, to drive policy and access change

The strongest and most consistent message: Advocacy must be based on robust, patient-generated evidence (surveys, outcomes, QoL data). Policymakers respond to measurable gaps, not just testimony.

Why this is important: Every major advocacy presentation stressed that without evidence, campaigns stall.

2. Build early and continuous collaboration with clinicians—ensure key conversations happen

Advocates work to ensure that the conversations around diagnostic, communication, and treatment occur early between patients and haematologists.

Why this is important: Communication failures were identified as a universal barrier across countries.

3. Strengthen awareness of leukemia symptoms and encourage early diagnosis pathways

Multiple presenters emphasised symptom awareness as a *life-saving* entry point, especially where advanced care is delayed.

Why this is important: Patients overwhelmingly did not recognise symptoms; delays directly affect survival.

4. Ensure patient organisations participate meaningfully in HTA (Health Technology Assessment)

Advocacy groups must:

- identify patient experts quickly,
- train them,
- ensure they represent leukemia voices,
- stay alert for rapid HTA consultation timelines.

Why this is important: HTA outcomes determine what treatments patients can access.

5. Strengthen the presence of advocates inside hospitals and clinical pathways

Patient organisations can :

- provide navigation support,
- help with treatment explanation,
- gain formal training to be trusted by clinicians.

Why this is important: This is one of the few interventions shown to directly reduce patient confusion and mistrust.

6. Collect high-quality, patient-relevant data and—crucially—use it

Recommendations included:

- "no more surveys unless we use the data,"
- collect the *right* data (needs, experiences, unmet needs),
- avoid biased or inaccessible data structures.

Why this is important: Data becomes advocacy power only when transformed into action.

7. Tailor advocacy goals to national systems and capacities

Advocates must choose realistic, system-specific priorities. No single advocacy model fits all countries.

Why this is important: Universal across EU, OECD, and LMIC talks: context determines what is possible.

8. Work collectively—advocates must raise their voices together

The message was explicit: Advocacy impact grows when NGOs speak with a unified, sustained voice.

Why this is important: Fragmentation was repeatedly identified as a systemic weakness.

9. Use storytelling and peer navigation to humanise the journey and improve support

Recommendations included:

- sharing real patient stories to influence policy,
- supporting newly diagnosed patients through lived-experience guides,
- integrating emotional and psychological needs into care.

Why this is important: Narratives bridge emotional and data-driven advocacy—and reach public audiences.

10. Improve communication competencies of healthcare professionals

Advocate for

- better clinician training,
- compassionate communication,
- structured information pathways.

Why this is important: Communication drives trust, adherence, and patient safety; failures were universal.

Attendees:

Name	Country
Ajda Ccvelbar	Slovenia
Anne-Pierre Pickaert	France
Ashleigh Bell	Australia
Carolina Garcez Aguiar Martins	Portugal
Charles McGrath	UK
Chul-hwan Lee	South Korea
Claudia Poguntke	Austria
Dick Ettema	Netherlands
Diego Villalón García	Spain
Elo Mapelu	Kenya
Geun-hwa Jung	South Korea
Giovanni Marconi	Italy
Hasmik Tshermakyan	Armenia
Jan Geissler	Germany
Jana Pelouchova	Czech Republic
Kairi Jets	Estonia
Lauren Pretorius	South Africa
Marija Vuk	North Macedonia
Moses Phanuel Shekihiyo	Tanzania
Ojelabi Ayodele Andrew	Nigeria
Pasusant Wattanaboonya	Thailand
Rita O. Christensen	Denmark
Rosie Shaw	New Zealand
Shova Karki	Nepal
Silvia Castillo De Armas	Guatemala
Sindy Yang	Thailand
Sophie Wintrich	UK
Stacey Koleszar	USA
Tullet Marine	France
Yolima Méndez	Colombia
Samantha Nier	Switzerland
Leiser Christine	
Alastair Gray	
Mariel Thottam	

Name	Organisation
Beyza Klein	Johnson & Johnson
Chris Allen	Thermofisher
Esther Garcia Buscalla	Amgen
Hamda Munawar	Daiichi Sankyo
Kristina Schultz	Kura Oncology
Zack Pemberton Whiteley	Autolus

Day 1 - 7th November 2025

Welcome and Opening

Presenter(s): Jan Geissler, Samantha Nier

The opening session set the tone for the entire summit by emphasising the importance of reflection, honesty, and partnership. Jan Geissler spoke about ALAN's origins as a network created to meet the unmet needs of acute leukemia patient organisations. He highlighted the unique nature of the disease - its urgency, emotional toll, and the difficulty of engaging patients early in their diagnosis. His remarks underscored the central purpose of ALAN: strengthening organisations, not replacing them, and building global alignment around advocacy priorities.

Samantha Nier offered a reflective overview of ALAN's growth since the previous summit. She presented tangible achievements such as increased membership, rising international visibility, and substantial engagement with digital tools and awareness campaigns. Her contribution grounded the strategic vision in practical evidence of progress. She also reviewed major research initiatives - global surveys and preference studies - that are beginning to influence conversations in clinical and regulatory settings.

Both speakers stressed the importance of sustainable funding and organisational governance. Jan described the ongoing challenges of securing consistent support, noting how advocacy networks often operate with limited resources and high volunteer dependence. Samantha added insights on operational realities, including the workload required to coordinate multiple international projects with limited staff. The session balanced optimism with realism, acknowledging success while recognising that much remains to be done.

"We don't want praise. We want your criticism, your ideas, your reflective thinking"

The opening concluded with a call for active participation. Attendees were encouraged to challenge assumptions, question priorities, and use the summit as a platform to strengthen the global movement for acute leukemia advocacy. The message was clear: ALAN's achievements are significant, but its future direction must be shaped collaboratively by its community.

Session: Medical Updates on Acute Leukemias

Presenter(s): Dr Giovanni Marconi, Carolina Garcez Aguiar Martins, Charles McGrath

This session offered an integrated view of acute leukemias by combining clinical insight, lived experience, and reflections on the realities faced across different health systems. The clinical overview introduced the group to the rapidly shifting landscape of acute leukemias, where treatment decisions are closely tied to diagnosis timing, disease aggressiveness, and evolving therapeutic options. The presentation emphasised how the intensity of the disease often leaves very little room for shared decision-making and how this contributes to the distinctive complexity of acute leukemia care.

"it costs approximately $4 to have a complete blood count."

A personal dimension emerged through the contribution of a speaker who had studied medicine before becoming a leukemia patient. Her reflections captured the emotional disruption that comes with suddenly moving from clinical observer to patient, experiencing firsthand the speed at which decisions must be made, the fear that accompanies each step, and the abrupt inversion of roles. Her perspective underscored how even well-informed individuals struggle with the pace and intensity of the disease, highlighting the human vulnerability that sits behind clinical descriptions.

A broader systems view followed, touching on practical constraints in the real-world delivery of acute leukemia care. The reflections pointed to gaps between what is medically possible

and what health systems are prepared to support. These included disparities in diagnostic pathways, limited awareness of acute leukemia symptoms among the general public, and the uneven access to advanced treatments depending on country or institutional resources. The session made clear that scientific progress cannot be separated from the contexts in which patients live and receive care.

"The guidelines are made to do at 1,000 people, the best for 1,000 people. And the patient is not 1,000 people."

Together, the presenters illustrated how acute leukemia sits at the intersection of evolving clinical knowledge, profound personal impact, and persistent systemic challenges. Their combined perspectives reinforced the need for advocacy that recognises all three layers: the science, the person experiencing it, and the system that must respond. The session left a strong impression of how intertwined medical and emotional realities are for those affected by acute leukemias, and how advocacy must address both to make meaningful change.

Session: Transition Toward Advocacy - From Experience to Action

This session centred on the journey from individual experience to structured advocacy, showing how deeply personal motivations often underpin the growth of patient organisations. The speakers approached the topic from different angles, but all reflected on the need for sustainable structures and community-building. The tone of the session reflected both hope and realism: advocacy can emerge from personal need, but it requires long-term commitment, organisational discipline, and continued learning.

A recurring theme was the emotional and practical transition from being directly affected by leukemia to becoming someone who supports others. Several presenters acknowledged the difficulty of stepping from one identity into another, especially when the disease experience is still fresh or unresolved. The session highlighted how personal stories can become a foundation for change, but how they must be channeled into well-designed initiatives to achieve broader impact.

Throughout the presentations, speakers demonstrated that advocacy rarely starts as a strategic undertaking. Instead, it grows from the urgency to fill gaps in care, information, or emotional support. Over time, these individual efforts evolve into structured organisations with defined missions and shared responsibilities. This evolution - moving from personal experience into collective action - was the binding thread of the entire session.

Presentation: Building and Advancing the Patient Association

Presenter: Chul-hwan Lee

Chul-hwan Lee, from South Korea, described the development of his patient association by grounding it in the realities of building trust and mobilising community participation. He discussed how his organisation emerged not out of formal planning, but out of a need to create support structures where few existed. His reflection emphasised that advocacy organisations often begin with small steps - connecting individuals, responding to immediate needs, and gradually establishing credibility within the patient community.

"Let's create a patient group to support each other."

His presentation highlighted how cultural context plays a significant role in shaping an organisation's development. Chul-hwan noted that in some regions, patients may hesitate to speak publicly about their diagnosis or engage in advocacy activities, which can slow organisational growth. Overcoming these barriers requires patience, visibility, and a willingness to demonstrate that advocacy groups can provide safe, useful, and trustworthy spaces for patients.

He also spoke about the importance of sustainability. While passion and personal motivation can ignite an organisation, maintaining long-term momentum requires formal structure,

volunteer engagement, and consistent communication. His message stressed that the strength of an advocacy organisation is not measured solely by its size, but by its capacity to respond to the needs of its community.

Presentation: Transition Toward Advocacy - Experience to Action

Presenter: Anne-Pierre Pickaert

Anne-Pierre Pickaert shared a perspective shaped by her personal journey into advocacy, describing how individual experience connects to larger structural needs. She reflected on the shift from private coping to public engagement, emphasising the emotional complexities involved in choosing to speak, organise, and lead. Her account illustrated that advocacy often arises from a desire to transform personal experience into something that can alleviate the burdens faced by others.

Her presentation underscored the importance of building credibility. Anne-Pierre noted that while lived experience provides authenticity, effective advocacy also requires understanding systems, policies, and community expectations. This balance - between emotional insight and strategic competence - was a central message of her discussion. She highlighted how learning to navigate institutional processes becomes a crucial part of turning experience into action.

Anne-Pierre also spoke to the value of collaboration. She indicated that advocacy is strongest when it draws on networks, aligns with shared goals, and avoids isolation. Her reflections presented a realistic picture: advocacy is empowering, but not effortless, and it requires continuous development and mutual support among advocates.

Presentation: Transition Toward Advocacy – Being a carer to an Advocate

Presenter: Marine Tullet

Marine Tullet offered a series of reflections on how personal need can evolve into structured initiatives. She described situations where individuals, confronted with inadequate support or fragmented information, choose to take matters into their own hands - initially out of necessity, and later out of a sense of responsibility to others. Her examples illustrated the emotional turning points that often spark advocacy work.

Marine emphasised that advocacy requires perseverance, especially when initial efforts meet limited recognition or slow progress. She situated her reflections in the broader reality of acute leukemia: because patients often have very little time to process their diagnosis, advocates must work against both emotional and institutional barriers to create environments where support is accessible. Her remarks showed that advocacy is as much about persistence as it is about vision.

She concluded by reflecting on how personal motivation can become an engine for long-term change. The process may begin with a single story, but it grows through collective effort, structured planning, and sustained commitment. Her message reinforced the session's central theme: advocacy develops from experience but must ultimately mature into organised action.

Presentation: From Medical Student to Patient… to maybe Doctor?

Presenter: Carolina Garcez Aguiar Martins

In one of the most personal presentations of Day 1, Carolina described her abrupt transition from studying medicine to becoming a leukemia patient. Her story centred on the emotional shock of losing the sense of control and certainty she once had as a clinician-in-training. She spoke about how the rapid pace of acute leukemia treatment left little time to process what was happening, forcing her to adapt quickly to a new reality.

"So one ordinary day during my final year as a medical student, I woke up, I went to the hospital with my stethoscope, my notes, and by the end of that same day, I was sleeping in a different hospital, 100 kilometers from home in the hematology ward."

Carolina reflected on the duality of knowledge and vulnerability. Although her medical background provided an understanding of treatment procedures, it did not shield her from the fear and uncertainty that accompany an acute leukemia diagnosis. She conveyed the disorientation of experiencing invasive procedures and complex decisions not as a future physician but as a patient with limited time to weigh options.

Her account also illuminated the importance of empathy and sensitivity in care. She spoke about moments when small gestures, clear communication, or emotional acknowledgement made significant differences in how she navigated her treatment. Her narrative reinforced one of the summit's broader messages: clinical expertise alone is insufficient without a grounding in human connection. Her story demonstrated why advocacy must continually remind healthcare systems of the person behind the disease.

Day 2 - 8th November 2025

Workshop: Advocacy in the Acute Setting - What Is Our Reality and What Can We Do?

This workshop brought participants together to confront the difficult realities of advocating for patients with acute leukemia. The nature of acute leukemia creates inherent challenges in advocacy: patients are often diagnosed suddenly, decisions are made under urgent conditions, and individuals and families may not have the time or emotional capacity to engage with patient organisations during the early stages of treatment.

The workshop framework encouraged attendees to reflect honestly on these constraints rather than overlook them. Participants were invited to compare regional realities, highlight systemic differences, and share lived experiences from the perspectives of patients, caregivers, and organisational leaders. The feedback sessions indicate that participants wrestled with practical issues such as limited engagement time, digital and organisational limitations, healthcare pathway fragmentation, and chronic underfunding.

Because acute leukemia advocacy is intensely affected by time pressure and emotional strain, the workshop served as an essential foundation for the day's remaining sessions, anchoring technical and organisational discussions in the human and structural realities of the disease. It emphasised that any effective advocacy strategy must start from a clear understanding of these conditions.

Feedback: Organisational Challenges and Digital Solutions

Presenter: Marine Tullet

Marine Tullet presented her group's reflections on the internal and operational challenges faced by many acute leukemia organisations. She highlighted that advocates frequently operate with minimal staffing, often relying heavily on volunteers who balance advocacy work with personal or professional commitments. This creates pressure points that affect planning, communication, and consistency. Marine emphasised that organisations often find themselves reactive rather than proactive, simply because they lack the infrastructure to manage long-term strategies while responding to immediate needs.

"QR codes that could be shared by nurses"

Her presentation underscored the uneven adoption of digital tools across organisations. Some groups have embraced digital platforms for communication, resource sharing, or patient engagement, but many others still rely on manual processes that slow down their work and limit their reach. Marine pointed out that digital gaps can prevent organisations from maintaining visibility or responding quickly to emerging needs. These challenges are compounded in regions where digital literacy or access to reliable technology varies significantly.

Marine's feedback suggested that strengthening digital capacity is not merely a technological issue but a structural one. Effective digital tools can support continuity, record-keeping, broader outreach, and cross-border collaboration. However, she also recognised that adopting these tools requires training, investment, and time - resources that many organisations struggle to secure. Her summary stressed the need for balanced expectations: digital transformation can improve advocacy, but it must be supported by infrastructure and realistic timelines.

Feedback: Limited Interaction with Acute Leukemia Patients

Presenter: Charles McGrath

Charles McGrath presented a candid reflection on why meaningful interaction with newly diagnosed acute leukemia patients is often limited. He noted that the rapid progression of the disease, combined with urgent hospitalisation and the emotional intensity of the first days, leaves little room for structured engagement with advocacy organisations. Patients may be overwhelmed, frightened, or simply trying to survive the immediate shock of diagnosis, making outreach extremely challenging.

"There is a very small window of time where patient advocacy groups can engage with patients who are given an acute leukaemia diagnosis."

Charles highlighted that these constraints place unique burdens on advocacy groups. While other cancer organisations may form relationships with patients early and build them over time, acute leukemia advocates often meet patients later in their treatment journey - or sometimes not at all. This limitation affects data collection, community building, and the visibility of advocacy services. Organisations may struggle to reach the individuals they most want to support simply because the timing is so compressed.

He also noted that health systems often do not facilitate early introductions between patients and advocacy groups. In many regions, clinicians may not be aware of patient organisations, or they may prioritise immediate medical needs over psychosocial support. Charles suggested that improving these pathways requires both structured communication with healthcare providers and persistent advocacy for the inclusion of patient organisations in standard care processes. His reflections emphasised the need for creativity and patience when working in a field where contact is inherently constrained.

Feedback: Fundraising for Advocacy Efforts

Presenter: Beyza Klein

Beyza Klein's feedback focused on one of the most persistent challenges across patient organisations: the scarcity and instability of funding. She described how advocacy groups often depend on a small pool of donors, partners, or sponsors, making their financial foundations fragile. Beyza noted that donor fatigue is a real concern, especially in regions where philanthropic resources are limited or where health-related fundraising competes with many other societal priorities.

"Should I be fundraising or should I be driving impact with the funds I have raised?"

She also observed that organisations frequently rely on industry-related funding because alternative sources - public grants, philanthropic foundations, or local fundraising campaigns - may be inconsistent or unavailable. This reliance can place pressure on organisations to diversify their financial models, but diversification itself requires capacity, planning, and relationships that take time to develop. Beyza highlighted that smaller organisations often feel these pressures most acutely.

Her feedback pointed toward the need for sustainable financial strategies, clearer communication of organisational value, and the development of partnerships that extend beyond single-year commitments. She acknowledged, however, that this is difficult work;

advocacy organisations must maintain transparency and independence while still ensuring their survival. Her reflections captured the emotional weight of managing an organisation where financial insecurity is an ever-present concern.

Session: Let's Talk About Data

Presenter: Marine Tullet

Marine Tullet opened this presentation by explaining how structured global surveys can reveal the lived reality of hematological cancer patients in a way that anecdotal narratives or isolated national reports cannot. She described the Lymphoma Coalition's long-running survey methodology, its international reach, and how its design allows for consistent cross-country comparisons. Marine emphasised that patient-reported data offers a "ground-level view" of the systemic gaps that patients experience in access, information, quality of care, psychosocial support, and long-term survivorship outcomes.

She highlighted several recurring patterns that appear across countries, regardless of income level or health-system structure. These include delays in diagnosis, inconsistent communication about treatment intent and side effects, and large variations in whether patients feel they truly understand their disease. Marine noted that such trends are particularly concerning in acute hematological cancers, where patients have very little time to process information and choices. Survey responses show that many individuals feel unprepared, unsupported, or emotionally overwhelmed during early decision-making.

"66% of patients report fatigue … but *you can make it even stronger when you turn this into evidence that is understandable by everyone"*

Marine then discussed how survey data can make invisible barriers visible. By quantifying the proportion of patients who struggle with mental health, cannot access specialist care, or feel excluded from treatment decisions, the data equips advocacy organisations with concrete evidence to take to policymakers, clinicians, and funders. She underscored that narratives alone rarely shift systems — but narratives *linked to robust data* can force institutions to confront uncomfortable realities.

She concluded by emphasising the importance of using survey findings strategically. Marine encouraged organisations to translate insights into targeted advocacy goals: improving diagnostic pathways, strengthening communication standards, expanding psychological support, and reducing cross-regional inequities. Her presentation showed how data can function as both a diagnostic tool for advocacy itself and a unifying language when engaging stakeholders at all levels.

Session: Let's Talk About Data

Presenter: Samantha Nier

Samantha Nier followed by presenting the ALAN-specific survey findings, highlighting that acute leukemia patients face an even more compressed and emotionally destabilising experience than many other hematology patient groups. She explained that ALAN's data reflects the unique intensity of acute leukemia: lightning-fast diagnosis, immediate treatment, limited time for patient comprehension, and high levels of fear and uncertainty. Nier emphasised that the survey captures "the first seventy-two hours of chaos" that patients frequently report.

"90% did not know the symptoms of leukemia … with that evidence, we said we have to raise awareness of leukemia symptoms"

She outlined several themes emerging from ALAN's global responses. Many patients reported receiving insufficient explanation at diagnosis due to rushed hospital environments, a lack of specialist availability, or the overwhelming nature of the situation. Samantha stressed that the

issue is not clinician intent but system constraints. She also noted that acute leukemia patients consistently reported the need for clearer, repeated communication, better orientation at admission, and more transparent information about roles within the medical team.

Samantha used the survey results to illustrate how acute leukemia patients often fall through the cracks of standard cancer communication frameworks. Traditional brochures or long educational sessions are rarely usable in the acute setting, where patients are frightened, sedated, or cognitively overloaded. Survey responses highlight a need for concise, modular information tools that can be delivered in small pieces as patients stabilise. She emphasised that this is exactly where patient organisations can intervene effectively.

"We are going to show to pharma, to regulators, to academics, that what they use as a tool is not good"

In her conclusion, Samantha framed the ALAN data as an advocacy roadmap. The findings point toward several actionable priorities: standardising the first conversation after diagnosis, embedding emotional support early, ensuring families are not excluded from critical discussions, and developing acute-phase information materials designed specifically for highly stressed patients. Her contribution demonstrated how ALAN intends to use its own data not only to document unmet needs but to drive measurable improvements in acute leukemia care worldwide.

Session: Turning Insights into Action

This session shifted the focus from data and reflection toward practical tools and initiatives that organisations can apply in their daily work. Across the presentations, speakers described how insights from surveys, lived experience, and organisational learning were being transformed into resources that advocates could use to strengthen awareness, improve communication, and support patients. The session emphasised that even small-scale tools can have substantial impact when applied thoughtfully and consistently.

The speakers collectively highlighted the role of adaptability: different regions require different tools, and patient needs vary widely. The presentations showed a broader commitment within ALAN to provide flexible, ready-to-use materials that organisations can tailor to their contexts. Themes of empowerment, accessibility, and collaboration ran throughout the session. While each presentation was short, together they provided a comprehensive picture of how insights can become action.

Presentation: Awareness of Leukemia

Presenter: Pasusant Wattanaboonya

Pasusant focused on the persistent gaps in public awareness surrounding acute leukemia. He discussed how low visibility contributes not only to delayed diagnoses but also to misunderstandings about the disease and its treatment. His remarks conveyed that effective awareness campaigns must strike a balance: simplifying information without losing accuracy and reaching the public where they already are - not expecting them to seek out specialised information.

He highlighted that stigma and silence often surround leukemia in many regions, with individuals hesitant to speak openly about symptoms or experiences. This reality complicates awareness efforts, especially in communities where conversations about cancer remain sensitive. Pasusant's presentation suggested that emotionally resonant messages and culturally appropriate campaigns are essential to breaking through these barriers.

"I invite all of you to think about your country. What is one simple step you can take to increase awareness and support patients? Because together as a network, this small step becomes a global movement for change."

His insights reminded the audience that awareness is not solely about visibility - it is about building understanding, prompting earlier care-seeking behaviour, and showing that support exists. His contribution set the stage for the subsequent presentations on educational materials and support tools.

Presentation: Acute Leukemia Booklet

Presenter: Diego Villalón García

Diego presented the acute leukemia booklet as a practical resource designed to meet the immediate informational needs of patients and families. He described how the booklet was created to offer clear, structured explanations of the disease, its treatments, and its emotional and practical implications. Diego emphasised that patients often face information overload at diagnosis, and the booklet aims to provide clarity during a disorienting time.

His remarks underscored the importance of accessibility. The booklet uses language that is understandable without oversimplifying medical realities. Diego highlighted that the booklet can also support caregivers, who often shoulder significant emotional and logistical responsibilities. He positioned the resource as a bridge between clinical explanations and personal coping.

Diego's presentation reinforced the broader message of the session: educational materials are essential tools for empowering patients and easing the initial shock of diagnosis. He encouraged organisations to adapt the booklet for regional needs where appropriate.

Presentation: ALAN Resource Center

Presenter: Alastair Gray

Alastair Gray introduced the ALAN Resource Center as a growing repository of tools designed to support patient organisations. He explained that many advocates lack the time or capacity to produce high-quality materials from scratch, making a shared resource hub essential. The center consolidates guides, templates, infographics, and educational tools so organisations can quickly access and adapt them.

Alastair emphasised that the resource center aims to reduce duplication of effort. Rather than each organisation reinventing materials, the hub allows advocates to download and tailor existing resources. He highlighted the need for materials that are accurate, visually clear, and easily translatable into multiple languages, aligning with ALAN's global mandate.

His presentation stressed that resource-sharing strengthens the entire network. When organisations have access to reliable tools, they can focus more on patient support, outreach, and policy engagement. Alastair encouraged attendees to explore the center regularly and to request new materials where gaps exist.

Presentation: Toolkit for Patients and Physicians

Presenter: Samantha Nier

https://drive.google.com/drive/folders/1JZbDDLeGgFiybH-En5ZzGVlq1f-jNxVp?usp=sharing

Samantha presented a toolkit designed to facilitate communication between patients and clinicians. She explained that acute leukemia's urgency often compresses conversations and leaves little room for thoughtful dialogue. The toolkit aims to help patients articulate their concerns and questions more effectively while supporting clinicians in providing clear, structured information.

Her discussion highlighted that such tools could help address the emotional and informational imbalance that often occurs at diagnosis. Patients may feel overwhelmed, while clinicians may struggle to gauge how much information can be absorbed in a single interaction. Samantha

explained that the toolkit can help bridge this gap, encouraging shared understanding even in high-pressure clinical environments.

She concluded by noting that communication support is not a luxury - it is essential for patient empowerment. The toolkit helps ensure that patients feel heard and engaged, and that clinicians can provide care that aligns with patient needs and expectations.

Presentation: Enhancing Support Using Digital Platforms

Presenter: Sophie Wintrich

Sophie Wintrich discussed digital approaches to patient support, noting that online platforms have become increasingly important, particularly for communities that are geographically dispersed or unable to attend in-person programs. She described tools that can offer emotional support, educational content, and connection to peer communities.

Sophie reflected on the benefits and limitations of digital platforms. While they can dramatically extend reach, they also require digital literacy, reliable internet access, and careful design to avoid overwhelming users. She emphasised that effective digital support should prioritise clarity, usability, and emotional safety.

"*Only 30% of the data that is shared in consultation is actually retained by the patients*"

Her presentation framed digital tools not as replacements for human connection but as extensions of it. She highlighted that when used thoughtfully, these platforms can provide a lifeline for patients and caregivers navigating the isolating experience of acute leukemia.

Presentation: Using Country-Specific Data for Advocacy

Presenter: Jana Pelouchova

Jana Pelouchova explained how national-level data can enhance advocacy by providing concrete, region-specific evidence to support policy discussions. She highlighted the importance of understanding local patient experiences, healthcare system constraints, and cultural differences when presenting arguments to decision-makers.

Her remarks focused on how advocates can translate survey findings into persuasive narratives tailored to national audiences. Jana emphasised that data must be framed in ways that resonate with the priorities of local health authorities, such as patient outcomes, quality of care, or accessibility.

She encouraged organisations to use the global survey results as a foundation but to enrich them with country-specific insights. Jana's presentation reinforced the idea that effective advocacy is always context-sensitive, even when supported by global data.

Presentation: Country Example - Think Tank

Presenter: Lauren Pretorius

Lauren Pretorius presented a country-level think tank model designed to improve policy conversations around acute leukemia. She described how structured, multi-stakeholder discussions can help identify national gaps in diagnosis, treatment access, and patient support. Her example showed how organised dialogue can build consensus and create momentum for reform.

"You have to create relationships. You have to start to speak to people and understand what the problems are from each side"

Lauren highlighted that think tanks can elevate patient voices by placing them at the same table as policymakers, clinicians, and researchers. This structure helps ensure that patient experience is not treated as an afterthought but is integrated into planning and decision-making processes.

“They're used to being denied things and things that are rightfully theirs and they should be getting anyway”

Her presentation demonstrated that systematic, collaborative approaches can produce more coherent and sustainable solutions than isolated advocacy efforts. Lauren encouraged other organisations to explore similar models tailored to their national contexts.

Presentation: Emotional Support

Presenter: Claudia Poguntke

Claudia Poguntke explored the emotional toll of acute leukemia and the necessity of support structures throughout the patient journey. She described how patients experience a cascade of emotional challenges - fear, uncertainty, isolation - especially in the early days of diagnosis when information is abundant, but processing capacity is limited.

Claudia emphasised that emotional support must be present at every stage of treatment, from diagnosis to remission or relapse. She noted that caregivers often experience parallel emotional stress, and that support programs must address their needs as well. Her discussion highlighted that emotional care is not supplementary but foundational to patient well-being.

She concluded by stressing that advocacy organisations must integrate emotional support into their programs wherever possible. Whether through peer networks, information materials, or structured support groups, offering emotional reassurance is critical to helping patients and families navigate the overwhelming experience of acute leukemia.

Session: From data collection to advocacy

This session built directly on the themes of the morning by shifting the focus from understanding data to using it as leverage for real-world change. The overall message was that while evidence is crucial, it must be strategically applied to influence how health systems, policymakers, and institutions respond to acute leukemia patients. The speakers framed access not only as a matter of treatment availability but as part of a wider ecosystem in which data, communication, and advocacy must interact.

The parent session created a bridge between the reflective tone of earlier discussions and the more technical considerations that followed. Access was presented not simply as a logistical or administrative problem but as a complex interaction between scientific advancement, regulatory processes, and the lived experiences of patients. The reflections embedded within the presentations demonstrated how insights gained from ALAN’s surveys and studies can be turned into specific, targeted actions at national and regional levels.

There was also an implicit recognition that access challenges differ widely across countries. Some regions face reimbursement delays, while others grapple with infrastructure constraints or limited awareness among policymakers. The session encouraged participants to adapt these lessons to their own environments, recognising that effective advocacy looks different depending on local context, policy structure, and healthcare culture.

Presentation: Evidence-Based Advocacy

Presenter: Jan Geissler

Jan emphasised the importance of grounding advocacy efforts in evidence rather than anecdote. He argued that data is essential to gaining credibility with stakeholders, particularly in health systems where decisions are increasingly driven by measurable outcomes, economic considerations, and documented need. His remarks connected back to earlier sessions by stressing that data from ALAN’s surveys - although challenging to collect in an acute leukemia population - is now substantial enough to influence discussions at national and international levels.

"...you need to base it on evidence because then you can tell how big the problem really is."

He reflected on how advocates can use evidence to highlight systemic gaps. Data on patient experiences, caregiver burden, diagnostic delays, and treatment obstacles can reveal patterns that policymakers may not see. Jan pointed out that presenting such findings in a structured, coherent way helps ensure that decision-makers cannot dismiss patient concerns as isolated cases. Instead, they must contend with documented trends that call for systemic responses.

Jan also spoke about the challenges of mobilising evidence within advocacy organisations. Data may exist, but it must be interpreted, communicated, and applied effectively to create impact. His message urged organisations to move beyond passive ownership of data and toward active implementation - using evidence to push for reforms, inform policy briefs, and shape conversations with healthcare institutions. His presentation underscored that credibility is earned through consistent, evidence-driven engagement.

Presentation: Now That We Have the Data - What Next? Leveraging the 5 As of Access for Acute Leukemia Care

Presenter: Anne-Pierre Pickaert

Anne-Pierre expanded on the practical side of evidence-based advocacy by exploring how organisations can transform data into actionable strategies. She acknowledged that having data is only the first step; the real challenge lies in using it to make influence tangible. Her reflections touched on the need for structured messaging, prioritisation, and an understanding of what policymakers respond to. Her perspective emphasised that advocates must present information in formats that are accessible, concise, and relevant to national priorities.

She also highlighted the emotional aspect of moving from knowledge to action. Many advocates enter this work because of personal experience, and translating data into policy requires both discipline and emotional resilience. Anne-Pierre described the learning curve involved in engaging with policy frameworks and regulatory systems, which can feel intimidating or inaccessible at first. Yet she stressed that advocates are uniquely positioned to articulate patient realities because their work is grounded in lived experience.

Her remarks reinforced the idea that evidence must support - not replace - the human voice of advocacy. Facts and figures can show trends, but they achieve impact only when combined with compelling storytelling and clear proposals for change. Anne-Pierre encouraged participants to view data as a tool that empowers them to speak confidently, persuasively, and strategically in settings where patient perspectives were historically overlooked.

Workshop: Barriers to Action

This workshop invited participants to examine the structural, financial, and cultural barriers that limit the impact of acute leukemia advocacy. Participants compared the strengths and weaknesses of various healthcare funding structures, highlighting how these systems shape access to treatment, diagnostic tools, supportive services, and long-term care.

The workshop format created a space to discuss the reality that many barriers extend beyond the immediate control of patient organisations and require long-term engagement with institutions, government bodies, and broader civil society. Participants examined how financial models influence patient behaviour, clinician decision-making, and overall system responsiveness. Across the different groups, there was a recognition that effective advocacy must adapt to structural realities rather than assume uniform solutions.

Because acute leukemia is both medically urgent and resource-intensive, the workshop reinforced why advocacy must extend beyond awareness-raising to include policy engagement and systems-level understanding. The session served as a reminder that meaningful change requires navigating complex environments rather than relying on singular interventions.

Feedback: Healthcare Model - Funded by Taxes, Services provided by government (UK, Spain, Italy, Denmark, Portugal, New Zealand)

Presenter: Charles McGrath

Charles summarised his group's reflections on tax-funded healthcare systems. The feedback addressed both strengths and challenges associated with public financing models. On one hand, such systems often aim to provide broad access, which in principle aligns well with the needs of acute leukemia patients who require rapid and intensive treatment. Charles acknowledged that tax-funded structures can reduce financial barriers and promote equity.

However, he also highlighted limitations. Public systems can be slow to adopt new treatments due to budget constraints, bureaucratic approval processes, or competing priorities within national health budgets. In the context of acute leukemia - where treatment innovations emerge quickly - this can create delays that have real consequences for patients. Charles's feedback pointed to the tension between equitable intent and practical limitations, illustrating that universal coverage does not always translate into timely access.

His summary underscored the need for advocates to monitor how public systems prioritise new treatments and to engage proactively with health authorities to ensure that acute leukemia remains visible in policy discussions. The group's reflections suggested that even in systems designed to be fair, advocacy plays a vital role in ensuring that new advances reach patients without delay.

Feedback: Healthcare Model - Funded by employer/employee payroll deductions; insurers are non-profit (Germany, France, Netherlands, Austria, Czech Republic, Estonia, Slovenia)

Presenter: Claudia Poguntke

Claudia described the dynamics of systems built on payroll-funded insurance. She noted that these models can create fragmentation, with access varying across insurance providers or employment sectors. Although such systems may offer robust coverage for some, they can leave significant gaps for individuals who are unemployed, self-employed, or in precarious work situations.

She reflected on the emotional and financial stress this creates for acute leukemia patients, who often confront sudden loss of income or employment at diagnosis. Claudia highlighted that the reliability of care in these systems can depend heavily on a patient's employment history, introducing inequities that have little to do with medical need. Her group recognised that while payroll-funded systems can provide high-quality care for many, they are inherently vulnerable to socioeconomic disparities.

Claudia's feedback emphasised that advocates must work to ensure that employment status does not dictate quality of care. Her reflections suggested that system reforms or complementary support structures are often needed to close the gaps created by insurance-based funding models.

Feedback: Healthcare Model - Government-Funded, Privately Delivered (South Korea, Australia)

Presenter: Ashleigh Bell

Ashleigh presented a system in which government funding supports private-sector delivery. She noted that such models can offer flexibility, choice, and innovation, as private providers may be more agile in adopting new treatments and technologies. This can be advantageous in acute leukemia, where rapid advances in care require responsiveness from institutions.

However, Ashleigh also identified potential risks. When care is delivered privately, financial incentives may shape service availability or prioritisation. Even with government funding, disparities can emerge in how institutions allocate resources or manage capacity. Her group discussed how patients may encounter differences in service quality or waiting times depending on where they receive treatment.

The feedback suggested that while hybrid models can offer valuable combinations of public and private care, they require strong regulation and monitoring to ensure that patient needs are prioritised over commercial interests. Advocates, Ashleigh noted, have a role in monitoring these dynamics and raising concerns when disparities arise.

Feedback: Healthcare Model - Primarily out-of-pocket expenses or heavy disparities (Kenya, Tanzania, Nigeria, Nepal, Guatemala, Armenia)

Presenter: Elo Mapelu

Elo presented the challenges of systems heavily reliant on out-of-pocket payment. His feedback was grounded in the realities of patients in countries where individuals must shoulder a large share of the cost of diagnosis and treatment. He outlined how financial barriers can delay or interrupt care or prevent access to the most appropriate treatments. For a disease as aggressive as acute leukemia, these barriers can be devastating.

"In Tanzania … there's only one treatment facility for cancer [the country's population is 70 million]. And people have to travel hundreds of kilometers to get there"

He reflected on the emotional toll on families who must make extremely difficult decisions under financial strain. Patients and their relatives may be forced to seek help from extended networks, fundraising efforts, or other precarious forms of support. Elo's group emphasised that advocacy in such systems must extend beyond awareness and into broader conversations about financing and national health priorities.

His feedback highlighted the urgency of addressing these inequities. Acute leukemia cannot be effectively treated when access depends on personal wealth, and his reflections made clear that systemic change is essential for meaningful improvement.

Feedback: Healthcare Model - Combination of Private and Public Financing (USA, South Africa, Thailand, Colombia, Macedonia)

Presenter(s): Sindy Yang, Pasusant Wattanaboonya

Sindy Yang summarised the complexities of mixed financing systems, where public programs coexist with private insurance or direct payments. She noted that these arrangements can produce both flexibility and uncertainty. In some cases, mixed systems expand access by providing multiple routes to care. In others, they create administrative burdens, unequal pathways, or gaps in coverage that disproportionately affect vulnerable patients.

Her feedback highlighted that patients may find themselves navigating multiple bureaucracies to secure the care they need. The complexity can become overwhelming, especially for those newly diagnosed and already dealing with emotional shock. Sindy explained that the mixture of funding streams can produce confusion about eligibility, reimbursement, and continuity of care.

Pasusant contributed reflections on the practical implications of this complexity, noting that mixed systems can result in fluctuating standards of care depending on which provider or funder is involved at a given moment. Together, their feedback underscored that while mixed financing models offer potential advantages, they demand strong support structures and clear communication to ensure that patients with acute leukemia do not fall through the cracks.

Day 3 - 9th November 2025

Session: Access Global Realities and Solutions

This session brought together perspectives from different regions to illustrate how access to acute leukemia treatment varies dramatically across the world. Although the speakers' contexts differed - ranging from Europe to New Zealand to low- and middle-income countries - the unifying theme was the need for advocacy that is deeply informed by local realities. The session framed access not as a single problem but as a constellation of issues shaped by policy environments, regulatory systems, health infrastructure, and economic conditions.

The speakers emphasised that access is rarely determined solely by the availability of treatments. Instead, it reflects the capacity of systems to diagnose, fund, deliver, and sustain those treatments. Some countries face delays in reimbursement processes; others struggle with shortages of trained clinicians, inconsistent diagnostic pathways, or geographic barriers that limit timely care. The discussion made clear that acute leukemia exposes both the strengths and vulnerabilities of national health systems.

A recurring point was the importance of patient participation and data in shaping access solutions. Evidence from patients and caregivers helps reveal barriers that are not always captured in clinical data or national statistics. Advocacy, therefore, must combine personal experience with concrete information, allowing advocates to push for improvements that are both humane and evidence based. This session set the stage for more detailed examples provided in the individual presentations that followed.

Presentation: Patient Participation in Joint Clinical Assessments

Presenter: Anne-Pierre Pickaert

Anne-Pierre's presentation focused on the role of patient participation in joint clinical assessments - collaborative evaluation processes increasingly used to determine the value of new therapies. She explained that these assessments are critical for determining access, as they influence reimbursement decisions, pricing negotiations, and timelines for availability across multiple countries. Her message underscored that patient involvement is no longer an optional addition but a necessary component for ensuring that assessments reflect real lived experience.

She reflected on the barriers patients face in participating effectively. These include the complexity of clinical assessments, the specialised terminology used in regulatory discussions, and the limited time patients often have to contribute due to their health circumstances. Anne-Pierre highlighted the emotional challenge of participating in highly technical processes while still processing one's own experiences with the disease. Her remarks conveyed that meaningful involvement requires support - training, preparation materials, and clear roles for participants.

Anne-Pierre emphasised that when patients are included and supported, their perspectives can shift the outcomes of assessments. They can help decision-makers understand the urgency of certain treatments, the impact of side effects, and the realities of living with acute leukemia. Her presentation reinforced a core message of the summit: patient voices are essential to shaping systems that serve patient needs.

Presentation: Shaping Policy for Modern Therapies in New Zealand

Presenter: Rosie Shaw

Rosie Shaw discussed the challenges and opportunities surrounding the adoption of modern therapies in New Zealand. She described how the country's health system grapples with limited budgets, slow regulatory processes, and geographically dispersed populations, all of which affect the availability of innovative treatments for acute leukemia. Rosie's presentation

emphasised that even in well-developed healthcare systems, access can lag behind scientific progress.

She reflected on the practical experience of advocating within a system where funding decisions are closely evaluated against constrained resources. Rosie highlighted the difficulties advocates face when attempting to balance emotional urgency with the structured, bureaucratic pace of national decision-making. Her remarks illustrated the tension between what patients need in the moment and what systems are prepared to provide. She also described how advocates can influence policy through persistent engagement, clear communication, and evidence tailored to national priorities.

Rosie concluded by noting that while New Zealand faces real challenges, progress is possible through coordinated advocacy efforts. Her message underscored the importance of patience, collaboration, and targeted messaging when working within small, resource-constrained health systems.

Presentation: Access to Acute Leukemia Care in LMICs

Presenter: Elo Mapelu

Elo Mapelu offered one of the starkest and emotionally resonant accounts of the summit, describing the realities of acute leukemia care in low- and middle-income countries. He explained that in many regions, access to diagnosis, treatment, and supportive care is severely limited by financial barriers, infrastructural gaps, and inconsistent availability of essential services. Elo spoke about the human consequences of these limitations, where treatment may be delayed, interrupted, or significantly constrained by cost.

"in high-income countries, a five-year survival for ANL is about 80%. … [In Kenya], the survival is 20%"

His reflections highlighted the emotional weight borne by patients and families who must navigate health systems that are not equipped for intensive, time-sensitive treatments like those required for acute leukemia. He described situations in which families rely on community support or fundraising to meet urgent medical needs, none of which provide the stability that leukemia care demands. His summary presented an unfiltered view of the inequities that shape patient outcomes in many LMIC contexts.

"for treatment, for better treatment, for better diagnostics, we have to resort to our pockets. We have to resort to crowdfunding"

Elo's message was clear: advocacy in these settings must address systemic and societal barriers, not just individual ones. He encouraged advocates to push for national investment in oncology infrastructure, more reliable access to essential services, and financial protections that prevent catastrophic health expenditures. His presentation highlighted that improving access requires engagement at all levels - community, national, and international.

"Global health equities in active leukemia care isn't just a moral imperative, it's an economic investment, and we are driving this on the deaths of our poorest people. So know that we do not only ask this as a favor, but it is a right, and an economic investment."

Session: Power in Partnership

Presenter(s): Samantha Nier, Rita O. Christensen

This session explored the importance of building strong partnerships across the healthcare ecosystem. The speakers emphasised that effective advocacy relies not only on patient organisations but also on productive relationships with clinicians, researchers, policymakers, and other stakeholders. The discussion stressed that collaboration must be grounded in mutual respect and shared objectives, ensuring that patient needs remain central to all joint efforts.

The presenters reflected on how partnerships can create opportunities that would be unattainable for organisations working alone. These include increased visibility, access to specialised knowledge, greater influence in decision-making, and the ability to amplify patient concerns across larger networks. They also acknowledged the challenges: maintaining independence, balancing different stakeholder priorities, and ensuring that partnerships do not compromise the organisation's mission or credibility.

Samantha and Rita emphasised that partnership-building is not a one-time task but an ongoing process that requires transparency, trust, and clear communication. They highlighted that when partnerships are approached thoughtfully, they can strengthen the impact of advocacy initiatives and open doors to meaningful change. The session underscored that patient advocacy is most effective when it operates within a collaborative ecosystem rather than in isolation.

Session: Lessons from the Field

This session brought together varied experiences from different regions, offering concrete examples of challenges and creative solutions within acute leukemia advocacy. The speakers shared stories rooted in lived experience and real-world constraints, providing a grounded counterpart to the more structural discussions earlier in the summit. Each presentation highlighted a different dimension of frontline advocacy, illustrating the diversity of needs and the ingenuity required to meet them.

The overarching theme of the session was adaptability. Whether dealing with resource limitations, high treatment costs, or gaps in national health systems, advocates constantly adjust their strategies to respond to local conditions. The speakers demonstrated how practical lessons from one region can spark new ideas in another, even when contexts differ widely. The session reinforced the value of cross-country dialogue as a way to expand the collective toolbox of advocacy approaches.

Presentation: Compassionate Use

Presenter: Marine Tullet

Marine discussed the complexities of compassionate use pathways - mechanisms that allow patients to access treatments outside of routine approval channels when no alternatives exist. She described how these pathways can offer hope but may also involve significant challenges, including administrative hurdles, inconsistent eligibility criteria, and limited awareness among clinicians or patients.

Her presentation reflected on the emotional stakes for families seeking last-resort treatments. Marine conveyed that compassionate use requests often occur at moments of crisis, and navigating the process can be overwhelming. Differences in procedures between countries and institutions further complicate the situation, leaving advocates to help families interpret unclear rules or shifting requirements.

Marine's reflections emphasised the need for clearer guidance, stronger communication, and advocacy aimed at improving the transparency of compassionate use frameworks. She suggested that patient organisations can play an important role by sharing knowledge, providing support, and pushing for more predictable processes.

Presentation: The Price of Life - High-Cost Drugs in Kenya

Presenter: Elo Mapelu

Elo delivered an impactful account of the financial burdens associated with high cost leukemia treatments in Kenya. He described how economic constraints force families to make extremely difficult decisions about whether and how to pursue treatment. His presentation illustrated that

even when therapies exist, they may remain out of reach for many patients because of cost and limited financial protection.

He spoke about the emotional trauma experienced by patients and families confronted with these financial barriers. The reality that survival may depend on the ability to mobilise resources from personal networks or fundraising created profound inequities that Elo highlighted with urgency. His reflections underscored that advocacy in such contexts must confront structural injustices rather than relying solely on awareness campaigns.

Elo suggested that meaningful progress requires systemic reforms, including stronger public support for high-cost treatments and mechanisms that reduce the direct financial burden on families. His presentation called for sustained advocacy to ensure that life-saving treatments do not remain accessible only to a privileged minority.

Presentation: Local Innovation in New Zealand

Presenter: Rosie Shaw

Rosie shared examples of innovative approaches used in New Zealand to address access challenges within a geographically dispersed population. She described how local initiatives can improve the consistency of care, encourage earlier diagnosis, or strengthen communication pathways between patients and clinicians. Her reflections demonstrated that innovation does not always require large budgets; sometimes, small adaptations can yield significant improvements.

She emphasised the importance of working closely with clinicians and policymakers to co-create solutions. By engaging directly with system stakeholders, advocates can help design processes that reflect real patient needs rather than assumptions. Rosie's examples illustrated how local knowledge and close community connections can drive effective change even in resource-limited settings.

Her presentation underscored that innovation grows out of flexibility, collaboration, and a willingness to experiment. She encouraged organisations to consider context-appropriate adaptations rather than relying exclusively on external models.

Questions: Lessons from the Field

(Multiple contributors)

This sub-session brought together advocates from diverse health systems who reflected on the practical realities of working directly with acute leukemia patients. Speakers highlighted how early barriers—particularly at the point of first symptoms and diagnosis—shape the entire patient journey. In several lower-resource settings, families must rely on personal funds or crowdfunding to access basic tests or treatment, while advocates in higher-income systems described delays linked to complex reimbursement pathways and administrative processes. Despite these differences, contributors agreed that understanding how one's national system functions is essential for effective intervention.

A strong theme was the importance of collective advocacy, particularly when governments are slow to respond. Some contributors shared examples of coordinated public action and coalition-building that helped drive policy discussions forward. They stressed that advocates rarely achieve impact alone; sustainable change requires unified voices and collaboration with professional societies, umbrella organisations, and community partners.

Speakers also acknowledged the emotional dimension of advocacy. Working closely with patients and families—especially in acute leukemia, where outcomes can change quickly—places a significant emotional load on advocates. Several reflected on the need for personal resilience and strategies that allow them to continue supporting others without becoming overwhelmed.

Participants emphasised the need for evidence-driven action. While individual stories resonate, advocates noted that policymakers respond most strongly to structured, quantifiable data on delays, access gaps, financial burdens, and unmet needs. Capturing and using these insights was presented as a foundational requirement for influencing national policies and improving patient outcomes.

At the close of the session, Lauren Pretorius made some powerful heartfelt statements and questions:

"we talk about collaboration, but really if two-thirds of the world's population are being excluded from treatment and cannot get treatment, how is that collaboration?

"You talk about global trials. … not one of [the] billion people in Africa were given the opportunity to go onto a trial."

"how can we have conversations about equity and accessibility when two thirds of the world do not have access?"

Workshop: what to advocate for locally? Individual reflections

Samantha Nier facilitated the concluding discussion for the session, inviting participants to reflect on how the lessons shared could be adapted to their own environments. She emphasised that while contexts differ widely, the underlying principles - persistence, creativity, and community engagement - are universal. Her role highlighted the importance of dialogue and collective interpretation, ensuring that the examples presented did not remain isolated stories but became shared learning.

She encouraged participants to question how local constraints shape advocacy strategies and to identify which practices might translate effectively across cultural or systemic boundaries. Anne-Pierre's contribution helped reinforce the idea that real-world examples become more valuable when critically examined and adapted rather than adopted wholesale.

This reflective close to the session underscored the summit's broader message: advocacy evolves through conversation, collaboration, and continuous reinterpretation of lived experience.

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Closing and Goodbye

Presenter(s): Jan Geissler, ALAN Steering Committee, Samantha Nier

The closing session brought the summit to a reflective and forward-looking conclusion. The speakers acknowledged the intensity of the discussions across the three days and expressed appreciation for the openness and commitment shown by participants. They highlighted that the strength of the network lies in its willingness to question itself, evolve, and grow based on collective feedback.

The reflections centred on the continued need for evidence-based advocacy, sustainable organisational models, and region-sensitive approaches to supporting acute leukemia patients. The speakers emphasised that the progress made since previous summits is significant but incomplete; the work ahead requires both persistence and creativity. They reiterated that advocacy must be responsive to the fast-changing scientific landscape while remaining grounded in the lived experiences of patients and caregivers.

The session closed with a call to maintain the spirit of collaboration beyond the summit. Participants were encouraged to continue working together, sharing knowledge, and supporting each other's efforts across regions. The goodbye was not framed as an ending but as an invitation to carry forward the momentum into the coming year's advocacy activities.

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