ALAN

Acute Leukemia Advocates Network

GLOBAL SUMMIT

7TH – 9TH NOVEMBER 2025

www.acuteleuk.org

SECOND
DAY OF
ALAN SUMMIT

MOVING INTO ACTION

TODAY'S AGENDA

8.15 AM	Grounding
8.30 AM	Workshop: Advocacy in the acute setting
10 AM	Mix and Mingle
10.30 AM	Let's talk about data
11 AM	Turning insights into action
12.30 PM	Group photo
12.45 PM	Lunch

DON'T FORGET!

- **We do not expect anyone to be an observer - Everyone is welcome and encourage to participate**
- **Activities proposed during the breaks are optional**
- **Bad english is the official language**

TO-DOS

- **Be on time !**
- **Keep your badge on**
- **Mute your phone and switch off your computer**

TODAY'S AGENDA

1.30 PM	From Data Collection to Advocacy
2.30 PM	Turning Insights into Access
3.30 PM	Marshmallow challenge
4 PM	Workshop: Barriers to access
5.30 PM	Yoga with chair
7 PM	Dinner (hotel)

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WORKSHOP:
ADVOCACY IN THE ACUTE SETTING

#ALANsummit

Workshop: Advocacy in the acute setting : what is our reality and what can we do?

3 groups (11 per groups)

1. **Organizational Challenges & Digital Solutions**
2. **Limited Interaction with Acute Leukemia Patients**
3. **Fundraising for Advocacy Efforts**

45 min –Group Breakout Discussions
30 min – Group Report-Outs (10 min per group including Q&A)

Reporting:

1-2 Key Insights (from challenges discussed)
1 Actionable Idea (to trial, test, or advocate for)

Organizational Challenges & Digital Solutions

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Team: Pasusant, Marine, Alastair

- **Theme**: How do internal structures, resource constraints, and digital tools impact advocacy?

- **Guiding Questions**:
  - What organizational barriers limit advocacy efforts for patients in acute settings?
  - Which time-consuming or repeatable tasks reduce frontline staff availability for advocacy?
  - How might AI or other digital platforms support advocacy (e.g. automated symptom tracking, digital consent tools, patient education portals)?
  - What are successful examples from other settings/fields?

Limited Interaction with Acute Leukemia Patients

Team: Sophie, Charles

- **Theme**: Challenges in meaningful patient engagement in acute contexts
- **Guiding Questions**:
  - Why are interactions with acute leukemia patients limited in acute settings (time, setting, physical condition)?
  - How does this affect advocacy and personalization of care?
  - How can we work with physicians and hospitals, so patients get referred to us as organizations?
  - Are there models from other specialties that we can adapt?
  - Could virtual check-ins, patient advocates, or family liaison roles be used more?

Fundraising for Advocacy Efforts

Team: Jan, Elo

- **Theme**: Building financial support for systemic and patient advocacy
- **Guiding Questions**:
  - What are the current gaps in funding advocacy for acute leukemia patients?
  - What success stories (even small-scale) can be shared?
  - How can organizations better position advocacy as fundable (e.g. showing outcomes, storytelling)?
  - Is it possible to involve patients and caregivers in fundraising?
  - Are there corporate or philanthropic partners to engage?

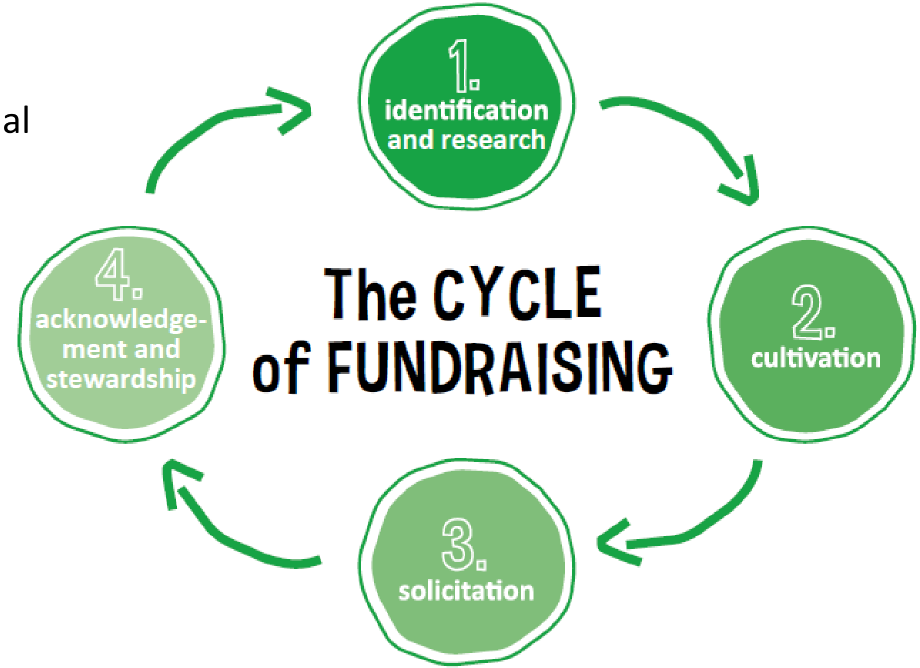
The fundraising cycle

- **Identification** and research of potential funders (e.g. check connections/network of your board members and members or volunteers to potential donors, or people with a similar interest…)

- **Cultivation of the relationship** with the prospective funders or funding programmes

- **Solicitation** = asking for funding with a specific request

- **Acknowledgement** and administration



The CYCLE of FUNDRAISING

1. identification and research

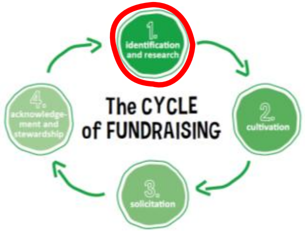
2. cultivation

3. solicitation

4. acknowledgement and stewardship

Step 1: Research and identification of potential funders:

Types of funders / funding sources



Public funding

- EU institutions
- EU funding programmes (e.g. research, health)
- National government, state, ministries' funding for NGOs
- National funding programmes (e.g. research, health)
- Statutory health insurance funds / sickness funds

Philanthropic funders

- Research organisations
- Non-profit organisations, foundations and societies
- Private donations (including high-level donations from philanthropists, charitable trusts)

Fundraising events and programmes

- Fundraising events and activities (e.g. cycle for cancer, marathons, etc)
- Donation programmes (e.g. people give €2 a month)
- Community fundraising (bake sales, coffee mornings etc)

Private funders

- Research organisations
- Insurance companies, sickness funds
- Pharma funding
- Healthcare/wellness-related companies

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BREAK – BE BACK AT 10.30 AM !

Mix and mingle

- With your buddy, find another buddy pair
- By group of 4, take 15 minutes to find out what you have in common and then link it to 1 or more emojis.
- Take a picture the 4 of you **#ALANSummit**

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LET’S TALK ABOUT DATA

Let’s talk about data.

A guide for your patient organisations to turn lived experience into evidence that drives change.

marine.tullet.pro@gmail.com

Who am I?

Marine, **Director of Data & AI** @Lalilo

* A worldwide edTech platform

* A team of **9 data experts**

* Mission: analyse and use the data and AI to **create personalised learning experiences** that help every child become a proficient reader

lalilo

Adaptive Learning

🧑‍🎓 **Education**: Dynamically adjusts reading exercises on Lalilo based on students' performance, pace and content difficulty.

🧑‍⚕️ **Health**: Helps doctors personalise treatment plans based on each patient's history, response, and recovery data.

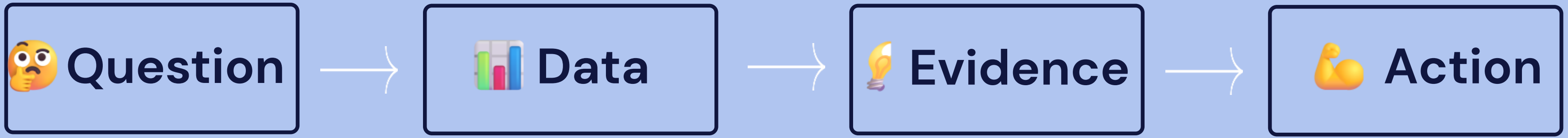
Speech Recognition

🧑‍🎓 **Education**: Develop exercices to make children speak aloud, automatically detect their errors and provide feedbacks live.

🧑‍⚕️ **Health**: Develop rehabilitation exercises for throat cancer survivors by identifying recurring speech and articulation patterns

“Advocacy without data-based evidence is like a compass without direction.”

How data can drive change



🤔 Question → 📊 Data → 💡 Evidence → 💪 Action

😲 Question | 📊 Data | 💡 Evidence | 💪 Action

Start small with a clear question

"What questions do matter to your patients and carers?"

Lymphoma Coalition
Global Patient Survey

* How are patients with lymphoma & CLL really doing beyond survival?

Start small with a clear question

Clarity	What exactly do we want to understand?
Context	Who is affected, and in what circumstances?
Connection	Why does this question matter to patients and carers?
Change	Will answers lead to something we can change?

Lymphoma Coalition
Global Patient Survey

Impact of lymphoma on daily life and well-being, not just survival.

Patients and carers across 80 countries and treatment stages.

QoL often overlooked in care, patients felt unheard.

Data led to QoL & fatigue added in clinical guidelines.

Collect real patient & carer data

“What and how patient organizations can collect data?”

Lymphoma Coalition
Global Patient Survey

* 50 000 participants from 80 countries since 2008.

* Launched every 2 years.

Collect real patient & carer data

What?

Who patients & carers are: demographics, diagnosis, treatment history
What patients & carers live: symptoms, side effects, emotions, QoL
What patients & carers need: access barrier, information gaps (treatment, clinical trials)

How?

Surveys using Mailchimp, Google Form, SurveyMonkey
Stories, interviews, registries, focus groups

> “What and how patient organizations can collect data?”

Lymphoma Coalition

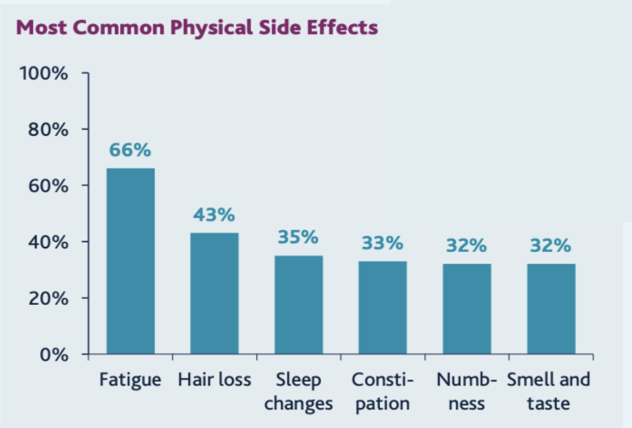
Global Patient Survey

- * 50 000 participants from 80 countries since 2008.
- * Launched every 2 years.

Turn data into evidence

> “What does the data *show*, and how strong is that claim?”

Turn data into evidence



“What does the data *show*, and how strong is that claim?”

Data

“66% of patients report fatigue.”

Evidence

“Year over year, fatigue continues to be the most common effect.”

Drive action 💪

> “How can this evidence drive advocacy or improve care?”

Lymphoma Coalition

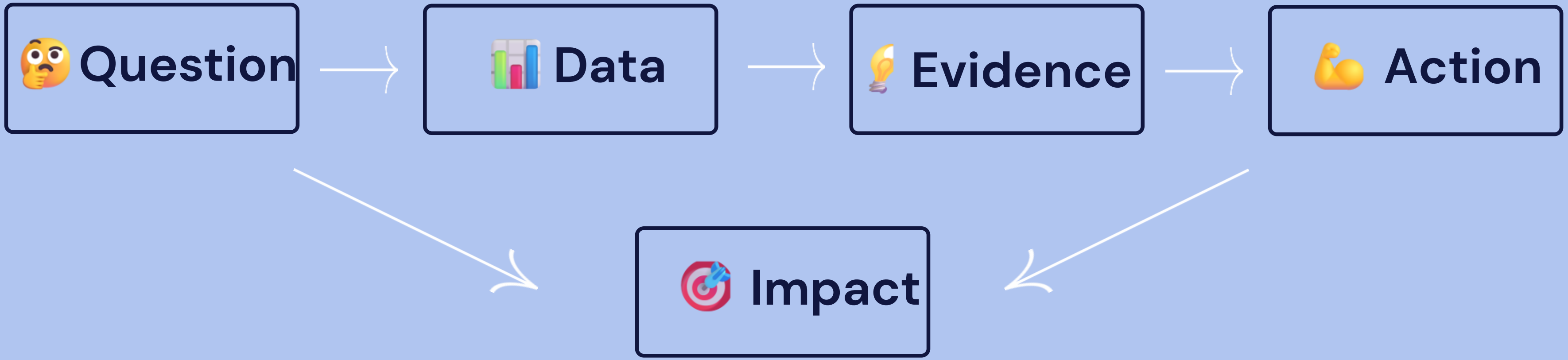
Global Patient Survey

- **Use survey data in advocacy influence**:
  - Results presented at key events (ASH, CL Foundation’s International Patient Conference…)
  - Country-specific reports made for national advocacy
- **Adapt awareness & thematic campaigns**
  - Theme *“It’s time to talk about how we’re feeling”* for World Lymphoma Awareness Day
- **Improve support for patients & carers**

Go even further...

🤔 Question → 📊 Data → 💡 Evidence → 💪 Action

Go even further…



🤔 Question

📊 Data

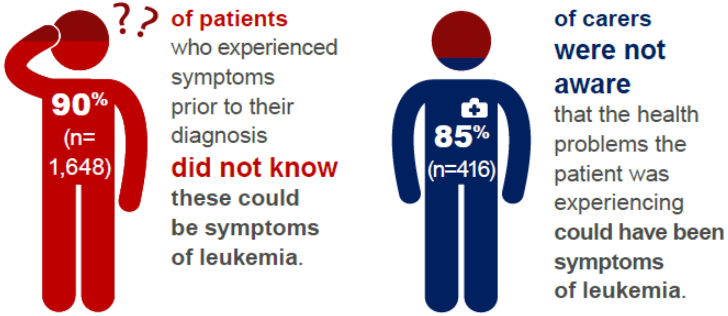
💡 Evidence

💪 Action

🎯 Impact

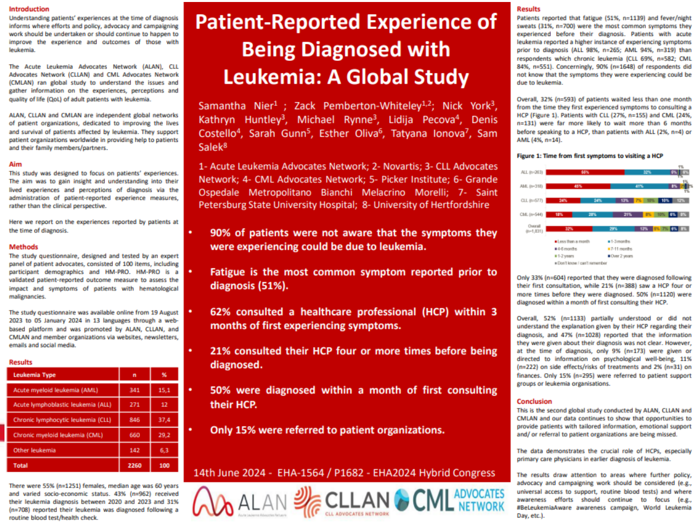
Data help to prioritize advocacy efforts

Awareness



90% (n= 1,648) **of patients** who experienced symptoms prior to their diagnosis **did not know these could be symptoms of leukemia.**

85% (n=416) **of carers were not aware** that the health problems the patient was experiencing **could have been symptoms of leukemia.**



Patient-Reported Experience of Being Diagnosed with Leukemia: A Global Study

Samantha Nier[1] ; Zack Pemberton-Whiteley[1,2]; Nick York[3], Kathryn Huntley[3], Michael Rynne[3], Lidija Pecova[4], Denis Costello[4], Sarah Gunn[5], Esther Oliva[6], Tatyana Ionova[7], Sam Salek[8]

1- Acute Leukemia Advocates Network; 2- Novartis; 3- CLL Advocates Network; 4- CML Advocates Network; 5- Picker Institute; 6- Grande Ospedale Metropolitano Bianchi Melacrino Morelli; 7- Saint Petersburg State University Hospital; 8- University of Hertfordshire

- **90% of patients were not aware that the symptoms they were experiencing could be due to leukemia.**
- **Fatigue is the most common symptom reported prior to diagnosis (51%).**
- **62% consulted a healthcare professional (HCP) within 3 months of first experiencing symptoms.**
- **21% consulted their HCP four or more times before being diagnosed.**
- **50% were diagnosed within a month of first consulting their HCP.**
- **Only 15% were referred to patient organizations.**

14th June 2024 - EHA-1564 / P1682 - EHA2024 Hybrid Congress

Introduction

Understanding patients' experiences at the time of diagnosis informs where efforts and policy, advocacy and campaigning work should be undertaken or should continue to happen to improve the experience and outcomes of those with leukemia.

The Acute Leukemia Advocates Network (ALAN), CLL Advocates Network (CLLAN) and CML Advocates Network (CMLAN) ran global study to understand the issues and gather information on the experiences, perceptions and quality of life (QoL) of adult patients with leukemia.

ALAN, CLLAN and CMLAN are independent global networks of patient organizations, dedicated to improving the lives and survival of patients affected by leukemia. They support patient organizations worldwide in providing help to patients and their family members/partners.

Aim

This study was designed to focus on patients' experiences. The aim was to gain insight and understanding into their lived experiences and perceptions of diagnosis via the administration of patient-reported experience measures, rather than the clinical perspective.

Here we report on the experiences reported by patients at the time of diagnosis.

Methods

The study questionnaire, designed and tested by an expert panel of patient advocates, consisted of 100 items, including participant demographics and HM-PRO. HM-PRO is a validated patient-reported outcome measure to assess the impact and symptoms of patients with hematological malignancies.

The study questionnaire was available online from 19 August 2023 to 05 January 2024 in 13 languages through a web-based platform and was promoted by ALAN, CLLAN, and CMLAN and member organizations via websites, newsletters, emails and social media.

Results

Leukemia Type	n	%
Acute myeloid leukemia (AML)	341	15,1
Acute lymphoblastic leukemia (ALL)	271	12
Chronic lymphocytic leukemia (CLL)	846	37,4
Chronic myeloid leukemia (CML)	660	29,2
Other leukemia	142	6,3
Total	**2260**	**100**

There were 55% (n=1251) females, median age was 60 years and varied socio-economic status. 43% (n=962) received their leukemia diagnosis between 2020 and 2023 and 31% (n=708) reported their leukemia was diagnosed following a routine blood test/health check.

Results

Patients reported that fatigue (51%, n=1139) and fever/night sweats (31%, n=700) were the most common symptoms they experienced before their diagnosis. Patients with acute leukemia reported a higher instance of experiencing symptoms prior to diagnosis (ALL 98%, n=265; AML 94%, n=319) than respondents which chronic leukemia (CLL 69%, n=582; CML 84%, n=551). Concerningly, 90% (n=1648) of respondents did not know that the symptoms they were experiencing could be due to leukemia.

Overall, 32% (n=593) of patients waited less than one month from the time they first experienced symptoms to consulting a HCP (Figure 1). Patients with CLL (27%, n=155) and CML (24%, n=131) were far more likely to wait more than 6 months before speaking to a HCP, than patients with ALL (2%, n=4) or AML (4%, n=14).

Figure 1: Time from first symptoms to visiting a HCP

Only 33% (n=604) reported that they were diagnosed following their first consultation, while 21% (n=388) saw a HCP four or more times before they were diagnosed. 50% (n=1120) were diagnosed within a month of first consulting their HCP.

Overall, 52% (n=1133) partially understood or did not understand the explanation given by their HCP regarding their diagnosis, and 47% (n=1028) reported that the information they were given about their diagnosis was not clear. However, at the time of diagnosis, only 9% (n=173) were given or directed to information on psychological well-being, 11% (n=222) on side effects/risks of treatments and 2% (n=31) on finances. Only 15% (n=295) were referred to patient support groups or leukemia organisations.

Conclusion

This is the second global study conducted by ALAN, CLLAN and CMLAN and our data continues to show that opportunities to provide patients with tailored information, emotional support and/ or referral to patient organizations are being missed.

The data demonstrates the crucial role of HCPs, especially primary care physicians in earlier diagnosis of leukemia.

The results draw attention to areas where further policy, advocacy and campaigning work should be considered (e.g., universal access to support, routine blood tests) and where awareness efforts should continue to focus (e.g., #BeLeukemiaAware awareness campaign, World Leukemia Day, etc.).

➔

- ☐ #BeLeukemiaAware
- ☐ World Leukemia Day
- ☐ BCAM
- ☐ #WeAreMen

Full report: https://acuteleuk.org/publications/

#ALANsummit

Data help to prioritize advocacy efforts

of patients reported that **their diagnosis** was completely **explained to them in a way they could understand.**

of carers who were told about the patient's **leukemia diagnosis by a healthcare professional** reported that their diagnosis was completely **explained to them in a way they could understand.**

Experiences and Views of Leukemia Patients: A Global Survey

Zack Pemberton-Whiteley[1]; Samantha Nier[1]; Nick York[2]; Deborah Baker[2]; Michael Rynne[2]; Nicole Schroeter[2]; Denis Costello[3]; Lidija Pecova[3]; Esther Nathalie Oliva[4]; Tatyana Ionova[4]; Sam Salek[4] and Jennie Bradley[5]

1- Acute Leukemia Advocates Network; 2- CLL Advocates Network; 3- CML Advocates Network; 4- HM-PRO; 5- IQVIA

- At diagnosis, 57 % of patients reported that they partially / did not understand information provided by their doctor.
- 51% of patients reported that they were not offered or directed to any support.
- 62 % of patients reported that they were not offered a choice of treatment and/or offered a clinical trial with a majority who wanted to be more involved.

2303 - 64th ASH Annual Meeting and Exposition - #ASH22

ALAN CLLAN CML ADVOCATES NETWORK

→ ☐ Resource center

Full report: https://acuteleuk.org/publications/

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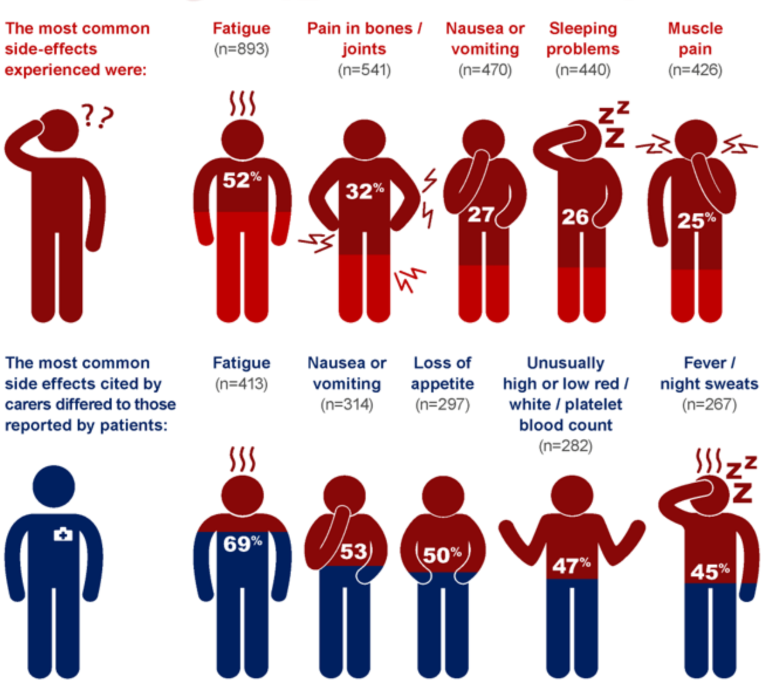
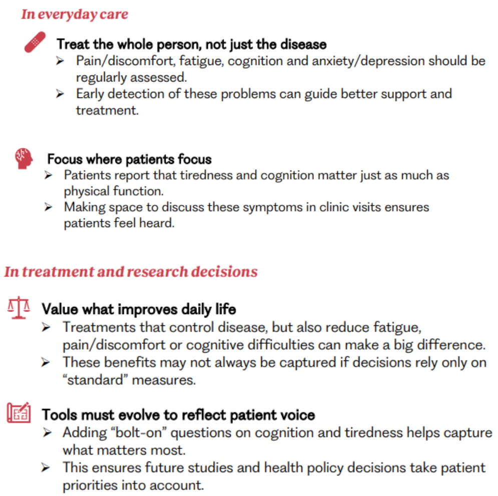
Data help to prioritize advocacy efforts



- ☐ Resource center –Know the basic serie
- ☐ Addition of bolt-on to EQ-5D



In everyday care

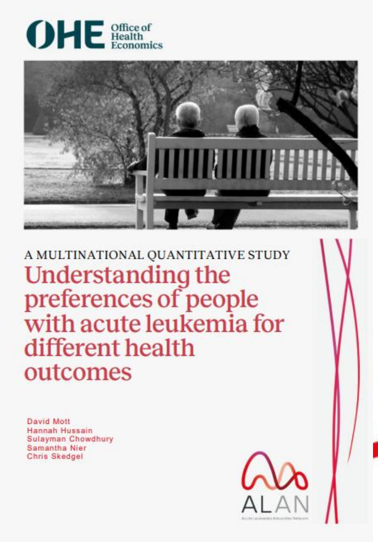
Treat the whole person, not just the disease
- Pain/discomfort, fatigue, cognition and anxiety/depression should be regularly assessed.
- Early detection of these problems can guide better support and treatment.

Focus where patients focus
- Patients report that tiredness and cognition matter just as much as physical function.
- Making space to discuss these symptoms in clinic visits ensures patients feel heard.

In treatment and research decisions

Value what improves daily life
- Treatments that control disease, but also reduce fatigue, pain/discomfort or cognitive difficulties can make a big difference.
- These benefits may not always be captured if decisions rely only on "standard" measures.

Tools must evolve to reflect patient voice
- Adding "bolt-on" questions on cognition and tiredness helps capture what matters most.
- This ensures future studies and health policy decisions take patient priorities into account.



OHE Office of Health Economics

A MULTINATIONAL QUANTITATIVE STUDY

Understanding the preferences of people with acute leukemia for different health outcomes

David Mott
Hannah Hussain
Sulayman Chowdhury
Samantha Nier
Chris Skedgel

ALAN

Full report: https://acuteleuk.org/publications/

Data help to prioritize advocacy efforts

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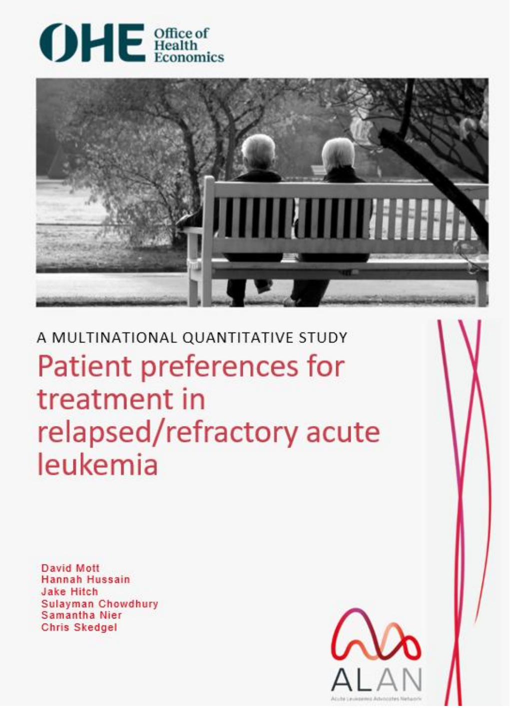
Acute Leukemia Advocates Network



OHE Office of Health Economics

A MULTINATIONAL QUANTITATIVE STUDY

Patient preferences for treatment in relapsed/refractory acute leukemia

David Mott
Hannah Hussain
Jake Hitch
Sulayman Chowdhury
Samantha Nier
Chris Skedgel

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AdvocateAuroraHealth

Journal of Patient-Centered Research and Reviews

Volume 10 | Issue 1 Article 3

1-17-2023

Understanding Quality of Life in Patients With Acute Leukemia, a Global Survey

Zack Pemberton-Whiteley
Samantha Nier
Jan Geissler
Sophie Wintrich
Bregje Verhoeven
Rita O. Christensen
Sam Salek
Esther Natalie Oliva
Tatyana Ionova
Jennie Bradley

Fitness assessment in AML : recommendations from an expert panel on behalf of the European LeukemiaNet:

- ❑ **… Moreover, the growing emphasis on patient-centered care, further highlights the importance of integrating *quality of life, patient preferences, patient self-reported physical and social functioning status, social support, and early integration of palliative care* into the assessment framework….**

Full report: https://acuteleuk.org/publications/

Thank you 🙏

Q&A

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TURNING INSIGHTS INTO ACTION

What ALAN and its members have done?

- Awareness of leukemia – ***Pasusant***
- Provision of information – ***Diego, Alastair, Samantha***
  - Acute leukemia booklet
  - ALAN Resources center
  - Toolkit for patients and physicians
- How can technology and digital platforms enhance patient education and patient support – ***Sophie***
- How country specific data from a global survey were used in advocacy work – ***Jana***
- Country example – report from Think Tank – ***Lauren***
- Emotional support – ***Claudia***
  - Case studies of program that alleviate psychological distress
  - How to provide emotional support

Turning Insights into Action - Awareness in Thailand

From global resources to
Local impact: Translating ALAN Materials into Thai for patients and caregivers

Turning Insights into Action – Awareness in Thailand

Key Actions & Impact

🌐 **Created Channels**
- Website, Facebook Page & Newsletter

📘 **Translated Materials**
- ALAN toolkits, infographics, awareness campaigns

📣 **Raised Awareness**
- World Leukemia Day campaigns in Thai

🤝 **Built Community**
- Growing patient trust & engagement

Small, consistent actions = stronger awareness, empowered patients.


ชมรมผู้ป่วยโรคมะเร็งเม็ดเลือดขาวชนิดเฉียบพลันประเทศไทย
Acute Leukemia Patient Advocacy Group Thailand
NewsLetter
April 21st 2025 Vol. 006
World AML Awareness Day : 21 April

https://www.facebook.com/profile.php?id=100092142705227
#AML #AMLAwarenessDay

"พลังของความรู้ ความหวังจากการกระทำ"
#BeLeukemiaAware
#ตระหนักรู้มะเร็งเม็ดเลือดขาว
Acute Leukemia Patient Advocacy Group Thailand
ชมรมผู้ป่วยโรคมะเร็งเม็ดเลือดขาวชนิดเฉียบพลันประเทศไทย
A Member of Acute Leukemia Advocates Network (ALAN)

www.thaileukemia.com
ข้อมูลดีๆมีประโยชน์เกี่ยวกับ
มะเร็งเม็ดเลือดขาว (leukemia)
- มะเร็งเม็ดเลือดขาวชนิดเฉียบพลัน — AML, ALL, APL
- มะเร็งเม็ดเลือดขาวชนิดเรื้อรัง — CML, CLL
- การปลูกถ่ายไขกระดูก
- อาหารและสุขภาวะที่ดี (อาหาร, สมรรถภาพร่างกาย)
- คำถามที่พบบ่อย
- คำถามที่ควรถามแพทย์
- แบ่งปันประสบการณ์จากผู้ป่วยมะเร็งเม็ดเลือดขาว
- สรุปการประชุม ALAN Global Summit
- แคมเปญ #Beleukemiaaware
- โพสต์กิจกรรมต่างๆ

#BeLuekemiaAware

ENTENDIENDO LAS
LEUCEMIAS AGUDAS
EN POBLACIÓN ADULTA
Guía para pacientes y familiares

Una iniciativa de: más que ideas fundación

Con el apoyo de: ALAN Acute Leukemia Advocates Network

Y con la colaboración de: AELCLÉS · SEHH Sociedad Española de Hematología y Hemoterapia · SEEO Sociedad Española de Enfermería Oncológica

Understanding
Acute Leukemias in Adults:
A Guide for Patients and Families

Diego Villalón García

más que ideas fundación

WHAT?

- Online and printed handbook containing detailed medical and health information about acute leukemia

- Aim: to provide accurate and comprehensive information to facilitate shared decision-making

WHY?

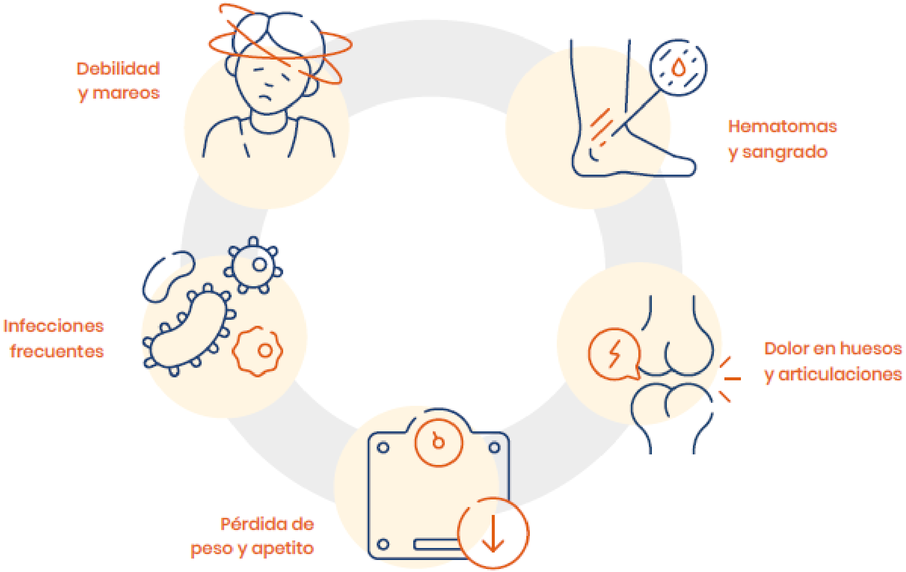
- Acute leukemia is a type of cancer for which there is very limited patient-friendly information available.

- **Javier Dávila San Segundo**. Person diagnosed with acute leukemia. Representative of the Spanish Association of Organizations Fighting Leukemia and Blood Diseases (AELCLÉS).
- **Yolima Méndez Camacho**. President of the Colombian Leukemia and Lymphoma Foundation, a member association of the Acute Leukemia Advocates Network (ALAN).
- **Natalia Pedraza García**. Nurse. Hematology Supervisor, 12 de Octubre University Hospital, Madrid. Representative of the Spanish Society of Oncology Nursing (SEEO).
- **Josefina Serrano López**. Hematologist. Reina Sofía University Hospital, Córdoba. Representative of the Spanish Society of Hematology and Hemotherapy (SEHH).

HOW?

- We created a multidisciplinary committee for the project
- The **table of contents** was developed in collaboration with the committee
- Handbook was **written by MQI**, according to literature research
- **Committee members reviewed** the content
- Information presented in a **friendly and accessible manner**, supplemented with visual images to enhance understanding.
- **Accessible**: Design, letter type and size, etc.
- **Respectful**: Diversity in photographies

Síntomas principales de las leucemias agudas



Debilidad y mareos

Hematomas y sangrado

Infecciones frecuentes

Dolor en huesos y articulaciones

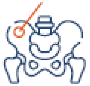
Pérdida de peso y apetito

Experimentar estos síntomas no siempre significa tener una leucemia aguda. Otras enfermedades más frecuentes y menos graves pueden presentarse de manera similar. De cualquier forma, no dudes en acudir a tu equipo médico si experimentas estos síntomas.

1.6. ¿De qué forma se diagnóstica?

El diagnóstico de la leucemia aguda implica una serie de pruebas y procedimientos. Los siguientes son los más habituales:

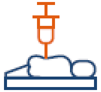
- **Análisis de sangre (hemograma).** Se evalúa el nivel de glóbulos rojos, blancos y plaquetas y se analizan la presencia de blastos en la sangre. Si los resultados arrojan una sospecha de leucemia, se procede con otras pruebas.



- **Aspirado y/o biopsia de médula ósea.** La extracción de una pequeña muestra de médula ósea (normalmente del hueso de la cadera o del esternón) es fundamental para confirmar el diagnóstico. La médula ósea se examina bajo el microscopio para continuar con el diagnóstico.

- **Pruebas genéticas y moleculares.** Permiten conocer más características de la enfermedad y "poner apellidos" al diagnóstico inicial, lo que puede ayudar a personalizar los tratamientos según las alteraciones y mutaciones genéticas presentes en las células cancerosas.

- **Pruebas de imagen.** En algunos casos, se utilizan pruebas de imagen como ecografías, tomografías computarizadas (TAC), PET o resonancias magnéticas para evaluar si la leucemia ha afectado a otras partes del cuerpo, como los ganglios linfáticos o el sistema nervioso central.



- **Análisis del líquido cefalorraquídeo (LCR).** Se realiza mediante una punción lumbar que permite extraer dicho líquido para evaluar si hay afectación en el sistema nervioso central. Además, de forma preventiva, se administra un tratamiento quimioterápico por inyección intratecal. Esta punción forma parte del tratamiento habitual en las leucemias linfoblásticas agudas.

3.5. ¿De qué forma mejorar el bienestar de las personas cuidadoras?

El bienestar de las personas cuidadoras es igualmente importante para mantener su salud y garantizar que puedan ofrecer el mejor apoyo posible a la persona con leucemia aguda.. A continuación, algunas estrategias para mejorar su bienestar:

1. **Apoyo emocional.** Las personas cuidadoras pueden beneficiarse de participar en grupos de apoyo o recibir asesoramiento psicológico. Compartir experiencias con otras personas en situaciones similares puede ser muy útil para gestionar el estrés y las emociones relacionadas con el cuidado de un ser querido con leucemia aguda.
2. **Delegar tareas.** Es importante no asumir todas las responsabilidades y aprender a delegar tareas, pidiendo ayuda a otras personas cuando sea posible. También se puede recurrir a servicios de atención domiciliaria para ayudar con las tareas diarias del cuidado.
3. **Tomarse descansos.** Las personas cuidadoras necesitan tener tiempo para sí mismas para descansar y recargar energías. Realizar actividades que disfruten, como leer, caminar o hacer ejercicio, puede ayudar a reducir el estrés y mejorar el bienestar emocional. Es fundamental darse permiso para cuidar de sí mismo.
4. **Cuidar de la propia salud.** Realizar chequeos médicos regulares y mantener una rutina saludable de alimentación y ejercicio es clave para evitar el agotamiento físico y emocional. Además, estar bien física y emocionalmente capacita para ofrecer un mejor apoyo al paciente.

3.6. ¿A qué recursos sociales se puede acceder?

Existen una serie de recursos sociales que pueden facilitar el proceso de tratamiento y mejorar la calidad de vida tanto del paciente como de su familia. A continuación, se describen algunos de los recursos más importantes:

1. **Trabajo social.** Las unidades de Trabajo Social, presentes en servicios sociales, hospitales y centros de salud, ofrecen asesoramiento para lograr una adecuada adaptación a la situación, poniendo la mirada en lo que puedes hacer para reducir el riesgo de problemáticas sociales afectadas como consecuencia del diagnóstico (impacto en familia, relaciones sociales, economía, trabajo, etc.). Además, te informarán de recursos y prestaciones, en función de tus necesidades.
2. **Organizaciones de apoyo y asociaciones de pacientes.** Además de Fundación MÁS QUE IDEAS, donde te ofrecemos recursos de apoyo e información de forma gratuita, te invitamos a conocer a las asociaciones miembro de la Agrupación Española de entidades de Lucha contra la Leucemia y Enfermedades de la Sangre (AELCLÉS). Podrás encontrar decenas de organizaciones que te brindarán apoyo y servicios como psicología o trabajo social, entre otros.
3. **Asesoramiento procedimental y legal.** A raíz de la enfermedad, puedes tener dudas sobre cuestiones como la discapacidad, la dependencia o las incapacidades laborales, entre otras. Mientras que de las dos primeras son cuestiones que puedes recibir asesoramiento en tu centro de servicios sociales, te podrás informar sobre cualquier aspecto relacionado con las incapacidades laborales en la Seguridad Social. En caso de tener alguna discrepancia, te invitamos a acudir a profesionales de la abogacía para que te asesoren y te representen en caso de procedimiento judicial por reclamación.

- **Fase de consolidación.** Incluso tras alcanzar la remisión completa, pueden persistir células leucémicas residuales que, en un momento dado, podrían comenzar a reproducirse y causar una recaída, es decir, que la enfermedad reaparezca. Por ello, se plantea continuar el tratamiento en esta fase de consolidación con el propósito de profundizar la respuesta, eliminar por completo las células leucémicas y prevenir una recaída. En los casos en los que no se pueda consolidar la remisión, el propósito de esta fase de consolidación será que la duración de la respuesta sea la mayor posible. Es decir, posponer al máximo la posibilidad de recaída o avance de la enfermedad.

- **Fase de mantenimiento.** El propósito de esta fase, que suele durar dos años, es evitar que la leucemia regrese. El tratamiento de mantenimiento se administra a las personas con leucemia linfoblástica aguda y solo en algunos casos de leucemia mieloide aguda. En esta fase se puede llevar una vida mucho más normalizada, con menos exigencias médicas y efectos secundarios, en comparación con las fases anteriores.

Leucemias agudas: fases del tratamiento

Inducción

Objetivos: controlar la enfermedad y lograr la remisión completa.

Consolidación

Objetivos: profundizar la respuesta, eliminar por completo las células leucémicas y prevenir una recaída.

Mantenimiento

Objetivos: evitar que la leucemia regrese.

RESULTS

- Launched: March 18th, 2025
- 143 printed guides have been distributed
- 154 downloads through our website
- Press release for the launch
- The SEHH included this material in its press release on the occasion of World AML Day.

ENTENDIENDO LAS
LEUCEMIAS AGUDAS
EN POBLACIÓN ADULTA
Guía para pacientes y familiares

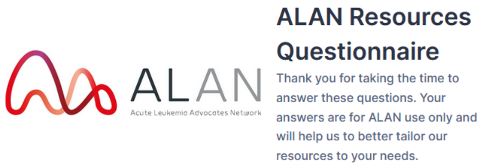
Una iniciativa de: más que ideas fundación

Con el apoyo de: ALAN

Y con la colaboración de: AELCLÉS · SEHH Sociedad Española de Hematología y Hemoterapia · SEEO Sociedad Española de Enfermería Oncológica

Diego Villalón García
diegovillalon@fundacionmasqueideas.org

ALAN Resources - Questionnaire



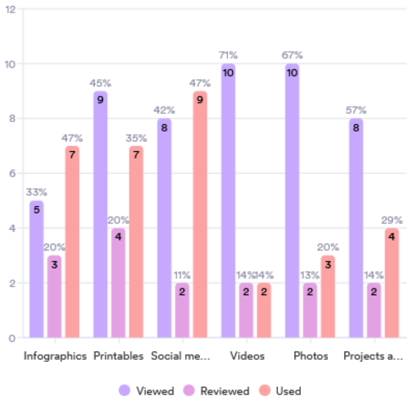
ALAN Resources Questionnaire

Thank you for taking the time to answer these questions. Your answers are for ALAN use only and will help us to better tailor our resources to your needs.

- 16 responses
- 8 languages *(+10 more in South Africa!)*
- 95% knew about ALAN resources

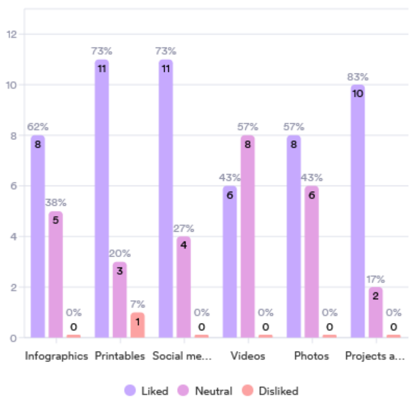
9. Have you looked at or used any of the materials available?

16 Responses



10. Do you have a strong opinion about any of them?

16 Responses



ALAN Resources - Infographics

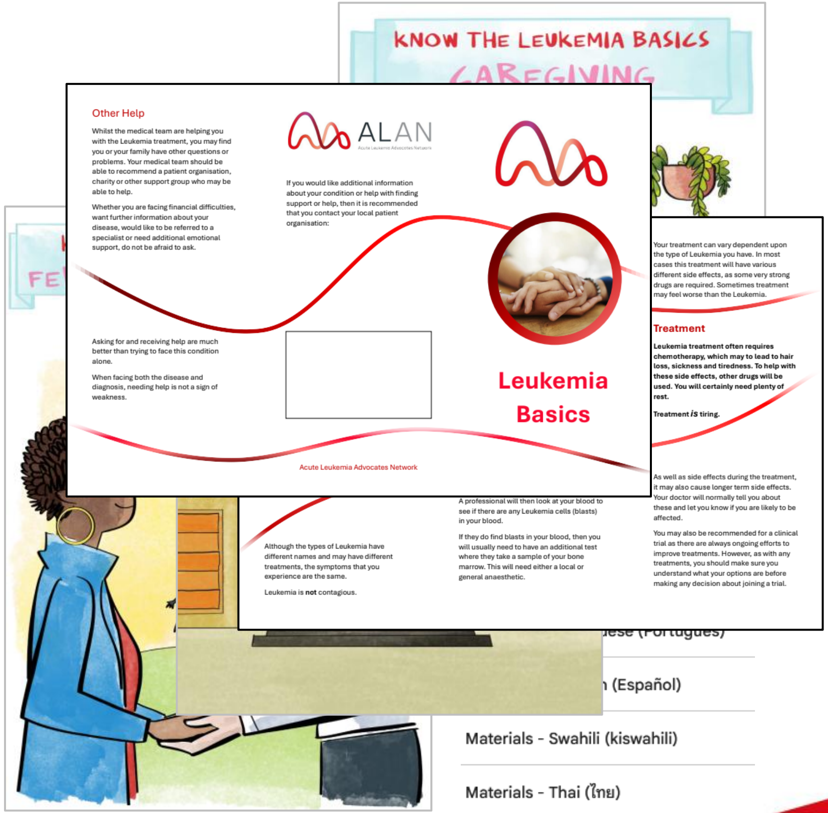
KNOW THE LEUKEMIA BASICS

- Multi-page, colourful

Leukemia

Basics

- Simpler – Tri-fold
  Quick and 'Easy' to translate



Other Help

Whilst the medical team are helping you with the Leukemia treatment, you may find you or your family have other questions or problems. Your medical team should be able to recommend a patient organisation, charity or other support group who may be able to help.

Whether you are facing financial difficulties, want further information about your disease, would like to be referred to a specialist or need additional emotional support, do not be afraid to ask.

Asking for and receiving help are much better than trying to face this condition alone.

When facing both the disease and diagnosis, needing help is not a sign of weakness.

ALAN
Acute Leukemia Advocates Network

If you would like additional information about your condition or help with finding support or help, then it is recommended that you contact your local patient organisation:

Acute Leukemia Advocates Network

Leukemia Basics

Although the types of Leukemia have different names and may have different treatments, the symptoms that you experience are the same.

Leukemia is **not** contagious.

A professional will then look at your blood to see if there are any Leukemia cells (blasts) in your blood.

If they do find blasts in your blood, then you will usually need to have an additional test where they take a sample of your bone marrow. This will need either a local or general anaesthetic.

Your treatment can vary dependent upon the type of Leukemia you have. In most cases this treatment will have various different side effects, as some very strong drugs are required. Sometimes treatment may feel worse than the Leukemia.

Treatment

Leukemia treatment often requires chemotherapy, which may to lead to hair loss, sickness and tiredness. To help with these side effects, other drugs will be used. You will certainly need plenty of rest.

Treatment *is* tiring.

As well as side effects during the treatment, it may also cause longer term side effects. Your doctor will normally tell you about these and let you know if you are likely to be affected.

You may also be recommended for a clinical trial as there are always ongoing efforts to improve treatments. However, as with any treatments, you should make sure you understand what your options are before making any decision about joining a trial.

Materials - Swahili (kiswahili)

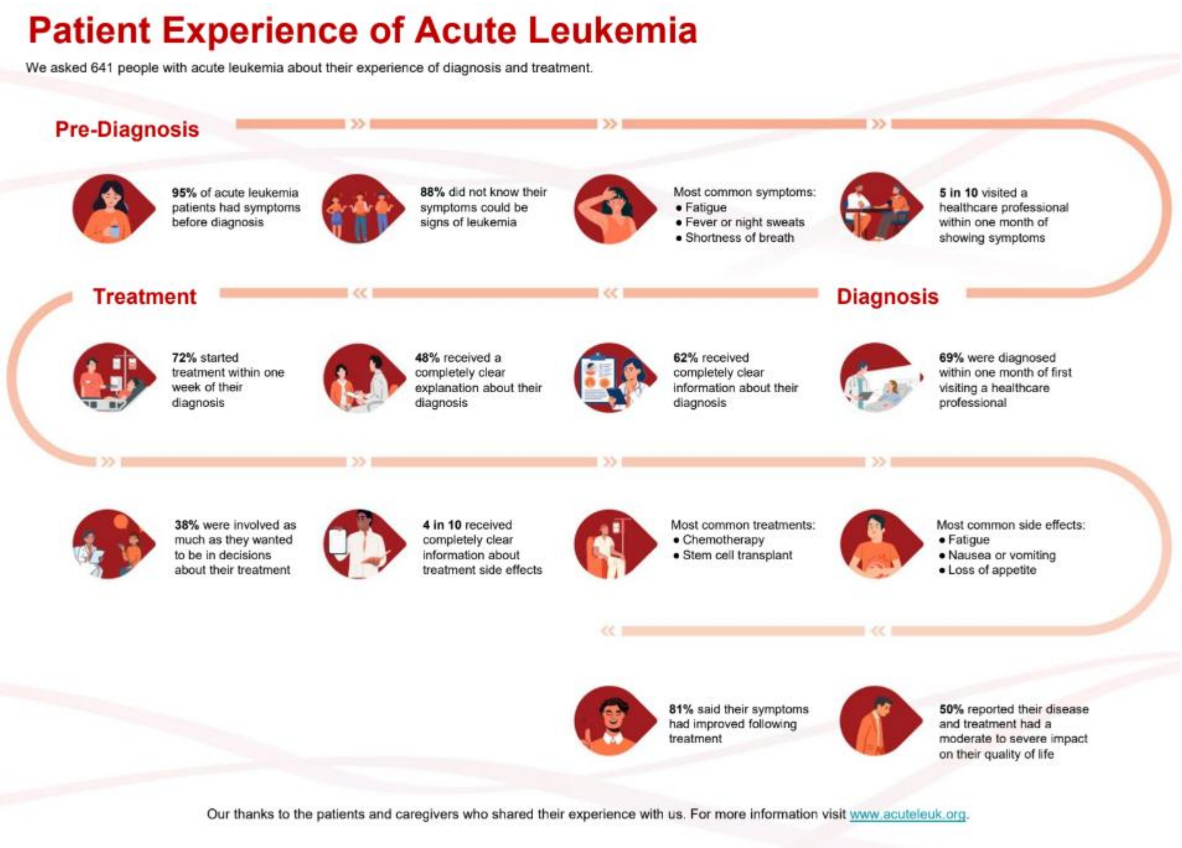
Materials - Thai (ไทย)

#ALANsummit

ALAN Resources - How can you help (us help you)?

- What communication challenges do <u>you</u> face?
- What resources do <u>you</u> need?
- What else would you like to see available?

Toolkit for patients and physicians



Patient Experience of Acute Leukemia

We asked 641 people with acute leukemia about their experience of diagnosis and treatment.

Pre-Diagnosis

95% of acute leukemia patients had symptoms before diagnosis

88% did not know their symptoms could be signs of leukemia

Most common symptoms:
- Fatigue
- Fever or night sweats
- Shortness of breath

5 in 10 visited a healthcare professional within one month of showing symptoms

Diagnosis

69% were diagnosed within one month of first visiting a healthcare professional

62% received completely clear information about their diagnosis

48% received a completely clear explanation about their diagnosis

Treatment

72% started treatment within one week of their diagnosis

38% were involved as much as they wanted to be in decisions about their treatment

4 in 10 received completely clear information about treatment side effects

Most common treatments:
- Chemotherapy
- Stem cell transplant

Most common side effects:
- Fatigue
- Nausea or vomiting
- Loss of appetite

81% said their symptoms had improved following treatment

50% reported their disease and treatment had a moderate to severe impact on their quality of life

Our thanks to the patients and caregivers who shared their experience with us. For more information visit www.acuteleuk.org.

Research summary

Acute Leukemia

What did patients tell us?

The Global Leukemia Experience Survey 2023 received 641 responses from acute leukemia* patients from 34 countries. The survey sought understanding and insight into the experiences of the patient, rather than from a clinical perspective. This report summarises survey findings to help understand the key issues, experiences, and unmet needs of acute leukemia patients. More information can be found at www.acuteleuk.org.

Diagnosis

Treatment

Information and support

90% (n=488) of patients were given or directed to at least one source of information or support during their treatment journey. The most common resources patients were given or directed to were:

- Side effects and risks of treatment (54% n=290)
- Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy (46%, n=249)
- Leukemia charities / associations / organisations (30%, n=162)

- Buddying or befriending (87%, n=93)
- Patient support groups (86%, n=89)

Quality of life

- Disease-related anxiety (79%, n=399)
- General anxiety (75%, n=379)
- Fear of dying (62%, n=313)
- Isolation (51%, n=256)
- Depression (50%, n=251)

Views on potential new treatments

- Improved / longer survival (80%, n=399)
- Improved quality of life (75%, n=374)

Recommendations

The following recommendations have been created to drive improvements in care quality and experience for acute leukemia patients.

Increase awareness of symptoms
Efforts to increase public awareness of symptoms must be undertaken to ensure patients visit a HCP early.

Information and explanations
HCPs must improve how they communicate with patients, ensuring patients receive vital information at key stages and are offered the opportunity to ask questions. Signposting patients and caregivers to patient organisation groups for further support and information should be a consistent part of the consultation process.

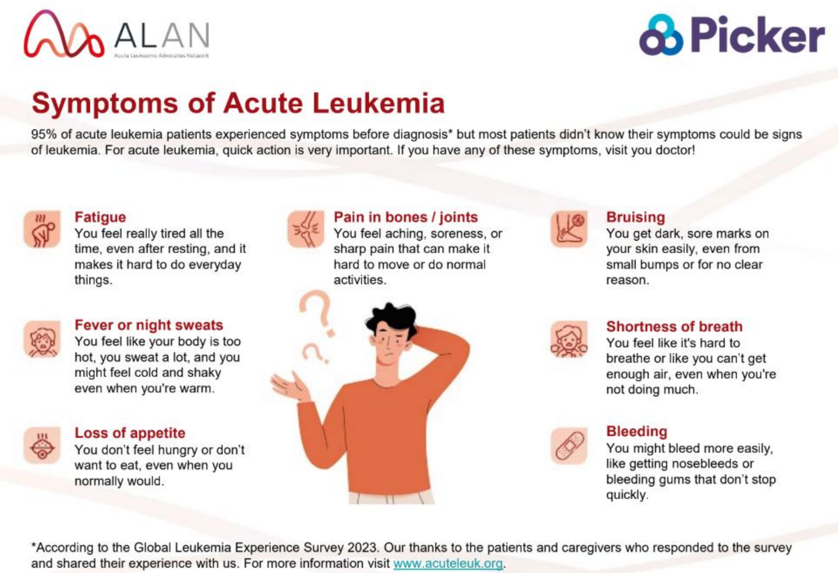
Involvement in decision-making
HCPs must work with patients and their caregivers, in partnership, to involve them in decision-making throughout their journey. As part of this process, HCPs must ensure patients are well informed and that their personal preferences are respected.

Directing patients to information and support resources
HCPs and advocacy groups should work towards greater facilitation and access to the resources acute leukemia patients found to be most helpful: buddying or befriending, patient support groups, and general wellbeing information.

Address variance in experience
Acute leukemia patients were more likely to experience barriers to treatment choices and report a greater impact to their quality of life than chronic leukemia patients. Enhanced care and support for acute leukemia patients should be enforced to mitigate this impact.

#ALANsummit

Toolkit for patients



Symptoms of Acute Leukemia

95% of acute leukemia patients experienced symptoms before diagnosis* but most patients didn't know their symptoms could be signs of leukemia. For acute leukemia, quick action is very important. If you have any of these symptoms, visit you doctor!

Fatigue
You feel really tired all the time, even after resting, and it makes it hard to do everyday things.

Fever or night sweats
You feel like your body is too hot, you sweat a lot, and you might feel cold and shaky even when you're warm.

Loss of appetite
You don't feel hungry or don't want to eat, even when you normally would.

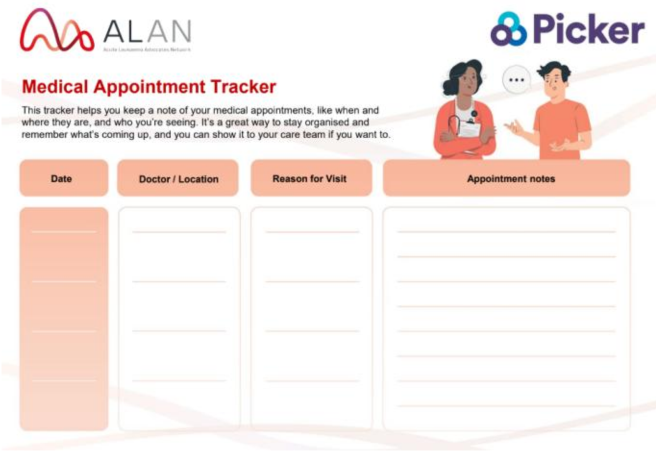
Pain in bones / joints
You feel aching, soreness, or sharp pain that can make it hard to move or do normal activities.

Bruising
You get dark, sore marks on your skin easily, even from small bumps or for no clear reason.

Shortness of breath
You feel like it's hard to breathe or like you can't get enough air, even when you're not doing much.

Bleeding
You might bleed more easily, like getting nosebleeds or bleeding gums that don't stop quickly.

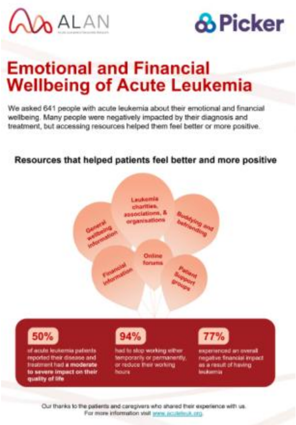
*According to the Global Leukemia Experience Survey 2023. Our thanks to the patients and caregivers who responded to the survey and shared their experience with us. For more information visit www.acuteleuk.org.



Medical Appointment Tracker

This tracker helps you keep a note of your medical appointments, like when and where they are, and who you're seeing. It's a great way to stay organised and remember what's coming up, and you can show it to your care team if you want to.

Date	Doctor / Location	Reason for Visit	Appointment notes



Emotional and Financial Wellbeing of Acute Leukemia

We asked 641 people with acute leukemia about their emotional and financial wellbeing. Many people were negatively impacted by their diagnosis and treatment, but accessing resources helped them feel better or more positive.

Resources that helped patients feel better and more positive

Leukemia charities, associations, & organisations
General wellbeing information
Buddying and befriending
Online forums
Financial information
Patient support groups

50% of acute leukemia patients reported their disease and treatment had **a moderate to severe impact on their quality of life**

94% had to stop **working** either temporarily or permanently, or reduce their working hours

77% experienced an overall negative financial impact as a result of having leukemia

Our thanks to the patients and caregivers who shared their experience with us.
For more information visit www.acuteleuk.org.

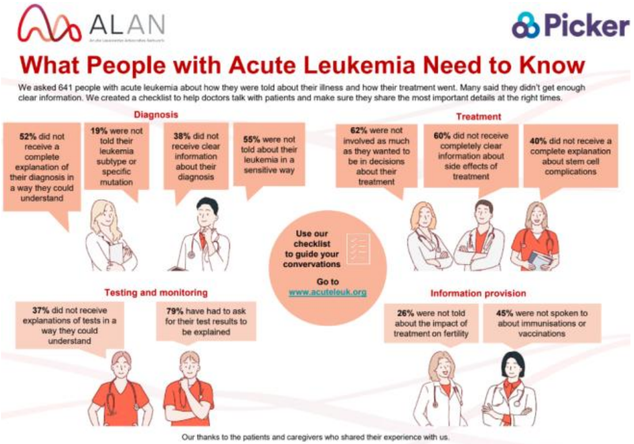
Wellbeing Tracker

Use this tracker to help you notice how you feel each day. Print out and write words, use colours, or draw smiley faces to show your mood and symptoms. Share this with your care team so they can better support you.

Start date: _ _ / _ _ / _ _	Daily Notes
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	

Use this space to summarise how you felt this week…

Toolkit for physicians



ALAN Picker

What People with Acute Leukemia Need to Know

We asked 641 people with acute leukemia about how they were told about their illness and how their treatment went. Many said they didn't get enough clear information. We created a checklist to help doctors talk with patients and make sure they share the most important details at the right times.

Diagnosis

- **52%** did not receive a complete explanation of their diagnosis in a way they could understand
- **19%** were not told their leukemia subtype or specific mutation
- **38%** did not receive clear information about their diagnosis
- **55%** were not told about their leukemia in a sensitive way

Treatment

- **62%** were not involved as much as they wanted to be in decisions about their treatment
- **60%** did not receive completely clear information about side effects of treatment
- **40%** did not receive a complete explanation about stem cell complications

Use our checklist to guide your convervations

Go to www.acuteleuk.org

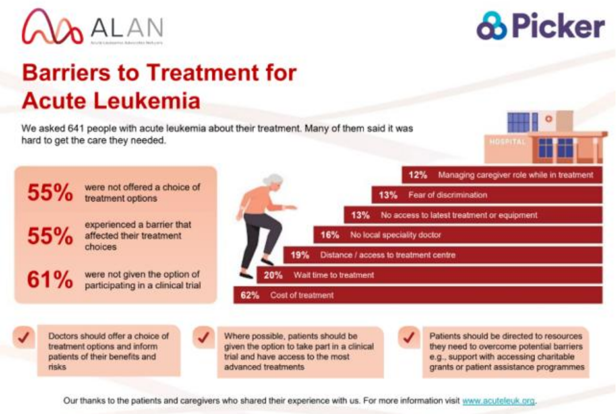
Testing and monitoring

- **37%** did not receive explanations of tests in a way they could understand
- **79%** have had to ask for their test results to be explained

Information provision

- **26%** were not told about the impact of treatment on fertility
- **45%** were not spoken to about immunisations or vaccinations

Our thanks to the patients and caregivers who shared their experience with us.



ALAN Picker

Barriers to Treatment for Acute Leukemia

We asked 641 people with acute leukemia about their treatment. Many of them said it was hard to get the care they needed.

55% were not offered a choice of treatment options

55% experienced a barrier that affected their treatment choices

61% were not given the option of participating in a clinical trial

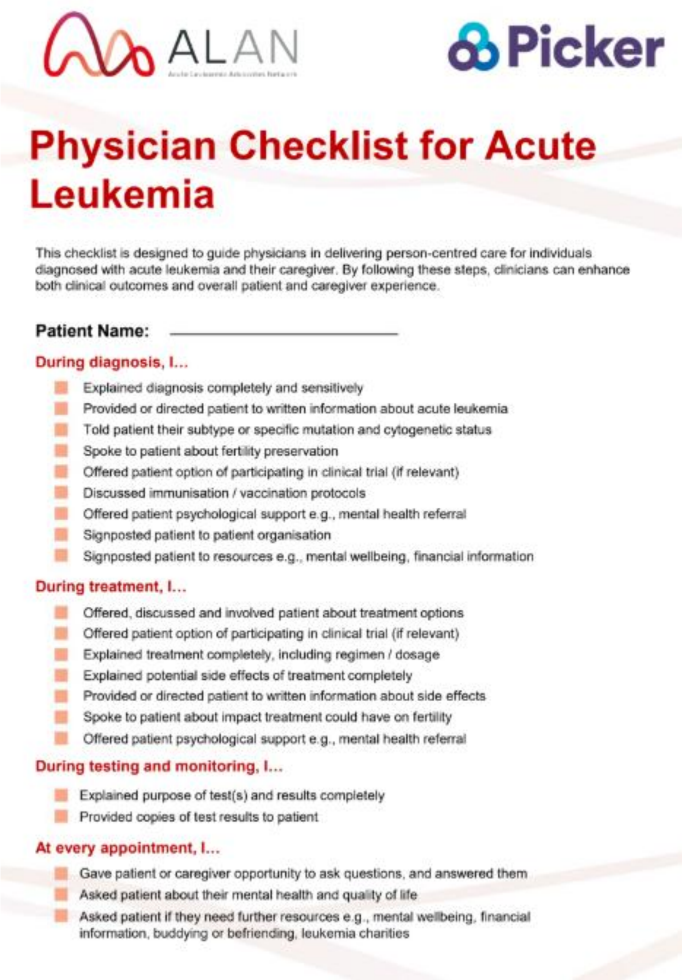
12%	Managing caregiver role while in treatment
13%	Fear of discrimination
13%	No access to latest treatment or equipment
16%	No local speciality doctor
19%	Distance / access to treatment centre
20%	Wait time to treatment
62%	Cost of treatment

✓ Doctors should offer a choice of treatment options and inform patients of their benefits and risks

✓ Where possible, patients should be given the option to take part in a clinical trial and have access to the most advanced treatments

✓ Patients should be directed to resources they need to overcome potential barriers e.g., support with accessing charitable grants or patient assistance programmes

Our thanks to the patients and caregivers who shared their experience with us. For more information visit www.acuteleuk.org.



ALAN Picker

Physician Checklist for Acute Leukemia

This checklist is designed to guide physicians in delivering person-centred care for individuals diagnosed with acute leukemia and their caregiver. By following these steps, clinicians can enhance both clinical outcomes and overall patient and caregiver experience.

Patient Name: ____________________

During diagnosis, I...

☐ Explained diagnosis completely and sensitively
☐ Provided or directed patient to written information about acute leukemia
☐ Told patient their subtype or specific mutation and cytogenetic status
☐ Spoke to patient about fertility preservation
☐ Offered patient option of participating in clinical trial (if relevant)
☐ Discussed immunisation / vaccination protocols
☐ Offered patient psychological support e.g., mental health referral
☐ Signposted patient to patient organisation
☐ Signposted patient to resources e.g., mental wellbeing, financial information

During treatment, I...

☐ Offered, discussed and involved patient about treatment options
☐ Offered patient option of participating in clinical trial (if relevant)
☐ Explained treatment completely, including regimen / dosage
☐ Explained potential side effects of treatment completely
☐ Provided or directed patient to written information about side effects
☐ Spoke to patient about impact treatment could have on fertility
☐ Offered patient psychological support e.g., mental health referral

During testing and monitoring, I...

☐ Explained purpose of test(s) and results completely
☐ Provided copies of test results to patient

At every appointment, I...

☐ Gave patient or caregiver opportunity to ask questions, and answered them
☐ Asked patient about their mental health and quality of life
☐ Asked patient if they need further resources e.g., mental wellbeing, financial information, buddying or befriending, leukemia charities

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#ALANsummit

Toolkit for patients and physicians

- Link https://drive.google.com/drive/folders/1JZbDDLeGgFiybH-En5ZzGVlq1f-jNxVp?usp=sharing
- Materials are editable and translatable
- Share within your organization, network including physicians, hospitals, etc.

How can technology and digital platforms enhance patient education and patient support ?

Sophie Wintrich

Information and Communication
To counter worries, isolation, partial information

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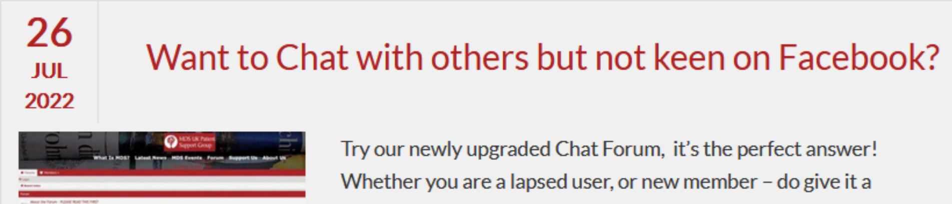
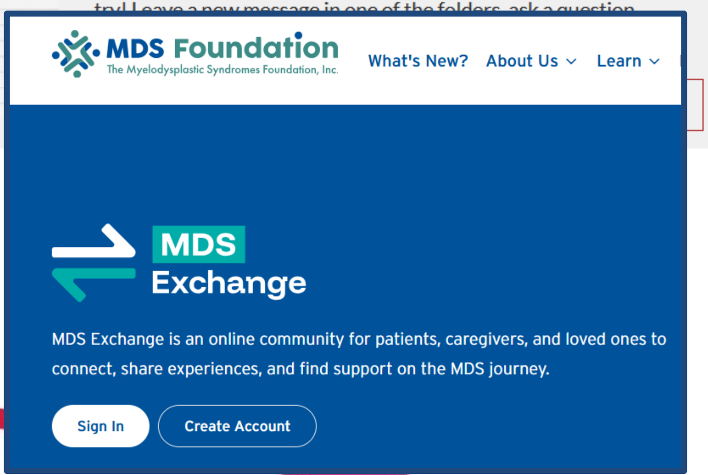
Increased use of chat forums & Facebook.
Popular topics: new treatment starting, infection risk, uncertainty, travel, supplements



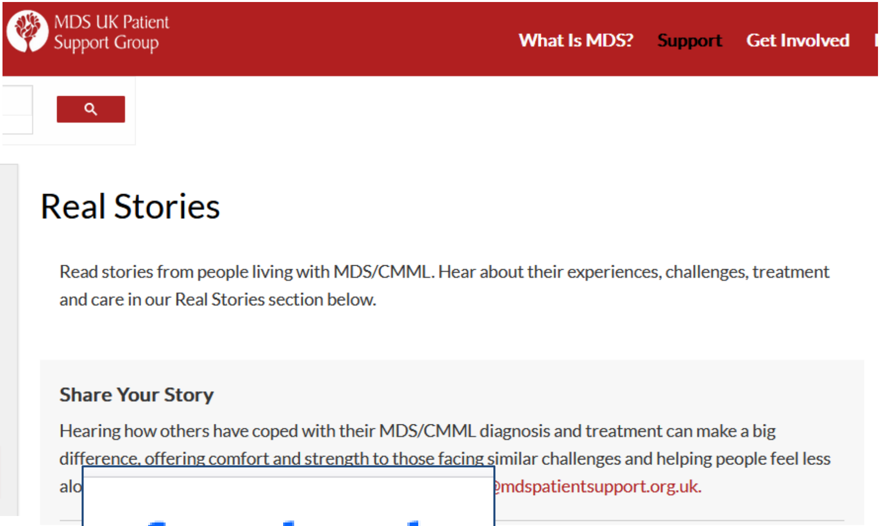
26
JUL
2022

Want to Chat with others but not keen on Facebook?

Try our newly upgraded Chat Forum, it's the perfect answer! Whether you are a lapsed user, or new member – do give it a try! Leave a new message in one of the folders, ask a question



MDS Exchange is an online community for patients, caregivers, and loved ones to connect, share experiences, and find support on the MDS journey.



Real Stories

Read stories from people living with MDS/CMML. Hear about their experiences, challenges, treatment and care in our Real Stories section below.

Share Your Story

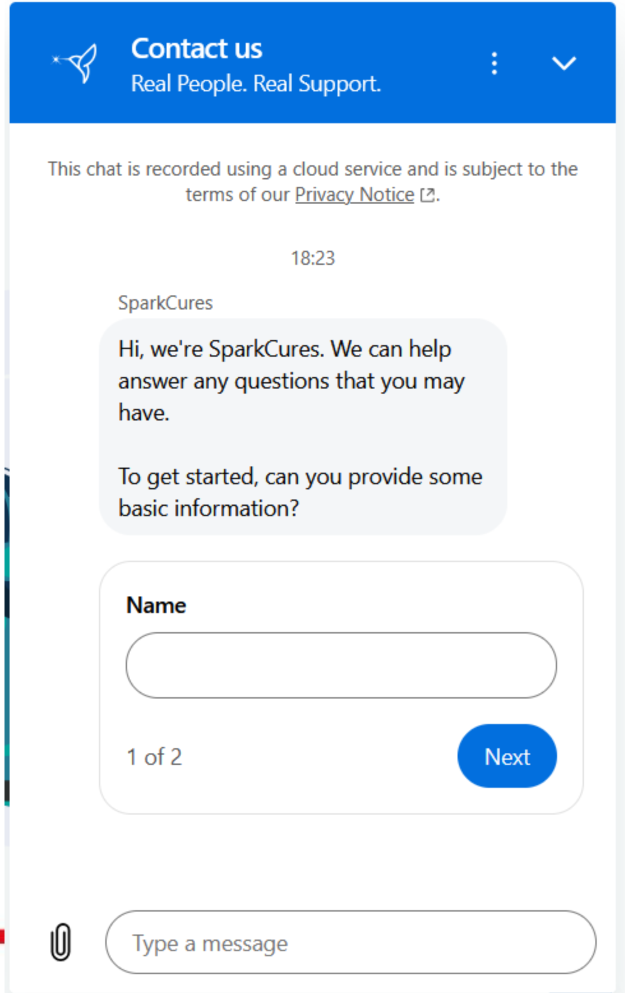
Hearing how others have coped with their MDS/CMML diagnosis and treatment can make a big difference, offering comfort and strength to those facing similar challenges and helping people feel less alo @mdspatientsupport.org.uk.

facebook

Leukaemia Care
YOUR Blood Cancer Charity

Buddy support for leukaemia patients

New methods and partnerships to make contact



This chat is recorded using a cloud service and is subject to the terms of our Privacy Notice.

18:23

SparkCures

Hi, we're SparkCures. We can help answer any questions that you may have.

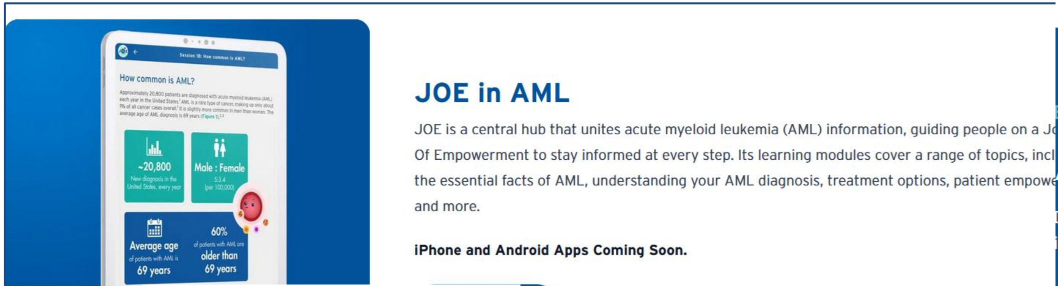
To get started, can you provide some basic information?

Name:

Leukaemia Care

Send a WhatsApp message to 07500 068 065
(weekdays 9am to 5pm)

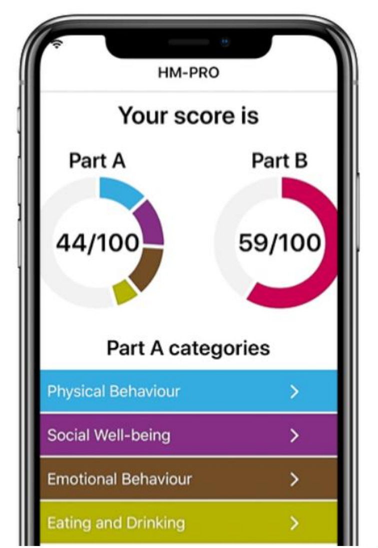
Digital apps for information and data collection
‘Journey of Empowerment’



JOE in AML

JOE is a central hub that unites acute myeloid leukemia (AML) information, guiding people on a Jo
Of Empowerment to stay informed at every step. Its learning modules cover a range of topics, incl
the essential facts of AML, understanding your AML diagnosis, treatment options, patient empowe
and more.

iPhone and Android Apps Coming Soon.



HM-PRO

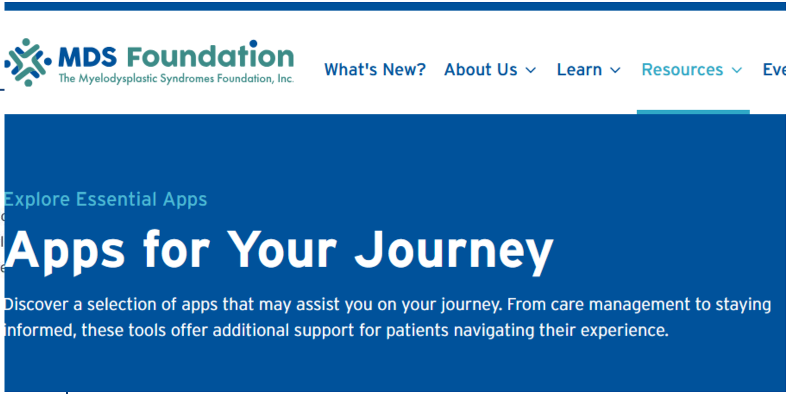
Your score is

Part A 44/100

Part B 59/100

Part A categories

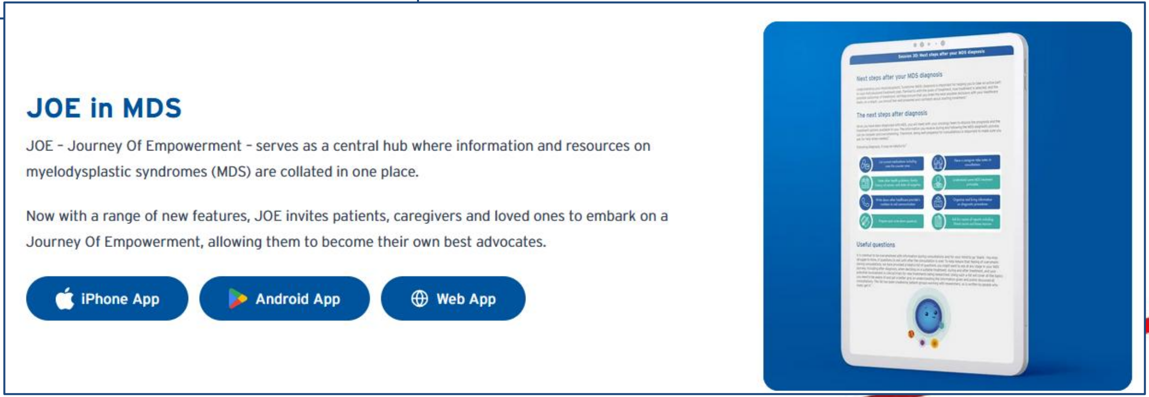
- Physical Behaviour >
- Social Well-being >
- Emotional Behaviour >
- Eating and Drinking >



Explore Essential Apps

Apps for Your Journey

Discover a selection of apps that may assist you on your journey. From care management to staying informed, these tools offer additional support for patients navigating their experience.



JOE in MDS

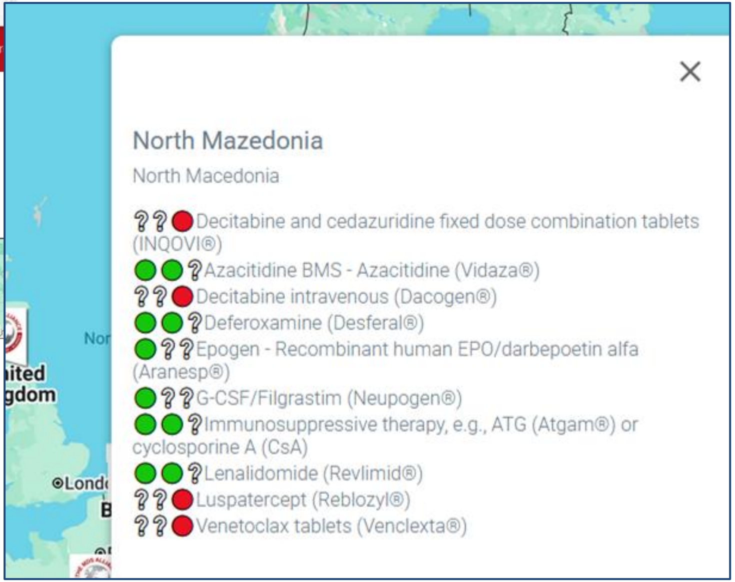
JOE - Journey Of Empowerment - serves as a central hub where information and resources on myelodysplastic syndromes (MDS) are collated in one place.

Now with a range of new features, JOE invites patients, caregivers and loved ones to embark on a Journey Of Empowerment, allowing them to become their own best advocates.

Data on treatment access to inform, empower & encourage to act

Helping to better serve the MDS patient and caregiver community globally through optimal car

MDS Treatment Access Portal



North Mazedonia

North Macedonia

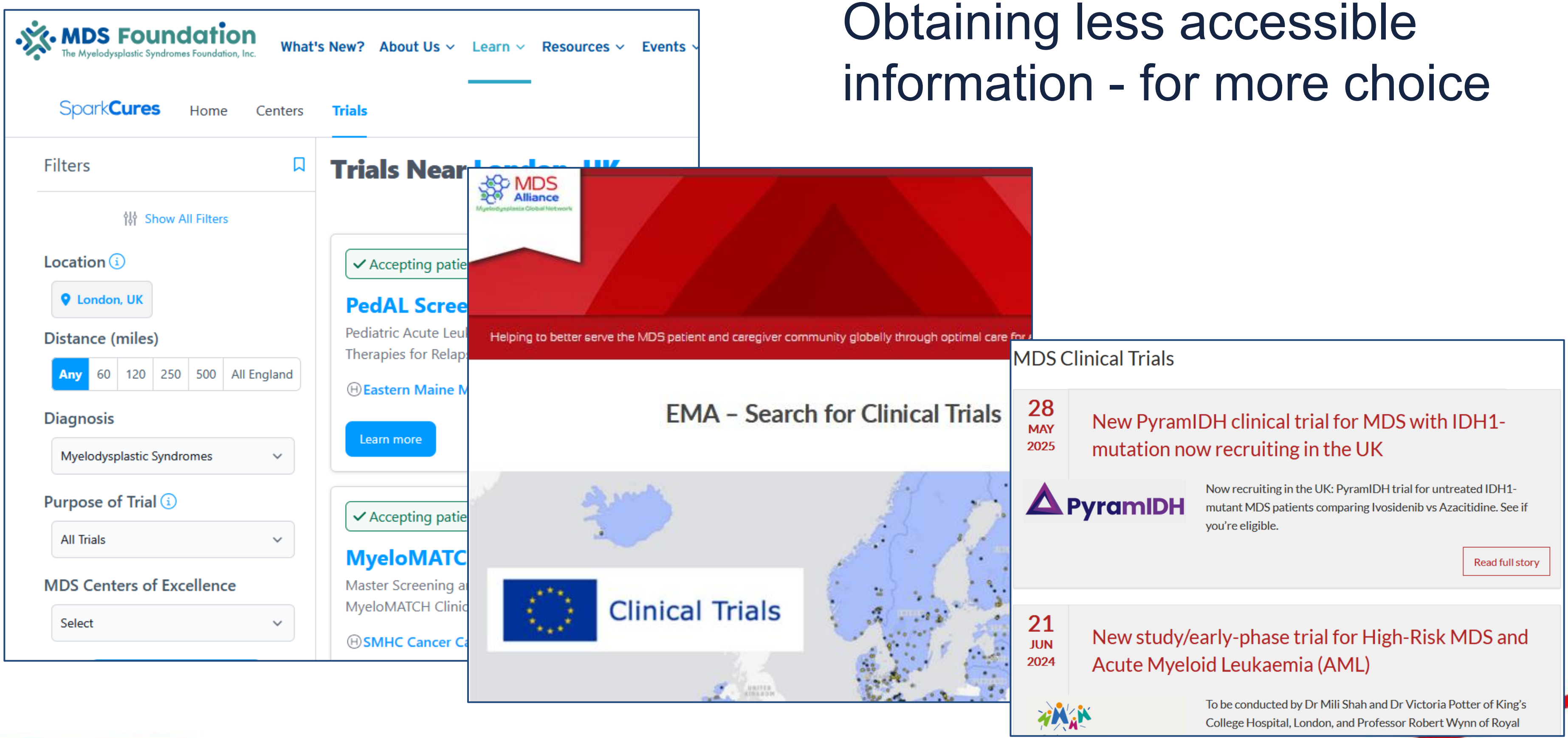
?? 🔴 Decitabine and cedazuridine fixed dose combination tablets (INQOVI®)
🟢🟢 ? Azacitidine BMS - Azacitidine (Vidaza®)
?? 🔴 Decitabine intravenous (Dacogen®)
🟢🟢 ? Deferoxamine (Desferal®)
🟢 ?? Epogen - Recombinant human EPO/darbepoetin alfa (Aranesp®)
🟢 ?? G-CSF/Filgrastim (Neupogen®)
🟢🟢 ? Immunosuppressive therapy, e.g., ATG (Atgam®) or cyclosporine A (CsA)
🟢🟢 ? Lenalidomide (Revlimid®)
?? 🔴 Luspatercept (Reblozyl®)
?? 🔴 Venetoclax tablets (Venclexta®)

MDS Latest News

What are NICE and SMC?

Final Report of the 2024 Global Survey

Obtaining less accessible information - for more choice



MDS Foundation
The Myelodysplastic Syndromes Foundation, Inc.
What's New? About Us Learn Resources Events

SparkCures Home Centers Trials

Filters
Show All Filters
Location
London, UK
Distance (miles)
Any 60 120 250 500 All England
Diagnosis
Myelodysplastic Syndromes
Purpose of Trial
All Trials
MDS Centers of Excellence
Select

Trials Near

✓ Accepting patie
PedAL Scree
Pediatric Acute Leu
Therapies for Relap
Eastern Maine M
Learn more

✓ Accepting patie
MyeloMATC
Master Screening a
MyeloMATCH Clinic
SMHC Cancer Ca

MDS Alliance
Myelodysplasia Global Network
Helping to better serve the MDS patient and caregiver community globally through optimal care for

EMA – Search for Clinical Trials

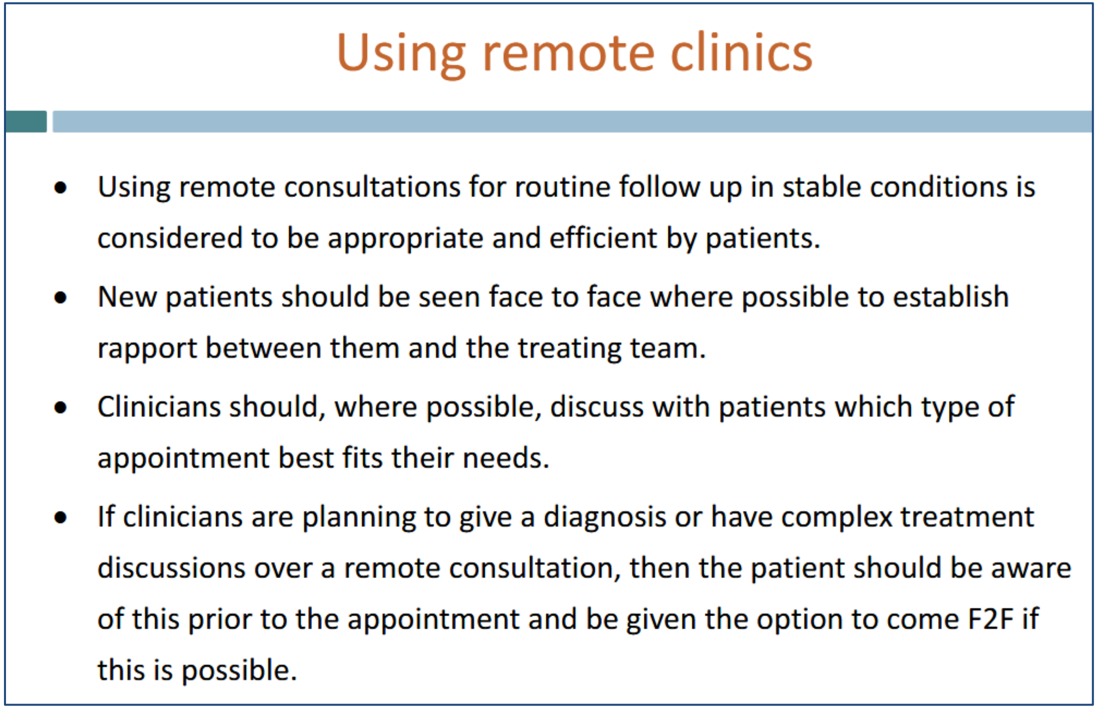
Clinical Trials

MDS Clinical Trials

28 MAY 2025
New PyramIDH clinical trial for MDS with IDH1-mutation now recruiting in the UK
PyramIDH
Now recruiting in the UK: PyramIDH trial for untreated IDH1-mutant MDS patients comparing Ivosidenib vs Azacitidine. See if you're eligible.
Read full story

21 JUN 2024
New study/early-phase trial for High-Risk MDS and Acute Myeloid Leukaemia (AML)
To be conducted by Dr Mili Shah and Dr Victoria Potter of King's College Hospital, London, and Professor Robert Wynn of Royal

Remote consultations for second opinions
A UK attempt !
Pros and cons



Using remote clinics

- Using remote consultations for routine follow up in stable conditions is considered to be appropriate and efficient by patients.
- New patients should be seen face to face where possible to establish rapport between them and the treating team.
- Clinicians should, where possible, discuss with patients which type of appointment best fits their needs.
- If clinicians are planning to give a diagnosis or have complex treatment discussions over a remote consultation, then the patient should be aware of this prior to the appointment and be given the option to come F2F if this is possible.

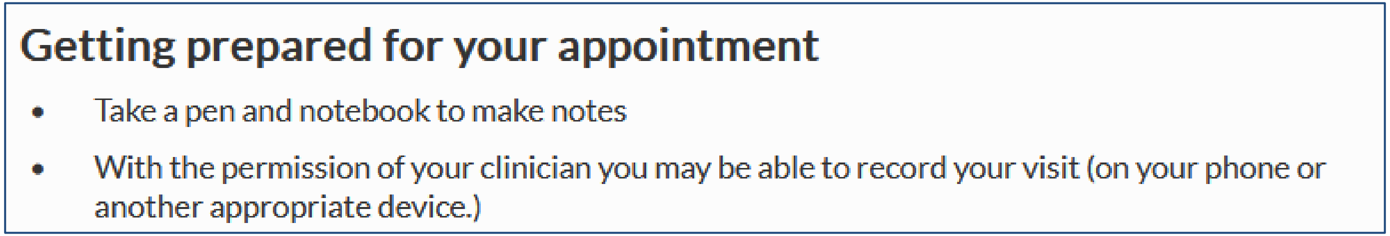
My husband quickly purchased a WebCam to enable me to take part in the appointment via Video with Professor Bowen. I must admit, we have never been involved in this type of technology before, but would highly recommend this type of appointment, but I can say that I was more worried about the technology working than I was about the interaction with Professor Bowen! The process was so simple by just placing the small camera with microphone on top of my monitor.

‘Lost Social contact in hospital but…great way to include family’

https://mdspatientsupport.org.uk/wp-content/uploads/2021/07/MDS-UK-presentation_Oxford-Remote-Consultations-July2021.pdf

Potential uses of AI

Note taking for patients during consultations - to date:



Getting prepared for your appointment

- Take a pen and notebook to make notes
- With the permission of your clinician you may be able to record your visit (on your phone or another appropriate device.)

In the UK, patients are ***legally permitted to record their own consultations*** *for personal use, even without the explicit consent of the clinician. This is considered personal "note-taking" and is exempt from data protection laws (UK GDPR)*

Next step?

AI to record and have the option to summarise the consultation?
Both for hospital medical notes - and patient’s own records.
Trialled in A&E for clinicians

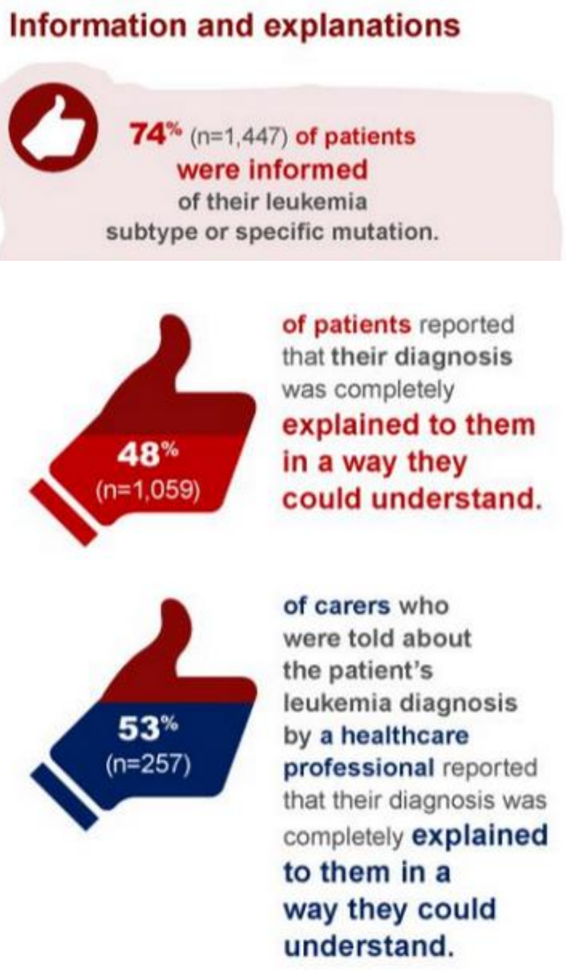
Support Slides

Data via ALAN Global survey
&
MDS Alliance Survey

Information about their sub-typ

Despite indicating they had been informed of their leukemia subtype or specific mutation, when asked, many patients did not know:

- 24% of AML patients did not know their form of genetic mutation
- 49% of ALL patients did not know their cytogenetic status



Information and explanations

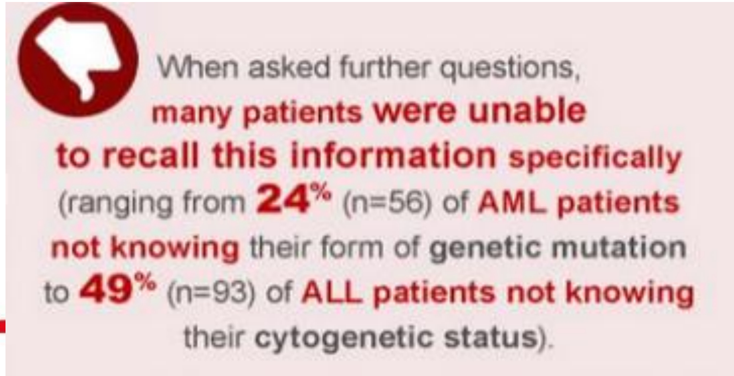
74% (n=1,447) **of patients were informed** of their leukemia subtype or specific mutation.

48% (n=1,059)

of patients reported that their diagnosis was completely **explained to them in a way they could understand.**

53% (n=257)

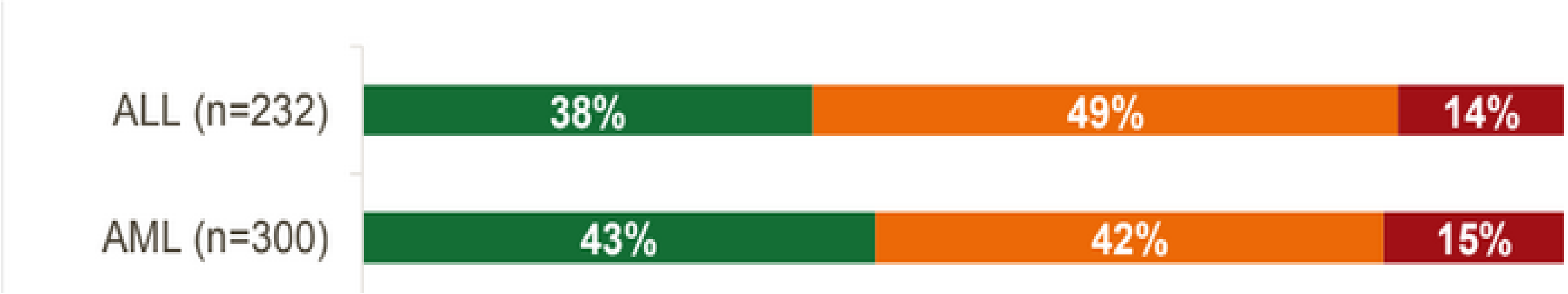
of carers who were told about the patient's leukemia diagnosis by **a healthcare professional** reported that their diagnosis was completely **explained to them in a way they could understand.**



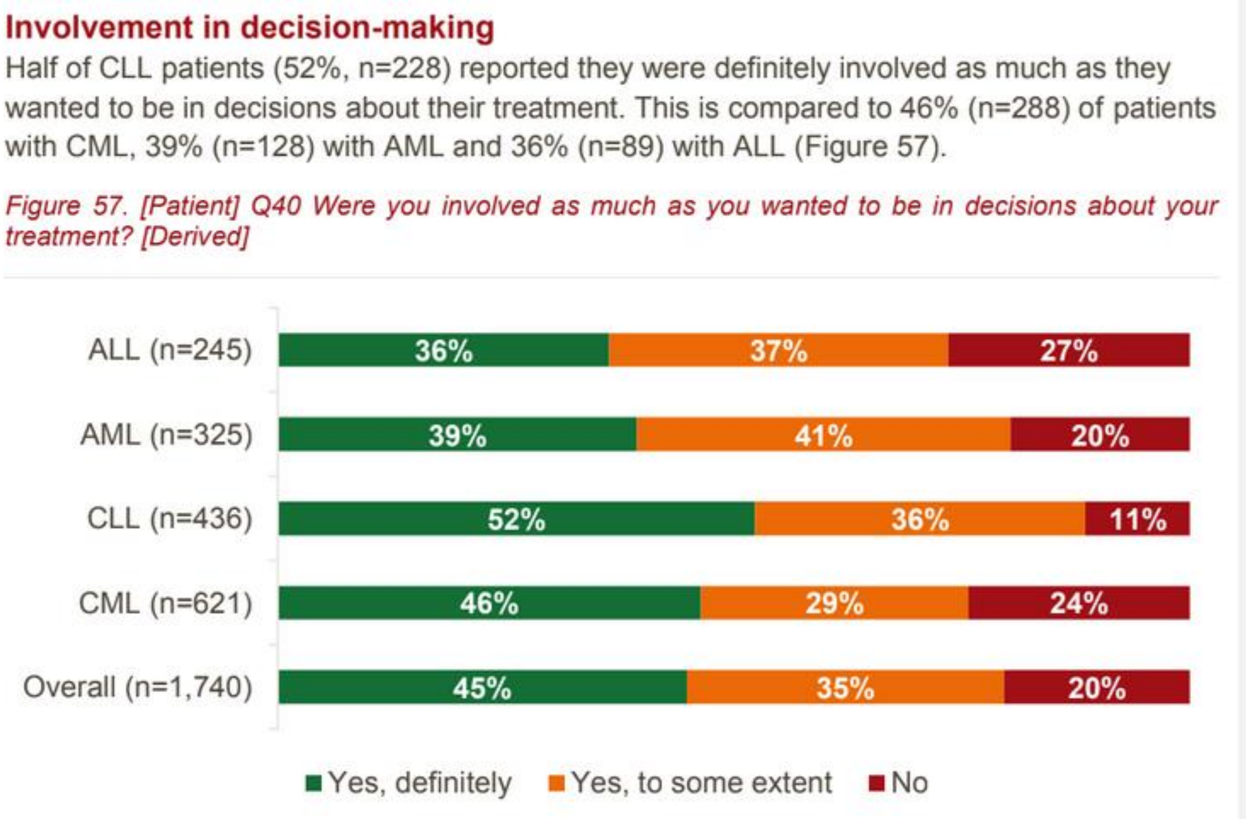
When asked further questions, **many patients were unable to recall this information specifically** (ranging from **24%** (n=56) of **AML patients not knowing** their form of **genetic mutation** to **49%** (n=93) of **ALL patients not knowing** their **cytogenetic status**).

Information about side-effects

Figure 70. [Patient] Q50 Were you given clear information about any side effects from your most recent or current treatment? [Derived]



Involvement in decision making - overall

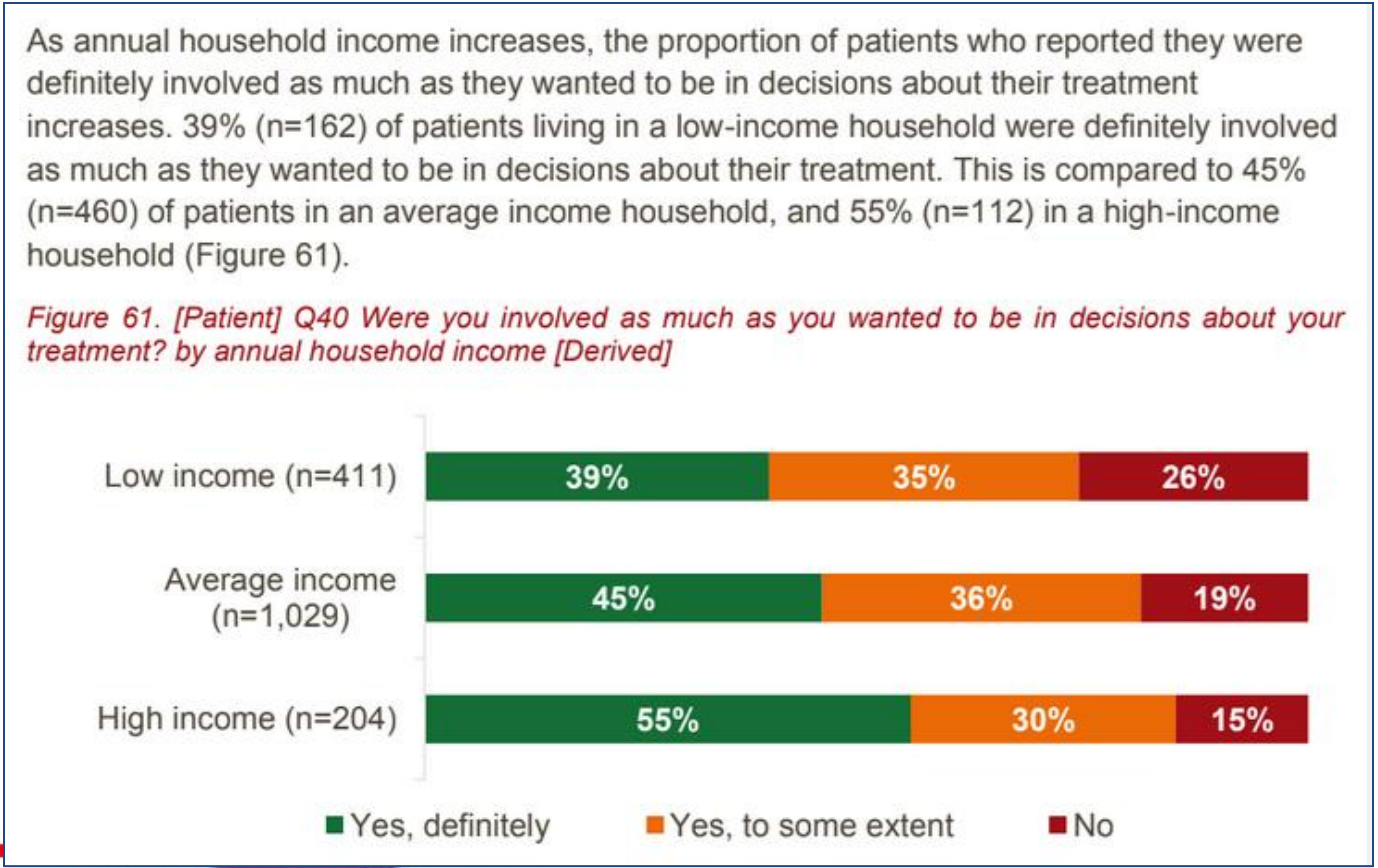


Involvement in decision-making

Half of CLL patients (52%, n=228) reported they were definitely involved as much as they wanted to be in decisions about their treatment. This is compared to 46% (n=288) of patients with CML, 39% (n=128) with AML and 36% (n=89) with ALL (Figure 57).

Figure 57. [Patient] Q40 Were you involved as much as you wanted to be in decisions about your treatment? [Derived]

Involvement in decisions (according to income level)



As annual household income increases, the proportion of patients who reported they were definitely involved as much as they wanted to be in decisions about their treatment increases. 39% (n=162) of patients living in a low-income household were definitely involved as much as they wanted to be in decisions about their treatment. This is compared to 45% (n=460) of patients in an average income household, and 55% (n=112) in a high-income household (Figure 61).

Figure 61. [Patient] Q40 Were you involved as much as you wanted to be in decisions about your treatment? by annual household income [Derived]

Barriers to treatment

No specialist nearby. Reason for start of remote 2nd opinions

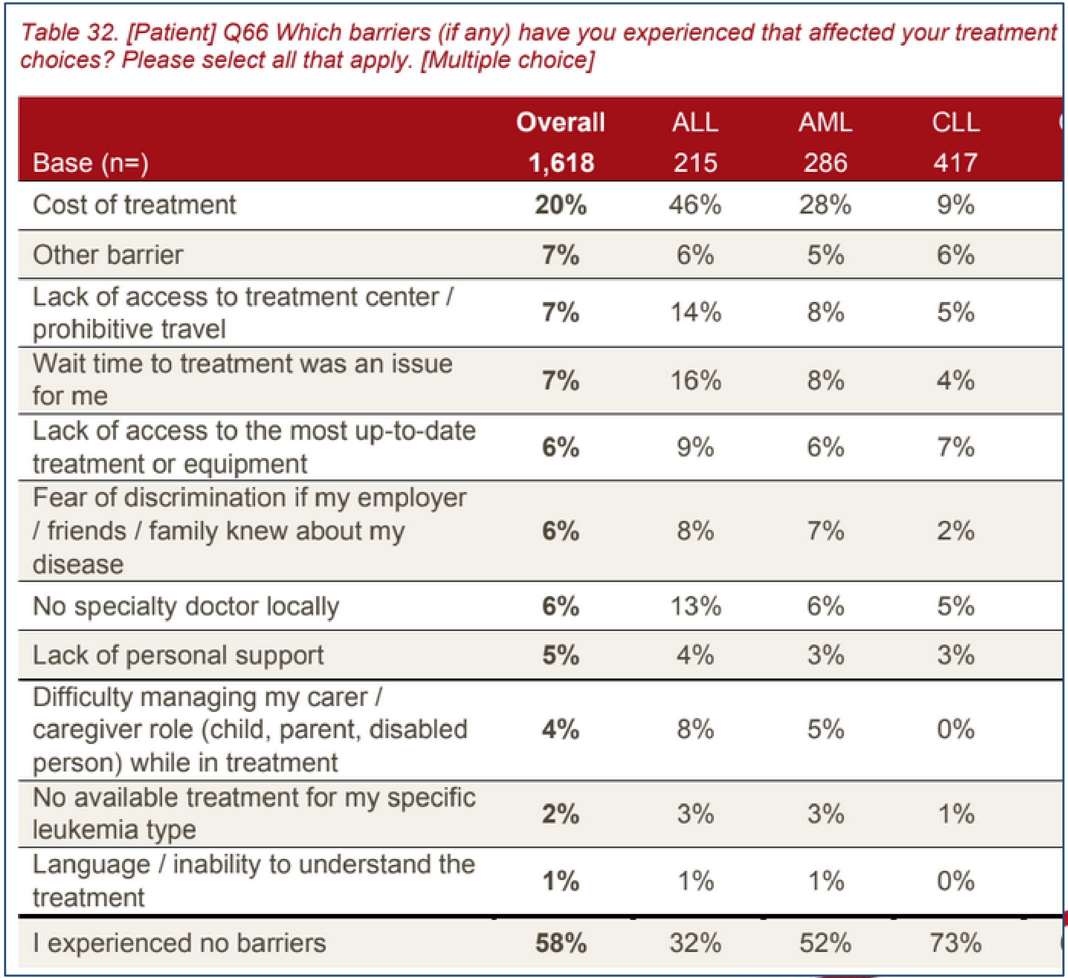
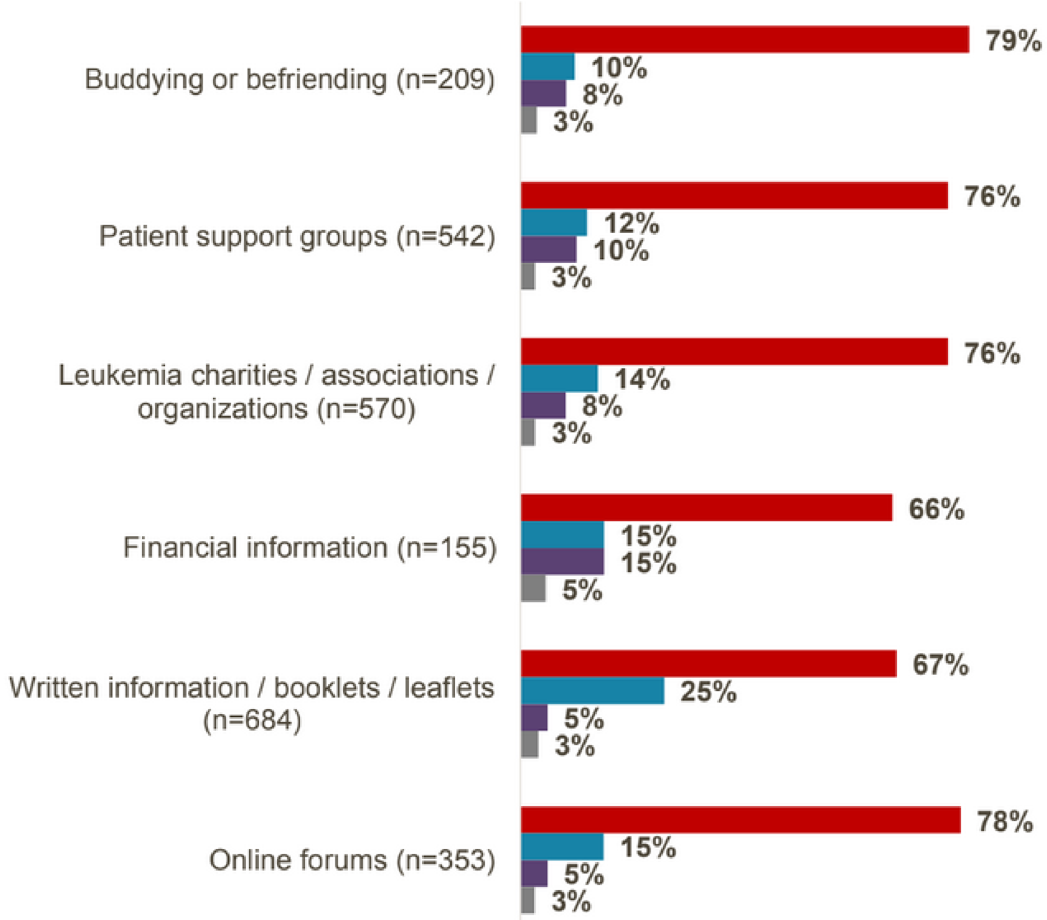


Table 32. [Patient] Q66 Which barriers (if any) have you experienced that affected your treatment choices? Please select all that apply. [Multiple choice]

Base (n=)	**Overall** **1,618**	ALL 215	AML 286	CLL 417
Cost of treatment	**20%**	46%	28%	9%
Other barrier	**7%**	6%	5%	6%
Lack of access to treatment center / prohibitive travel	**7%**	14%	8%	5%
Wait time to treatment was an issue for me	**7%**	16%	8%	4%
Lack of access to the most up-to-date treatment or equipment	**6%**	9%	6%	7%
Fear of discrimination if my employer / friends / family knew about my disease	**6%**	8%	7%	2%
No specialty doctor locally	**6%**	13%	6%	5%
Lack of personal support	**5%**	4%	3%	3%
Difficulty managing my carer / caregiver role (child, parent, disabled person) while in treatment	**4%**	8%	5%	0%
No available treatment for my specific leukemia type	**2%**	3%	3%	1%
Language / inability to understand the treatment	**1%**	1%	1%	0%
I experienced no barriers	**58%**	32%	52%	73%

Access to support and usefulness

Figure 133. [Patient] Q80 Did you access this support and did it help you? - Part B



Patients seeking more information

ALAN study
Only 43% of patients were given completely clear information about any **side effects from their most recent or current treatment.**

However, 18% of patients and 19% of carers said they always have to ask for the results to be explained.

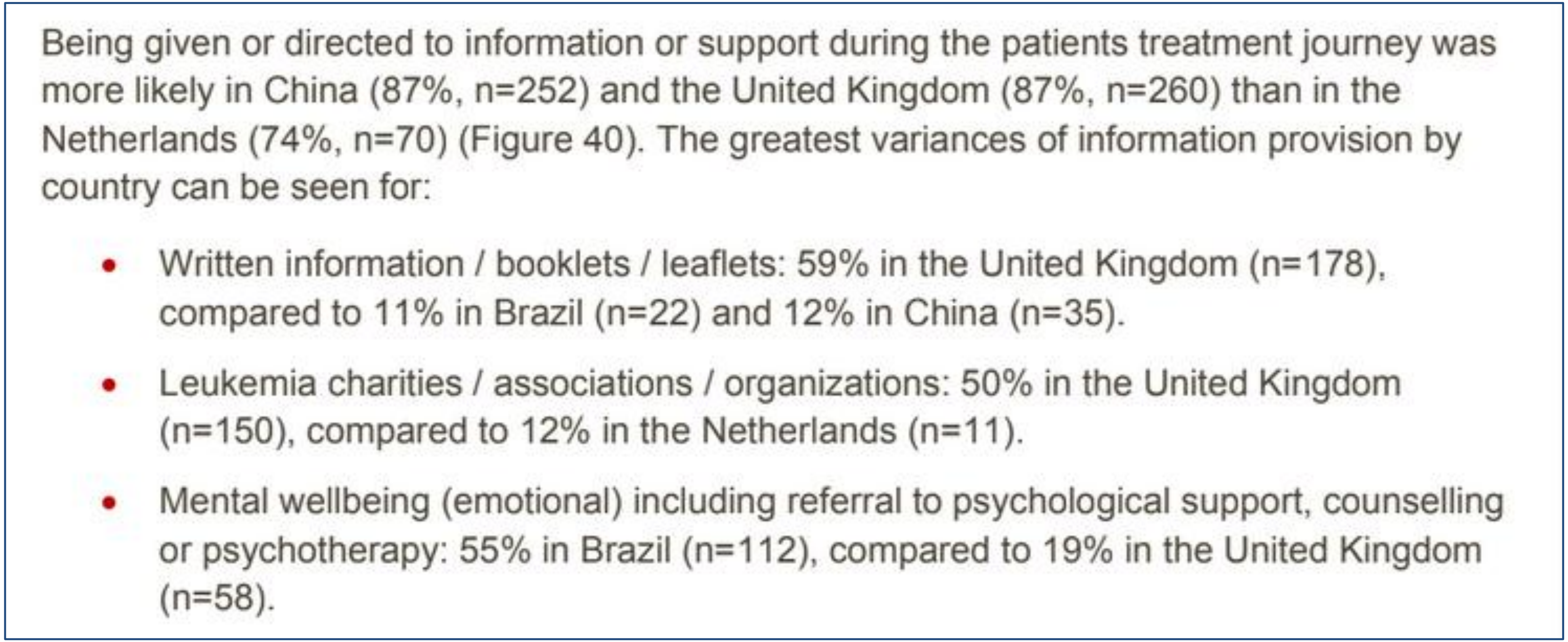
Information and support

82% of patients were given or directed to information or support during their treatment journey.

The most common resources patients were given or directed to were side effects and risks of treatment (39%) written information / booklets / leaflets (36% leukemia charities / associations / organizations (30%), mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy (29%), and patient support groups (29%)

Patients reported that the following types of information and support helped them feel better or more positive: **buddying or befriending (79%**), online forums (78%), patient support groups (76%) and leukemia charities / associations / organizations (76%).
The majority of patients (91%,) and carers (90%) conducted their own research into varying stages of the patient journey. Patients and carers researched the same top three topics: diagnosis (75% of patients, 74% of carers, treatments available (70% of patients); 73% of carers, and side effects (68% of patients; 70% of carers)

Directed to support organisations



Being given or directed to information or support during the patients treatment journey was more likely in China (87%, n=252) and the United Kingdom (87%, n=260) than in the Netherlands (74%, n=70) (Figure 40). The greatest variances of information provision by country can be seen for:

- Written information / booklets / leaflets: 59% in the United Kingdom (n=178), compared to 11% in Brazil (n=22) and 12% in China (n=35).
- Leukemia charities / associations / organizations: 50% in the United Kingdom (n=150), compared to 12% in the Netherlands (n=11).
- Mental wellbeing (emotional) including referral to psychological support, counselling or psychotherapy: 55% in Brazil (n=112), compared to 19% in the United Kingdom (n=58).

Directing patients to information and support resources:

The resources that patients rated as most helpful were not the most commonly cited resources patients were directed to.

Healthcare professionals and advocacy groups should work towards greater facilitation and access to buddying or befriending, online forums, patient support groups and leukemia charities / associations / organizations.

Why additional support is necessary:

Address variance in experience.

There are clear variances in experience by leukemia type, age, gender, country, annual household income and level of education.

RECOMMENDATIONS

Information and explanations:

‘…patients and carers are not receiving adequate levels of information and explanations at key points in the patient’s journey (during diagnosis, information on subtype or mutation, results of test(s), clear information about side effects of treatment…)’

Healthcare professionals must improve how they communicate with patients and carers (vital information at key stages + opportunity to ask questions and receive answers to these questions at each stage to aid understanding.

Signposting patients and carers to patient organizations groups for further support and information should become part of the consultation process.

Involvement in decision-making:

People have a right to be involved in and to make decisions about their health and care. Healthcare professionals must work with patients and their carers in partnership to involve them in decision-making throughout their journey. As part of this process, healthcare professionals must ensure patients are well informed and that their personal preferences are respected.

HOW COUNTRY SPECIFIC DATA FROM A GLOBAL SURVEY WERE USED IN ADVOCACY WORK

Jana Pelouchová

Leukemia Patient Advocates Foundation

Diagnoza leukemie, z.s.

Acute Leukemia Summit 2025, Madrid

Pilot project (one of few opportunities for a robust patient survey in Czech language)

Dissemination via personal emails to members and contact of patients, website, public facebook group of patient organisation, various closed FB patient discussion groups)

interesting data grouped into 1/ global results versus 2/ country specific results

OUTCOMES:

- approx. 90 respondents (from 350 members + number of patients' contacts from non-member database)
- clear challenges in answering disease-specific questions
- clear lack of practice in responding patient surveys
- few respondents from Slovakia (in spite of language similarity and patient engagement)

WORKING WITH THE DATA:

- publishing on social media with regards to Blood cancer awareness days
- presenting at Press Conference connected to Blood cancer awareness month + WCLL Day
- presenting on patient conferences (3 per year) and seminars (2 per year)
- underpinning our demands in negotiations of Patient Council at the Health Insurance Agency


NOVINKY Z ČINNOSTI SPOLKU NA DOMÁCÍM I ZAHRANIČNÍM POLI
Jana Pelouchová
diagnóza leukemie


diagnóza
leukemie
Nezůstávejte sa
se svou nemo


1. září
Světový den CLL 2025
Porozumět, rozhodovat se, prospívat!
Povědomí o onemocnění CLL
Zdravotní gramotnost
Spolurozhodování o léčbě
diagnóza
leukemie
- akutní a chronické leukemie
myelodysplastický syndrom

THANK YOU FOR YOUR ATTENTION

www.diagnoza-leukemie.cz

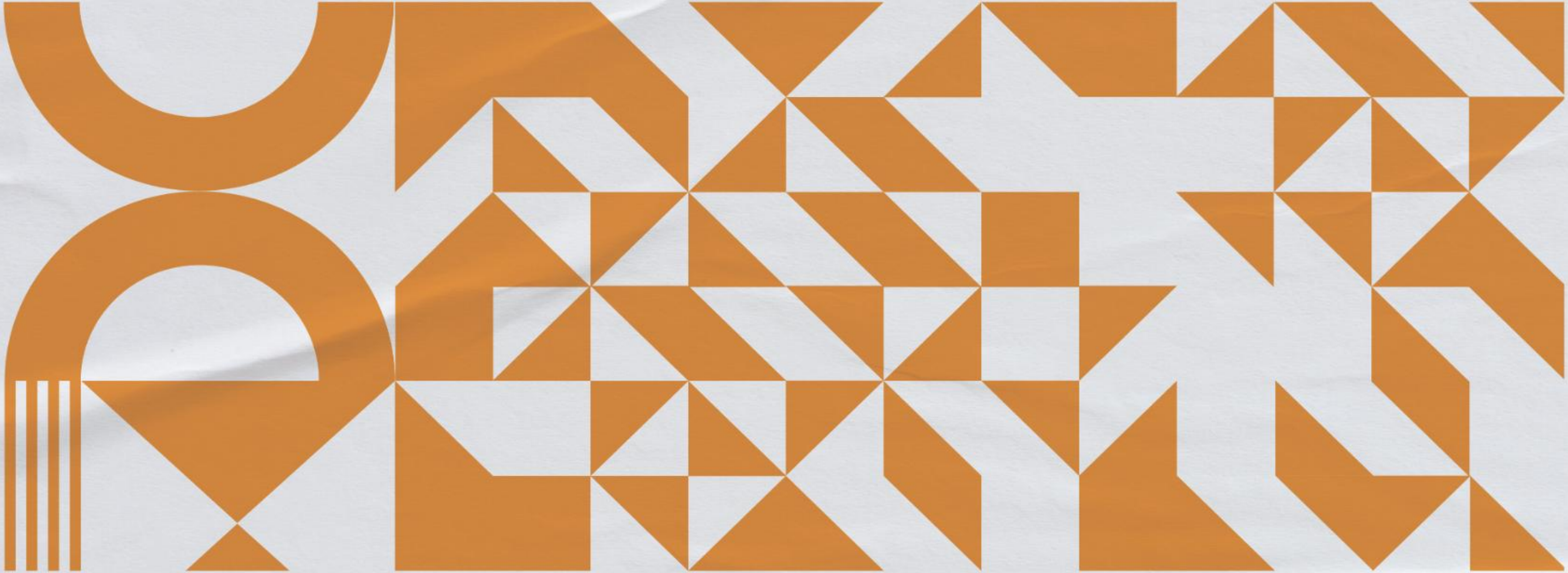
www.facebook.com/diagnoza.leukemie

jana.pelouchova@diagnozaleukemie.cz

Turning Insights into Action
THINK TANK

7 November **2025**

CAMPAIGNING
FOR CANCER



CAMPAIGNING
FOR CANCER

What we do

Vision

A South Africa into a place where people affected by cancer can expect fair, appropriate and respectful treatment and care.

Mission

Protect patients' rights by:

Ensuring dialogues amongst role-players, e.g. the government, health insurances, doctors and patients

Facilitating solutions regarding cancer prevention and treatment, e.g. regarding access to treatment denial for patients, or making sure that the government has a plan for how to deal with cancer

Representing patients, and those affected, about policy, healthcare costs and delivery

Informing South Africans about cancer and their rights as patients.

CAMPAIGNING
FOR CANCER

Dialogue & solutions

Stakeholder think tanks

To address access to treatment and care for South African patients with Leukaemia. Stakeholders from various sectors attended the multi-disciplinary events to discuss how health professionals and patient groups can collaborate to improve cancer and ensure that existing plans reach patients effectively.

Step 1: Identification of issues to be addressed in the meeting.
Step 2: Identification of stakeholders and role-players as well as subject matter experts in relation to the particular issue.
Step 3: Facilitated dialogue to explore innovative sustainability solutions for leukemia cancer multistakeholder engagement.
Step 4: Development of a report and establishment of distribution method.
Step 5: Communicating information and potential actions to role-players.

Leukemia

Education and Awareness	Advocacy and Testimonies	Research and Data Collection	Healthcare Access	Collaboration
• Evaluate how language is perceived. • Make sure education messaging is relevant to people we are talking to. • Back to basics – apply learnings from TB and HIV to educate patients in South Africa. • Use positive language to raise awareness. Example, educate around stigmas that exist ie. Palliative care • Provide Agency – give patients words to advocate for themselves • Native language – educational material development • Dedicated education at the Primary Healthcare level	• Create a Leukaemia network • Highlighting patient testimonies in the media (media include blogs, social media, digital media channels, print media, local media, radio, churches and religious groups, local community forums) • Train patients to be impactful spokespeople – C4C training, empower patients to use stories for good • Integrate leukaemia testing into other disease areas • Define referral pathways for adolescents • Target traditional healers in simple language with advocacy efforts • Conventional medicine and traditional healers – identify roles of groups to educate and empower without alienating • Door-to-door outreach programme to raise awareness for stem cell donations • Reach out to pharmacies as a channel for communication (Identify overlooked channels – like schools and local clinics)	• Enablers and barriers for patients • Mapping exercise to see where exactly Leukaemia is treated in SA • Identify evidence we need to develop to advocate from data that exist within multi-disciplinary groups • State hospital need: Data capturers and statisticians to improve access to data – ISPOR opportunity? • Looking at research resources – ISPOR and C4C	• Set up guidelines for alternative treatment plans and screening • Stem cell transplant should not be capped at 65 – patients should be evaluated • Ensure guidelines align with Essential Drug Lists • Blood transfusions – incentive-based blood • Educate decision makers on the impact of time wasted • Cost: how to get medicine to patients cheaper? Looking at alternate reimbursement models to improve access. Alternate reimbursement is a tool to promote equity.	• Create links to collaborate • Share resources to grow networks – collaborate through networking • Data collaboration - good quality data to be shared • Small group presentations on specified topics (expert presentations online to share information between multi-stakeholder groups) • Patient navigators are key to facilitate collaboration • Review findings from the sessions and have a work session to decide how it can be applied to stakeholders to ensure dedicated collaboration in the right areas. • Create a framework to enable stakeholders to contribute in areas where they have experience. • Treatment presentations to raise awareness

CAMPAIGNING FOR CANCER

Inform & Dialogue

National anti-stigma campaign

Turning cancer from an unpredictable struggle into a guided journey where patients, families and supporters know what to expect, what to do and how to open themselves up to support..

Emotional support

Inside the journey of an AML survivor

Claudia Poguntke
ALAN Summit Madrid, Nov 2025

My life as an AML Patient in Numbers

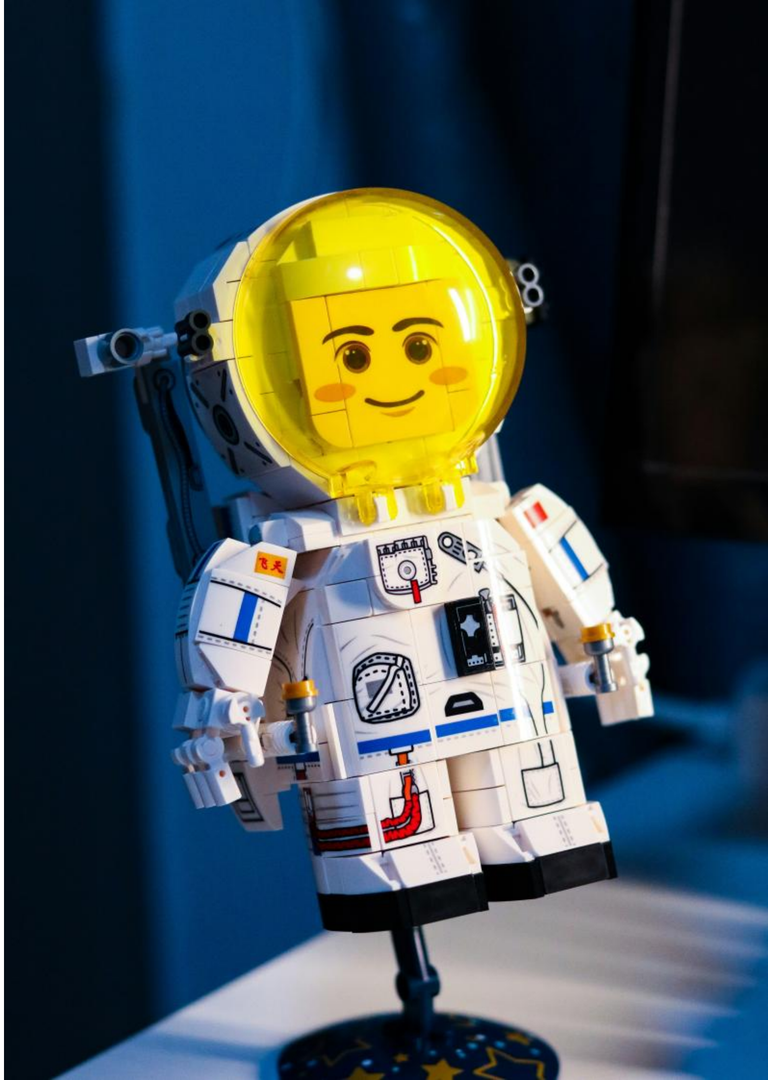
465	days I spent in hospital
152	days I spent at home in isolation
407	my disability pension entitlement in Euros
31	medication load per day after my stem cell transplant
7,5	hours I spent in a hospital's waiting area for my appointment
45	minutes I spent waiting on a toilet chair before receiving assistance from the oncology nurse

The New Normal

- Loss of identity
- Body image crisis
- Loss of independence and control
- Isolation, deprivation and loneliness
- Loss of future perspective
- Fear of relapse
- Reintegration struggle
- Survivors guilt

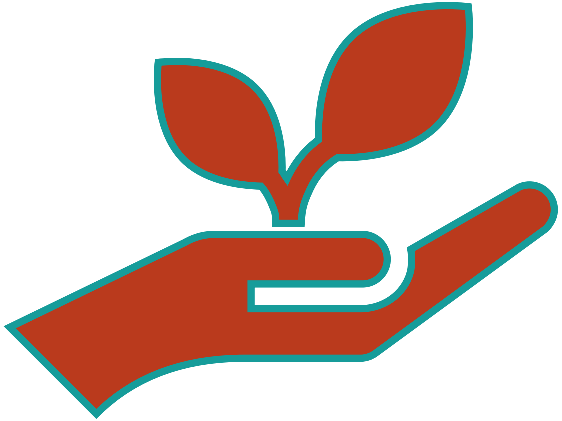
Emotional distress and depression are well documented long term side effects in AML

- Kuba K, Esser P, Mehnert A, Hinz A, Johansen C, Lordick F, Götze H. Risk for depression and anxiety in long-term survivors of hematologic cancer. Health Psychol. 2019 Mar;38(3):187-195. doi: 10.1037/hea0000713. PMID: 30762398
- Stefanski KJ, Anixt JS, Goodman P, Bowers K, Leisenring W, Scott Baker K, Burns K, Howell R, Davies S, Robison LL, Armstrong GT, Krull KR, Recklitis C. Long-Term Neurocognitive and Psychosocial Outcomes After Acute Myeloid Leukemia: A Childhood Cancer Survivor Study Report. J Natl Cancer Inst. 2021 Apr 6;113(4):481-495. doi: 10.1093/jnci/djaa102. PMID: 32797189; PMCID: PMC8023820.



A Global Wake-Up Call:
Emotional Needs in Acute Leukemia are widely unmet

Major Findings from the ALAN Global QoL Survey (2023)



- **Psychosocial unmet needs are widespread**
  Patients across regions report significant emotional strain, fear, uncertainty, and mental-health challenges throughout the leukemia journey.
- **Information and support gaps persist**
  Many patients feel they lack clear, timely, and understandable information – creating anxiety, confusion, and reduced empowerment.
- **Emotional and mental-health impact is among the top patient-reported issues**
  Emotional distress ranks alongside physical symptoms as one of the most burdensome aspects of living with acute leukemia.
- **Needs are universal**
  Across countries, ages, and leukemia subtypes, patients consistently highlight similar emotional, informational, and support unmet needs.

Shaping Stars:
The Power of Emotional Literacy

Ability to notice, name, understand, and express emotions.

Universally applicable – every patient, caregiver, clinician benefits.

Core to emotion regulation and communication.

Like health literacy, emotional literacy is a skillset essential for navigating care.

Builds resilience and shared understanding in care networks.

Enables earlier help seeking and better symptom reporting

Call to Action

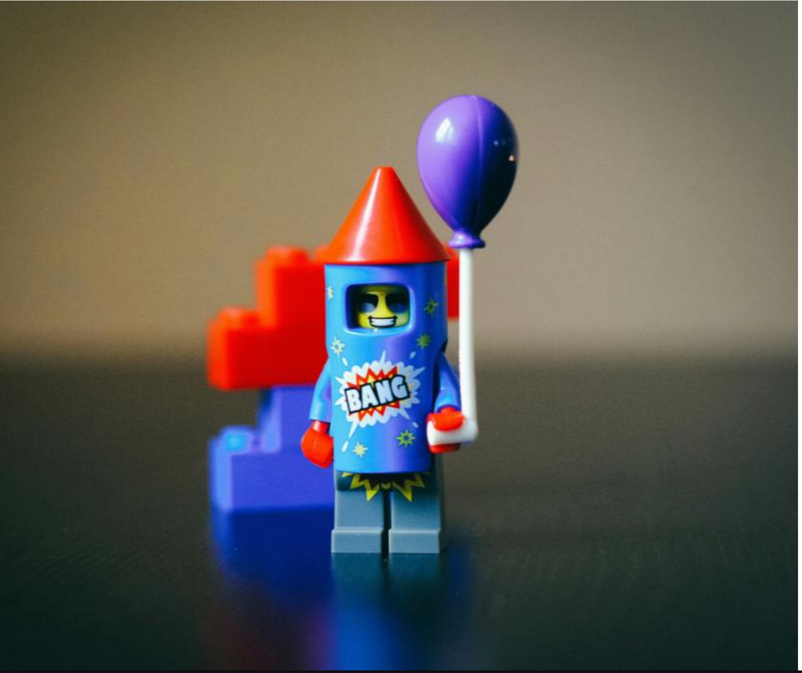
- **Emotional literacy and psychosocial care** to be integrated into every stage of leukemia treatment.
- Build **standardised psychosocial support pathways** in all cancer centres.
- Provide **tailored, accessible emotional-literacy resources** for patients and families.
- **Empower clinicians** with tools to identify emotional distress early.
- Use ALAN’s global evidence to push for **policy change and resource allocation**.

Professional Guidance

- **Psychooncological therapy**
- **Digital support**
  - cancer companionship apps
  - digital mindfulness
  - psychoeducational programs

Patient Experience Driven Support

- peer mentoring
- social & emotional support through cancer community networks



Creative Writing as Patient Empowerment

"As an AML survivor, patient advocate, and researcher in biographical and creative writing, I have experienced firsthand how storytelling and reflective writing can strengthen resilience, agency, and emotional coping during cancer.

My personal and professional journey—shaped by many years of lived experience, training as a yoga instructor and systemic coach in integrative oncology, patient advocacy, and digital health innovation—culminated in a Master's degree in Creative Writing with Cancer Patients, where I explored the transformative potential of writing as a tool for emotional coping and empowerment." Claudia Poguntke, ALAN Summit Madrid 2025

- Creative writing strengthens **emotional literacy, empowerment, and self-efficacy** by helping patients process emotions and regain control.
- Online writing groups maintain **social connection and engagement** when in-person support is limited.
- Integrating writing with **psycho-oncological principles** promotes resilience and activates inner resources.
- Writing fosters **meaning-making, reflection, and self-determination**, enhancing quality of life.

Six Seconds Self Assessment

How do YOU cope with emotions in the AML arena?

- as a patient
- as a caregiver (family / friends)
- as a member of medical staff
- as a patient advocate

When emotions become overwhelming, do you wish to release them physically?

Do you play dead...

or cool?

Do you want to run away?

Or do you show strength by seeking support?

Don't let your Vulcan half take over, work on your emotional literacy!

ALAN
Acute Leukemia Advocates Network

Group 1
Charles
Hasmik
Chul-hwan
So Waah
Rita
Beyza

Group 2
Elo
Marija
Dick
Kairi
Zack

Group 3
Anne-Pierre
Geun-hwa
Rosie
Andy
Elba

Group 4
Marine
Carolina
Silvia
Chris
Laura

Group 5
Jan
Yolima
Stacey
Sindy
Esther

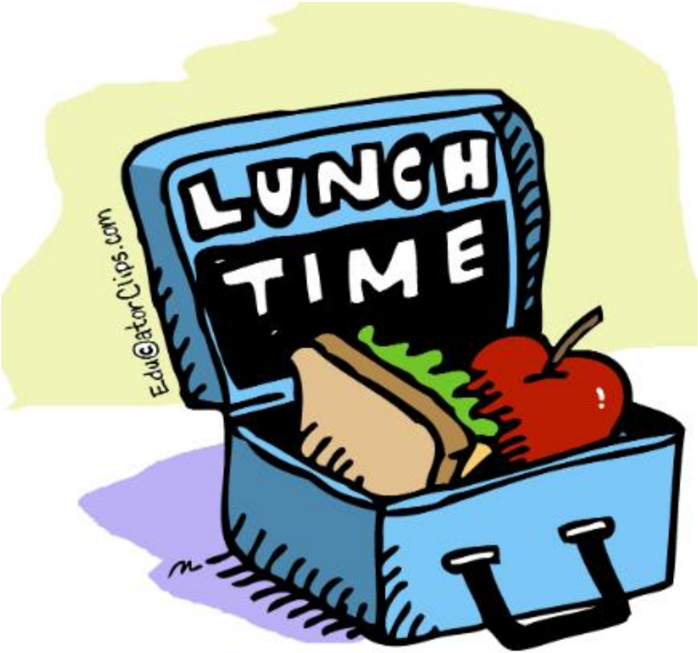
Group 6
Giovanni
Moses
Ashleigh
Ajda
Hamda
Kristina

Go around the tables
7 min per table

ALAN
Acute Leukemia Advocates Network

GROUP PHOTO

#ALANsummit



LUNCH – BE BACK AT 1.30 PM!