



**ALAN**

Acute Leukemia Advocates Network

**GLOBAL SUMMIT  
7<sup>TH</sup> – 9<sup>TH</sup> NOVEMBER 2025**

[www.acuteleuk.org](http://www.acuteleuk.org)



**MOVING INTO ACTION**

# TODAYS'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)**



## **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

# FROM DATA COLLECTION TO ADVOCACY



# Evidence-Based Advocacy: Moving from Data Collection to Advocacy

**ALAN Summit, 8 Nov 2025, Madrid**

**Jan Geissler**

**Co-founder, CML Advocates Network**

**Co-founder and Chair, Acute Leukemia Advocates Network**

**Past chair, WECAN (the Network of European Cancer Patient Advocacy Organisations)**

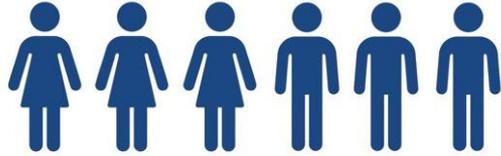
**CEO, Patvocates & European Patient Advocacy Institute**

# What I am going to cover in this session

- 1. Evidence-based advocacy**
  - principles
- 2. Types of evidence we can generate as advocates**
  - plus examples
- 3. Using and publishing our evidence**



# How can we make everyone understand patient reality?

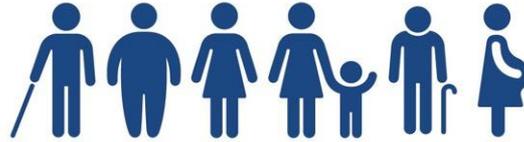


## Clinical Trial data

Evidence on clinical outcomes and other patient-relevant outcomes in a **well controlled setting – limited external validity**



**Clinical reality**



## Real-World Data

Evidence on **broader and more diverse populations with longer follow-up period**, incl. e.g. electronic health records, registries, mobile devices, sensors



**Patient reality**



## Patient Experience Data

Captures **patients' experiences, needs, and relative importance**, e.g. quality of life, ability to perform daily activities, patient preferences



# The fallacy of assumptions - what can researchers and institutions learn from the patient community?

**“Aren’t we all patients some day, so, I know well what patients need?”**

**No!** One needs to have gone through a life-changing experience to know what lack of health means

Patient community has unique insights into:

What is the burden of standard of care?	What is the meaningful benefit to patients?	What outcomes are important?
Are the risks worth the benefits?	Who will benefit most from a specific treatment?	What do changes in endpoints mean for patients?
How does taking the drug impact daily routine?	Are there particular needs for sub-populations?	What impact does a change in clinical practice have on patients?

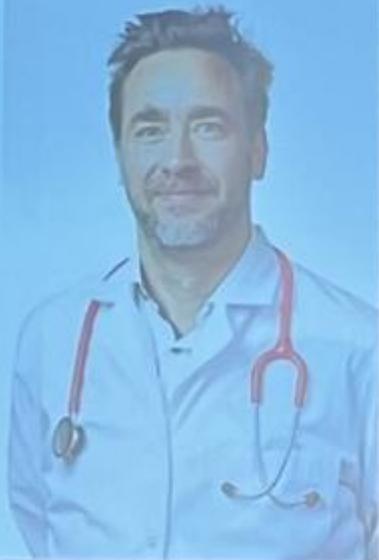
**WHAT IS THE PATIENT VALUE OF AN INTERVENTION?**

Is „patient knows best“ any better than „doctor knows best“? Base it on data!



WHY USE EVIDENCE? CREDIBILITY

'Doc Jan' is far  
more credible  
than 'Patient Jan'



WECAN  
Academy 2023



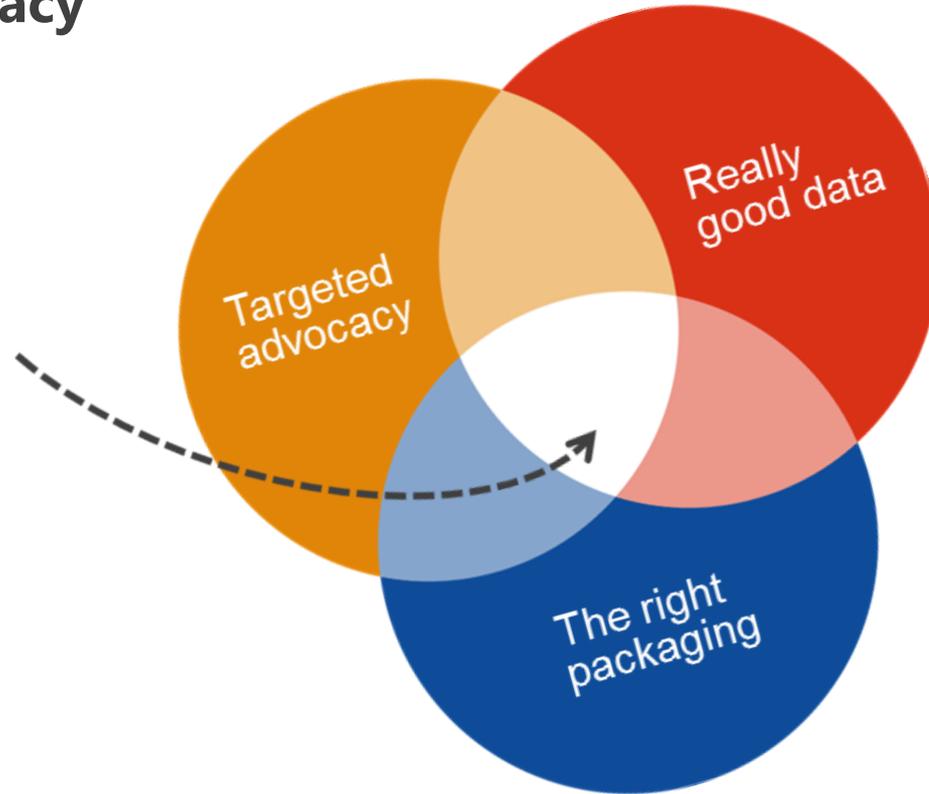
# Barking up the wrong tree: Think about who you'd like to influence

- EU level vs. national level (e.g. EMA, HTA/reimbursement)
- Medical societies vs. study groups vs. individual clinicians
- Companies (→ drugs) vs. industry associations (→ systems)
- Disease-specific action (→ acute leukemias, myeloma, lung cancer, ...) vs. cross-disease joint action (→ healthcare system)
- Know what you can do, and what your umbrella organisations can do best, within the limits we all have



# Evidence-based advocacy

Advocating in a targeted, evidence-based, well-educated and professional manner, and measure impact and outcomes of what we do



# How does evidence influence decision-making for different stakeholders?



## FUNDRAISING

Evidence supports fundraising by showcasing unmet needs, disease impact, and the importance of carrying out the study.

Types of PED: *QoL surveys, PROs, patient diary data, severity of the condition, unmet need, patient perspective on standard of care etc.*



## BASIC RESEARCH

Data ensures research questions are in alignment with the most relevant patient needs and issues.

Types of PED: *symptom diaries, benefit-risk acceptability, survey on unmet needs, treatment burden etc.*



## CLINICAL TRIALS

PED in clinical trials aligns therapy development with patient needs and preferences, as well as informing trial design and improving recruitment and retention.

Types of PED: *Patient preferences, PROs, adherence survey, QoL input etc.*



## POLICY

Patient evidence drives policy development and reform by highlighting real-world impacts of existing policies and identifying areas for improvement, ensuring policies are patient-centered and beneficial for the community.

Types of PED: *RWE, population-level surveys, health outcome assessments etc.*



## REGULATORY SETTING

Regulatory bodies increasingly use PED to make decisions reflecting patient perspectives, providing context on condition impact and treatment value in the real world.

Types of PED: *PROs, PREMs, Patient preferences, surveys highlighting patient perspective, patient value dossier etc.*



## POST-MARKETING & MEDICAL PRACTICE

In post-marketing monitoring and clinical practice, PED helps to monitor real world uptake, implementation barriers, effectiveness and safety of an intervention.

Types of PED: *RWE, PROs, PPS, patient satisfaction survey, QoL survey, adherence survey, PREMs, patient value, ADR reporting etc.*



## ADVOCACY

Evidence enables POs to advocate for healthcare changes, shape services, support programs, and allocate resources by highlighting specific needs and gaps.

Types of PED: *PROs, PPS, PREMs, surveys highlighting patient perspective, aggregated patient reports / testimonials etc.*



Patvocates

PATIENT ENGAGEMENT IS IN OUR DNA

# Generating evidence in patient advocacy

# Types of community-generated evidence - and some examples

## Disease mapping

- Patient experience
- Quality of life
- Burden of disease
- Unmet patient needs
- Adherence

## Patient preferences

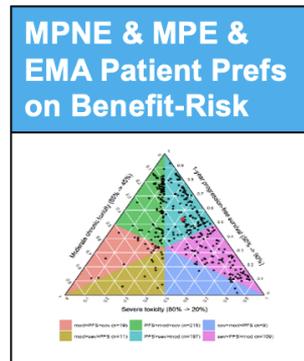
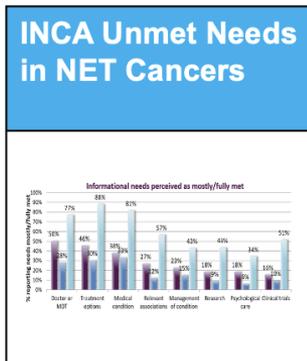
## Inequality mapping

- Worst outcomes
- Lowest access to diagnostics or treatment
- Vulnerable groups

# Types of community-generated evidence - and some examples

## Disease mapping

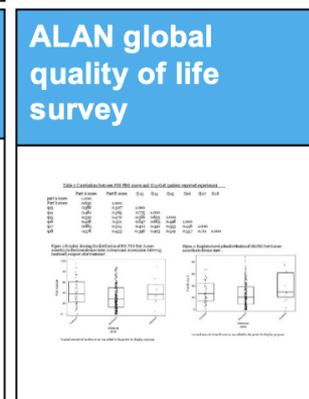
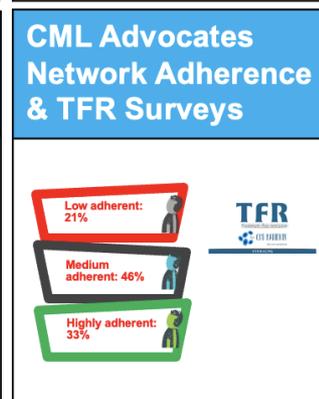
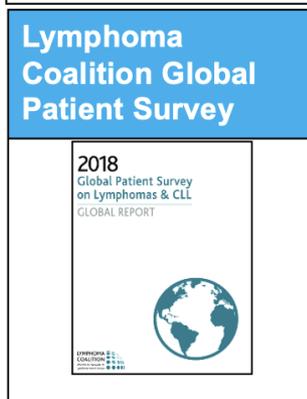
- Patient experience
- Quality of life
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- Adherence



## Patient preferences

## Inequality mapping

- Worst outcomes
- Lowest access to diagnostics or treatment
- Vulnerable groups



# Examples for evidence generation & use in patient advocacy

1. Disease mapping  
incl. patient preferences
2. Inequalities
3. Health policy

# Types of research & data: Example Patient Experience Data



## Patient Experience Data (PED):

Data directly collected from patients with no interpretation from HCPs, covering **outcomes, experiences** and **preferences**



Condition



Treatment



Care

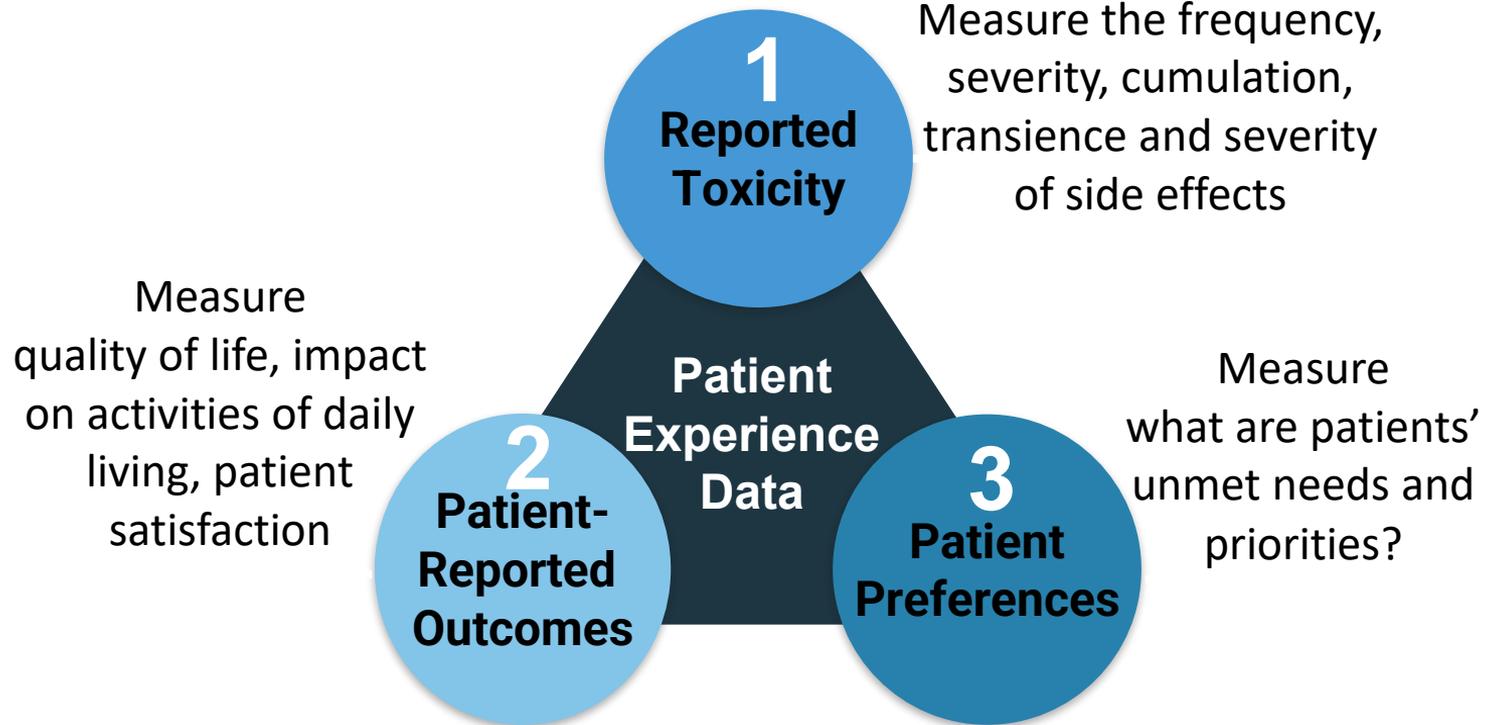
**Quantitative**

“What is happening”

**Qualitative**

“Why or how something is happening”

# The essential triangle on Patient Experience Data: Side effects, impact on daily life, and what patients prefer

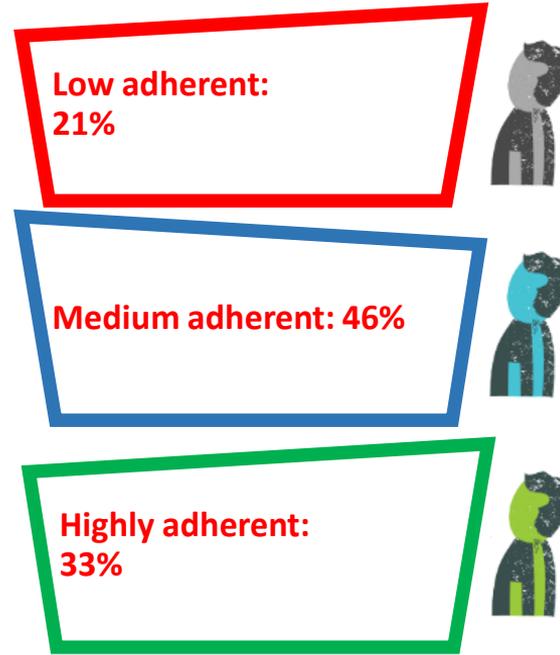
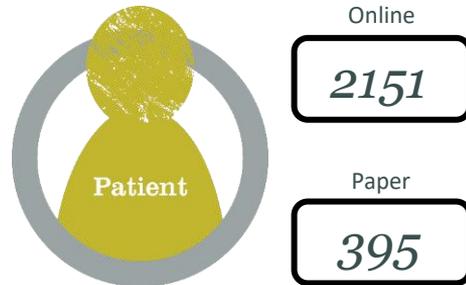




# Deploying evidence in advocacy on science and care: CML Advocates Network survey on adherence

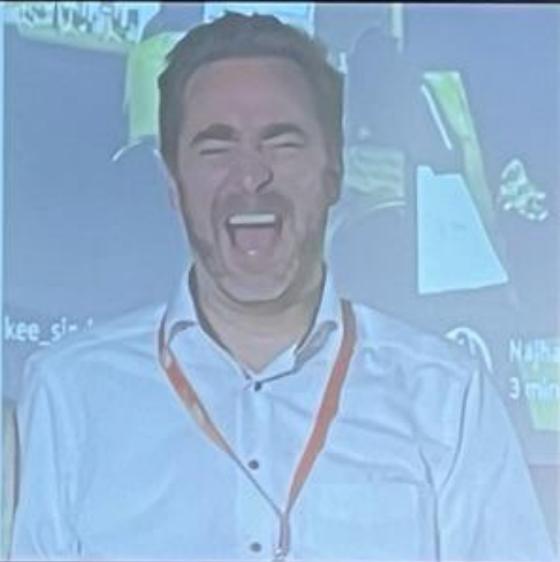
## Patient-led adherence research in CML:

- 12 languages, 2546 patients from 63 countries recruited in 3 months
- Use of validated adherence instrument
- Changes in dialogue between patients and clinicians
- Changes in treatment paradigm



OR **WE CAN** BE  
HAPPY IF WE  
LEARN FROM  
THE MISTAKES  
OF OTHERS

 WECAN  
Academy 2023



# CML Advocates Network Adherence Survey: Learnings

## What we did well

- **Ran a pilot** to test our hypothesis and survey design
- **Used a professional market research agency**
- **Used a validated instrument** for adherence measurement
- **Used our global network** of patient organisations to recruit 2546 CML patients
- **Cooperated with 4 clinical networks** for offline recruitment

## Where we should have been more strategic

- **No biostatistician involved**
- **Pre-publication pitfall:** Discrepancy between interim analysis data presented at conferences, and “proper analysis” for journal article: Rejection by journal
- **No publication strategy:** no professional writer from the start, too much time lost for high-impact journal: 3 years to get the data published
- **PRO legal license issues**
- **Less qualitative data** – hard to analyse
- **No resources for follow-up, so what?**

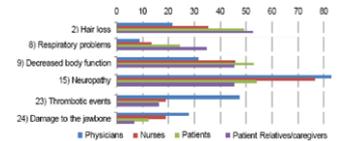
# Examples for evidence generation & use in patient advocacy

1. Disease mapping  
incl. patient preferences
2. Inequalities
3. Health policy

## Generating data on inequalities

- Evolution of disease mapping into the more complicated ‘inequality mapping’ – looking for subgroups with differences (e.g. worst outcomes, lowest access)
- Examples
  - Worst outcomes
  - Lowest access to diagnostics or treatment
  - Vulnerable groups

### Myeloma EuroNet Survey of side effects to patients/docs/nurses



### Myeloma Patients Europe's Access Atlas



### WECAN EuroACT

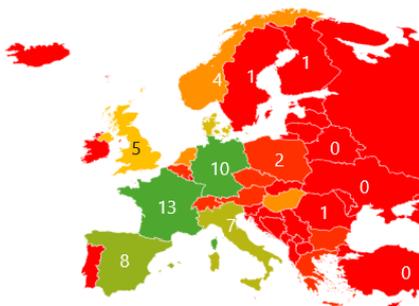


# Example: Inequalities in accessing clinical trials across Europe



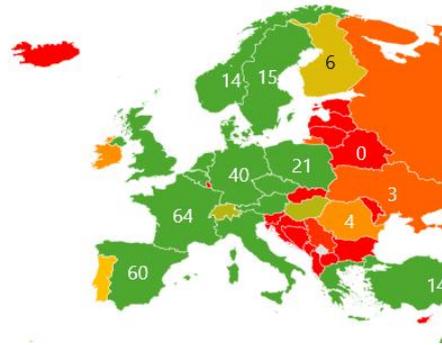
## Completed trials across Europe in Myeloma over the last 5 years

(EuroACT, myeloma)



## Currently recruiting trials across Europe in Myeloma

(MPE Trial Nav., myeloma)



## Completed trials in Cancer in the past 5 years

(EuroACT, cancers)

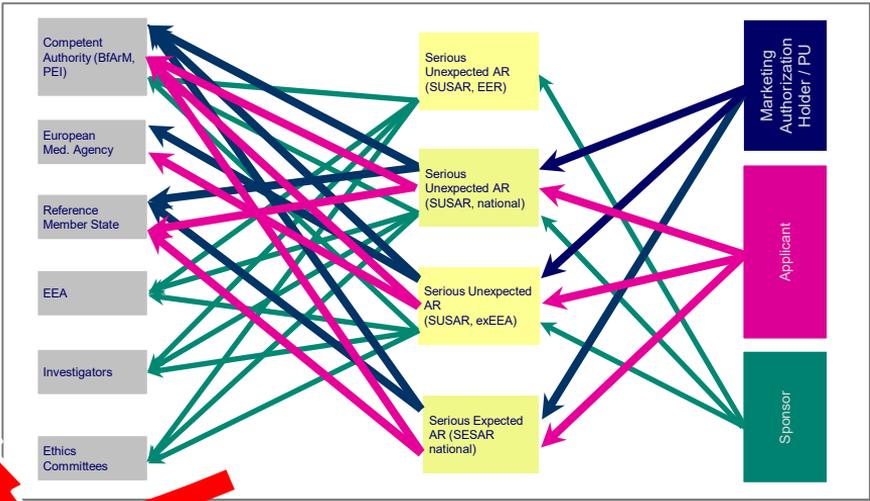
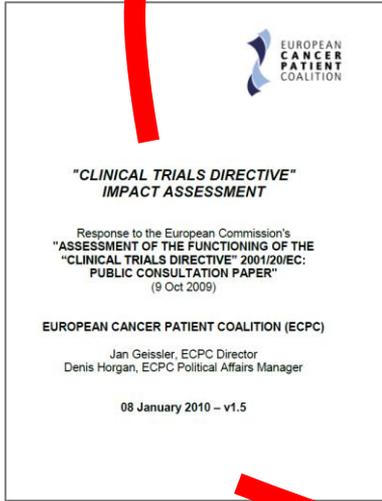


# Examples for evidence generation & use in patient advocacy

1. Disease mapping  
incl. patient preferences
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# Deploying evidence in policy advocacy: Revision of the EU Clinical Trials Directive

„[...] The German Hodgkin Study group was required to provide 100.000 copied pages of documents to Ethics reviews and authorities for a single study with 280 participating clinics and 65 ethics committees. Furthermore, the GMALL study group had to provide 35 folders and 12.000 pages for a study conducted in 13 centres. [...]”



Geißler, 2010

Obligatory reporting of unexpected adverse events, based on German implementation of EU Clinical Trials Directive 2001/20/EC in medicines law (§63b AMG) and GCP act (§13 GCP)

# Using evidence - and advocating effectively

# How to use evidence..

1. Listen to the evidence
2. Act on the evidence

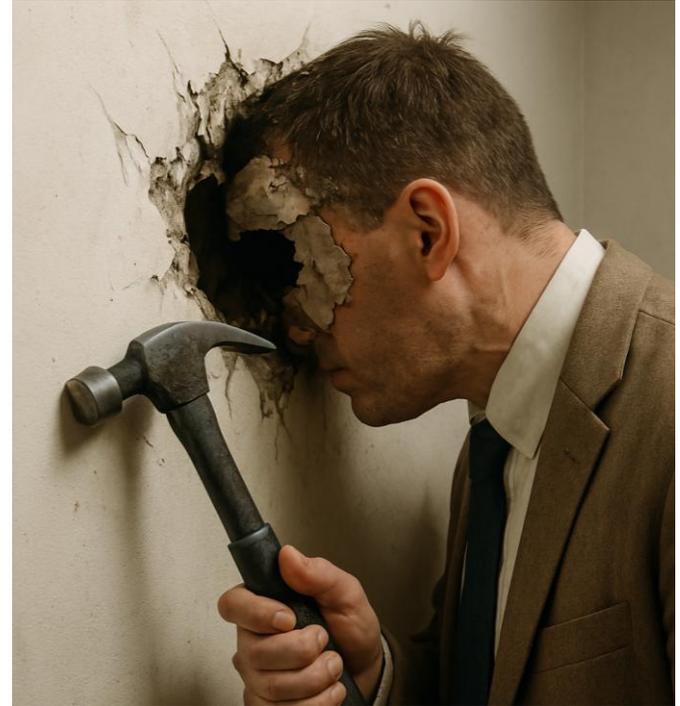
**DO NOT** use evidence just to back up your existing point of view



I see here that I'm right about everything.

# Negotiation tactics and building your case

- 1 • Define the outcome and if possible, a fallback position (alternative outcome)
- 2 • Consider the other party's position, possible resistance
- 3 • Be clear with your reasoning, the benefits, the risks
- 4 • Present evidence and proof to reassure
- 5 • Make your delivery compelling
- 6 • Explore barriers and resistance with empathy
- 7 • Represent your case, ask for commitment



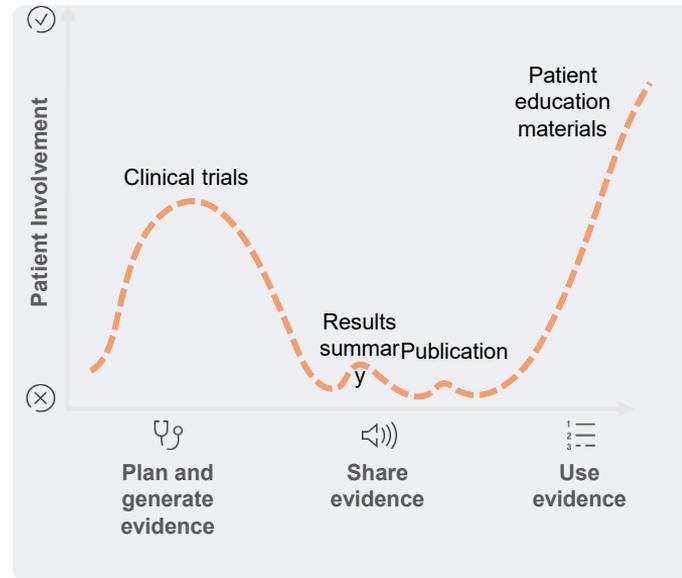
Source: Alison Dawkins, 360 Flexible Training Solutions @ ESO Masterclass (2018)

# Publish or Perish

Perceived Benefits versus Unintended Consequences



## Roles of patients (advocates) in publications



- We're advocates not academics, but for some stakeholders **'only published stuff counts'**
- However, when patient organisations conduct surveys, **results are often not published, so no one takes notice**
- Increasing demand on **patient involvement as co-authors** when researchers are publishing about trials or research

# WECAN training course on patient involvement in publications – 4 modules

After completing each module, patient advocates should be able to:



## Module 1

### Introduction

1. Assess the likelihood of publishing your research
2. Describe the key stages in the publication process
3. Identify the major guidelines that provide information on ethical publication practices
4. Describe the main responsibilities of being an author



## Module 2

### Publication planning

5. Explain what a Publication Steering Committee is
6. Recognise the value of preparing a publication plan
7. Estimate the time required to prepare a publication plan
8. Recall the main factors that should be considered when selecting a journal or a conference



## Module 3

### Publication writing

9. Identify the major guidelines that provide information on what should be reported in a publication
10. Describe the type of content that should be included in each section of a publication
11. Follow a logical sequence of steps to write a publication
12. Explain the difference between professional medical writing support and ghost-writing



## Module 4

### Submission, peer review, & beyond

13. Use a quick and free online artificial intelligence tool to help 'check' your publication
14. Prepare a suitable cover letter
15. Explain how to prepare a document to respond to peer-reviewers' comments
16. Propose practical ways to raise awareness of your published research (eg, plain language summaries of publications)

Digging deeper?  
Open-access trainings available to you



## Evidence-Based Advocacy **FUNDAMENTALS**

Access the course  
[academy.wecanadvocate.eu/course/eba-fundamentals](https://academy.wecanadvocate.eu/course/eba-fundamentals)

## Patients in **PUBLICATIONS**

Access the course  
[wecanadvocate.eu/patients-in-publications/](https://wecanadvocate.eu/patients-in-publications/)

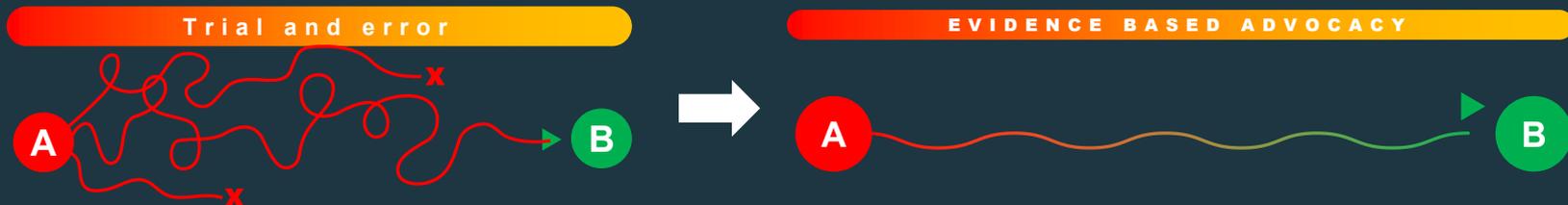


## **COMING SOON!**

PED Essentials  
A training resource for patient champions



Patvocates  
PATIENT ENGAGEMENT IS IN OUR DNA



**Underlining your opinion with data:  
Solid evidence often starts with a simple  
survey!**

Questions?

jan@patientadvocacy.eu

# TURNING INSIGHTS INTO ACCESS



ALAN

Acute Leukemia Advocates Network

## **NOW THAT WE HAVE THE DATA – HOW DO WE DRIVE CHANGE ? WHAT DO WE ADVOCATE FOR ?**

Leveraging the 5 As of Access for Acute Leukemia Care

Anne-Pierre Pickaert – November 9, 2025

[www.acuteleuk.org](http://www.acuteleuk.org)

# 16-year-old Dominica's story

Faced limited healthcare resources and political instability in Cameroon.

With no health insurance, her family struggled to afford treatment.

She relocated to the U.S. for treatment at Johns Hopkins — and survived.

Not every patient can seek cross-border care or move altogether!!

Her story highlights the **critical need for equitable access to leukemia care globally.**



<https://www.hopkinsmedicine.org/health/conditions-and-diseases/leukemia/acute-lymphocytic-leukemia/patient-story-dominica>

*How common do you think experiences like Dominica's are in your region?*



- *Very common*
- *Somewhat common*
- *Rare*
- *Very rare*
- *I don't know*



# ALL burden varies across regions

*What stands out to you about these regional differences?*

*Why do you think these disparities exist?*



Location (some examples)	Prevalence		Incidence		Death	
	Number	Age-standardised rate (ASR) per 10,000	Number	ASR per 10,000	Number	ASR per 10,000
<b>Central Asia</b>	2,117.8 (1,743.7–2,650.1)	2.2 (1.8–2.7)	839.7 (708.5–983.7)	0.9 (0.8–1)	686.3 (584.8–795.6)	0.7 (0.6–0.9)
<b>Western Europe</b>	43,555.5 (40,287.7–47,550.5)	16.7 (15.3–18.5)	6,869.7 (6,433.8–7,418.5)	2.2 (2.1–2.4)	2,568.5 (2,389.1–2,722.2)	0.4 (0.4–0.4)
<b>Central Sub-Saharan Africa</b>	1,151.9 (623.1–1,584.5)	0.8 (0.4–1.2)	745.4 (403.6–1,014.8)	0.6 (0.3–0.8)	45,74.6 (4,121.2–5,079.1)	1.8 (1.6–2)
<b>Southern Latin America</b>	2682.4 (2,309.6–3,134.1)	4.9 (4.1–6)	873.5 (797.4–957.8)	1.4 (1.2–1.5)	683.5 (634.2–738.9)	0.9 (0.9–1)
<b>Global</b>	386,812.6 (266,572.8–486,274)	5.4 (3.7–6.9)	103,727.2 (71,606.7–12,2516.7)	1.4 (0.9–1.6)	71,220.7 (49,169.2–83,167.3)	0.9 (0.6–1)

# What is access?

Access is

*the patient's ability to obtain medical care, including medicines,*

*and a measure of how many people reach appropriate health services.*



[https://www.freepik.com/free-vector/flat-world-health-day-background\\_23181009.htm](https://www.freepik.com/free-vector/flat-world-health-day-background_23181009.htm)>Image by freepik

# Barriers to access to medical care

- Efforts to improve access often focus on providing or improving **health coverage**.
- Other barriers to access can also be
  - **geographical** : distance to care
  - **organizational** : shortage of providers
  - **sociological** : education, health literacy, language barriers.



[https://www.freepik.com/premium-photo/businessmen-with-stairs-different-lengths-overcome-wall-that-hinders-them-grant-inequality-advantage-3d-render-images-models\\_1859571.htm](https://www.freepik.com/premium-photo/businessmen-with-stairs-different-lengths-overcome-wall-that-hinders-them-grant-inequality-advantage-3d-render-images-models_1859571.htm)

*How would you rank the following challenges to accessing healthcare in your region?*



- *Distance to providers*
- *Lack of available providers*
- *Affordability*
- *Lack of information or low health literacy (including language barriers).*



# Understanding the dimensions of access to health care for better advocacy

## 5 As of access

**Available**

**Services & resources exist**

**Accessible**

**Removal of information and practical barriers**

**Appropriate**

**Right care for patient needs**

**Adequate**

**Quality of care**

**Affordable**

**No care denied due to financial and human costs**

# Available: services and resources exist

## Why it Matters

Specialised services and every service conducive to good quality health care should be available to acute leukemia patients in their country

## Advocacy Role

- Push for policies that expand healthcare infrastructure: building or upgrading treatment centers
- Ensuring necessary resources and personnel are available;



Freepik

# Accessible: removal of information and practical barriers

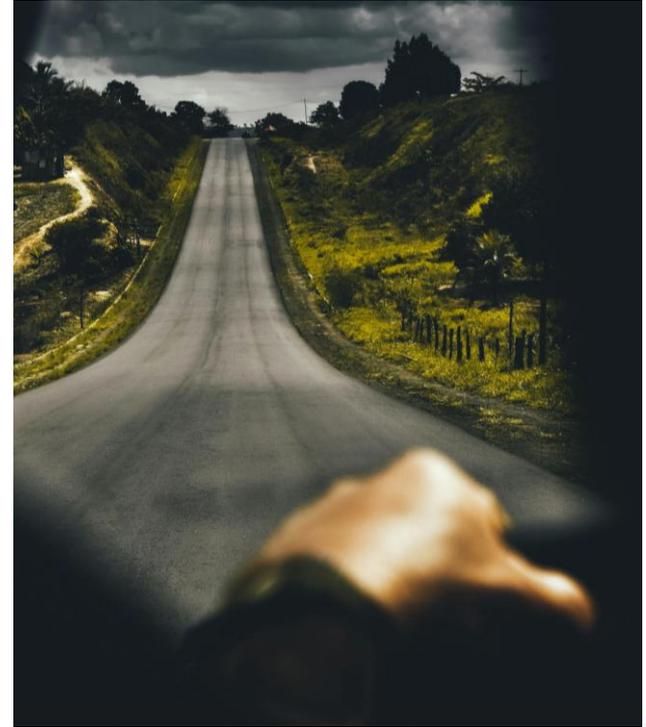
## Why it Matters

- Geographical and organizational barriers can prevent patients from accessing the care they need.
- Language barriers, low health literacy, and lack of clear information can hinder access.

## Advocacy Role

Create, co-create or push for

- Promote clear information, multilingual resources, and patient-friendly navigation.
- better transportation options for patients.



pexels-lucas-martins-785956-1649761

# Appropriate: right care for patient needs

## Why it Matters

Tailoring care to individual needs is critical for effective treatment and minimizing unnecessary interventions.

## Advocacy Role

- Ensure guidelines reflect up-to-date evidence and patient diversity
- Push for personalized treatment plans that reflect the latest evidence and best practices in leukemia care.



*Can you think of a time when outdated or lack of guidelines might have impacted patient care?*

# Adequate: quality of care

## Why it Matters

Healthcare professionals need ongoing training to stay updated on the latest treatments, technologies, and best practices in acute leukemia care.

## Advocacy Role

Call for

- investment in continuous training
  - sufficient staff and resources
- for best possible quality care.



Freepik

# **Affordable:** no care denied due to financial and human costs

## **Why it Matters**

- Acute leukemia treatments can be financially devastating. Ensuring affordability is critical to prevent patients from facing impossible choices between health and financial stability.

## **Advocacy Role**

Push for policies that

- cap out-of-pocket costs and expand reimbursement to avoid financial hardship
- offer financial assistance programs for patients in need.



*How do financial barriers impact patient adherence to treatment in your experience?*



- *Patients delay or skip appointments/medications due to cost*
- *Patients choose cheaper or less effective options.*
- *Patients rely on charity, crowdfunding, or family support to continue.*
- *Patients reduce spending on essentials (food, housing) to afford treatment.*
- *Financial barriers do not significantly affect adherence in my region.*



# How will you prioritise the 5 As for advocacy in 2026?

**Appropriateness**

**Right care for patient needs**

**Adequacy**

**Quality of care**

**Availability**

**Services & resources exist**

**Accessibility**

**Removal of information and practical barriers**

**Affordability**

**No care denied due to financial and human costs**



# From Data to Action: What We Take Away Today



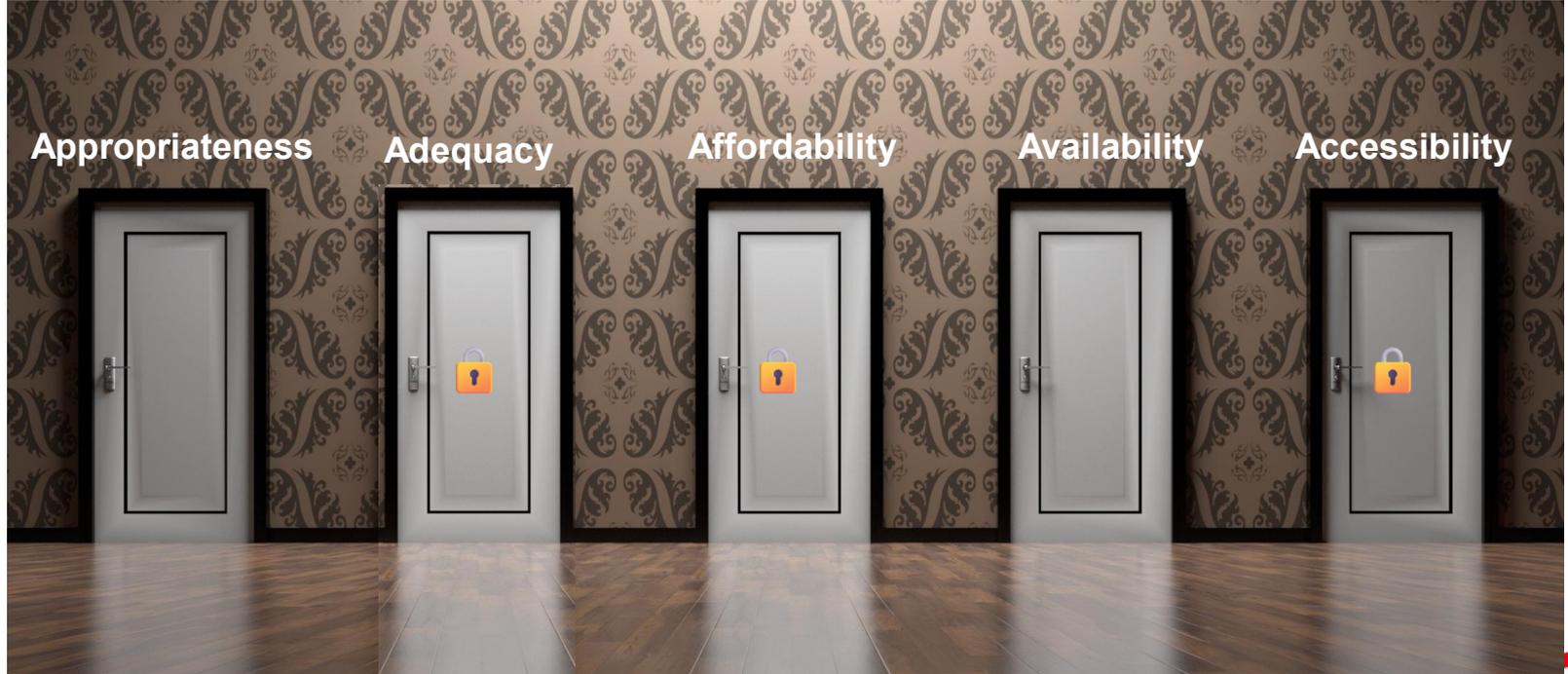
# From Data to Action: What We Take Away Today

Access is not a single door — it's made of five !!



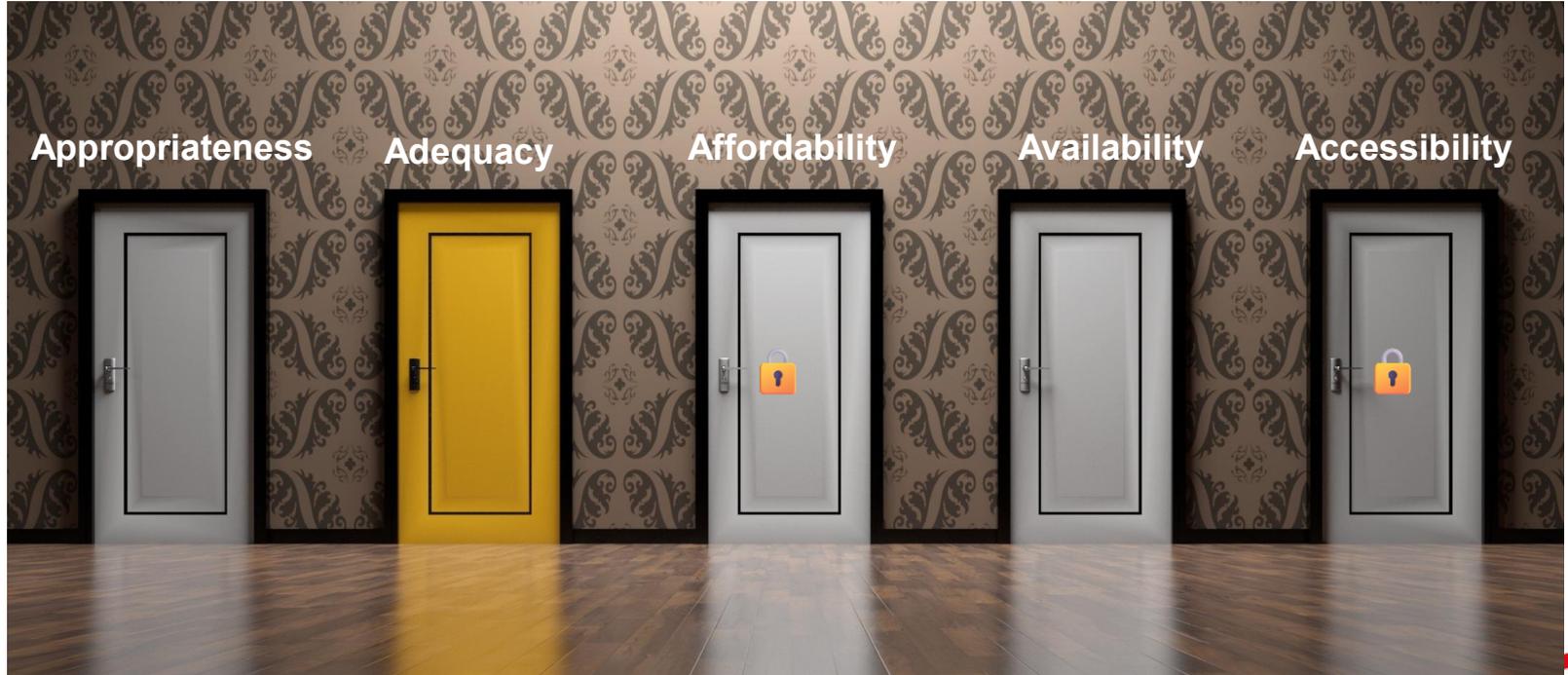
# From Data to Action: What We Take Away Today

Data show us which doors are locked.



# From Data to Action: What We Take Away Today

Advocacy unlocks them — one policy, one partnership at a time.



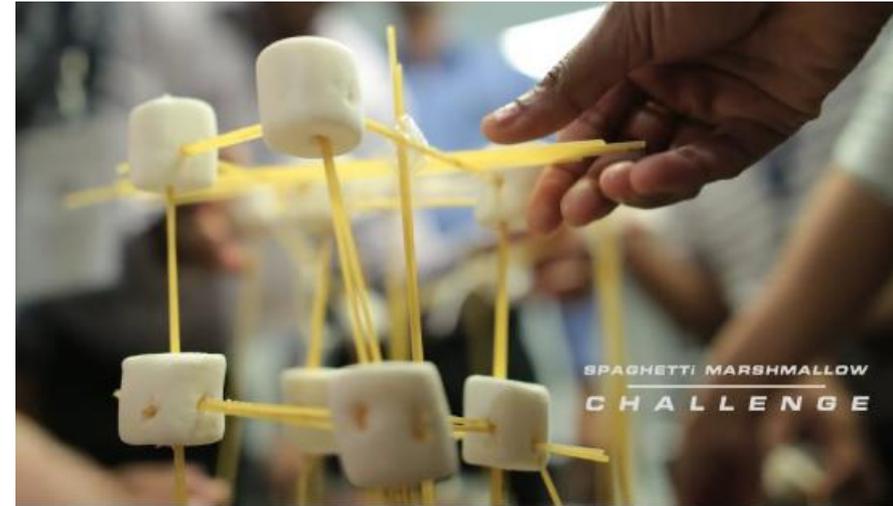
**THANK YOU!**

A decorative graphic at the bottom of the slide consists of a thick, wavy line that transitions from a deep red on the right to a purple on the left.

**BREAK – BE BACK AT 4 PM!**

# Marshmallow challenge

- Each pair of buddy gets
  - 20 sticks of dry spaghetti,
  - 95 cm of tape,
  - 95cm of string, and
  - one marshmallow.
- Each pair has 15 minutes to build the tallest structure with the marshmallow on top.
- Once the challenge is complete,
  - Take a picture **#ALANSummit**
  - discuss what part of the exercise was the most difficult, who failed at first, how did you managed, and what you think of the other designs.



# WORKSHOP: BARRIERS TO ACCESS

# Workshop: Barriers to access



## Access = Beyond Medication

It also means:

- Diagnostics (molecular testing, early diagnosis)
- Clinical trials (eligibility, site proximity)
- Specialists and care centers
- Support services (transport, interpretation)
- Financial protection or policy barriers
- And yes, drugs too — but not exclusively

# Workshop: Barriers to access



## Aim:

Bring together stakeholders across different regions to **identify one major barrier to access** in (acute) leukemia care and **co-create one tangible, regional solution** per group

**25 min** –Group Breakout Discussions

**50 min** – Group Report-Outs (10 min per group including Q&A)

- **Barrier:** What's the main issue in your region?
- **Solution:** What's the one proposed fix?
- **Who benefits:** Patients? Providers? Whole system?
- **What's needed:** Policy change? Training? Funding?
- **Call to Action:** “We’ve surfaced real barriers — now let’s keep the momentum. Which of these ideas can we test, fund, or advocate for together?”

# Workshop: Barriers to access



<b>Healthcare Model</b>	<b>Countries</b>
Funded by taxes, services provided by government.	<b>ROOM 2</b> UK, Spain, Italy, Denmark, Portugal, New Zealand
Funded by employer/employee payroll deductions; insurers are non-profit.	<b>ROOM 1</b> Germany, France, Netherlands, Austria, Czech Republic, Estonia, Slovenia
Funded by the government (via taxes), but healthcare delivery is private.	<b>ROOM 1</b> South Korea, Australia
Primarily out-of-pocket expenses or heavy disparities.	<b>ROOM 3</b> Kenya, Tanzania, Nigeria, Nepal, Guatemala, Armenia
Combination of private and public financing; often fragmented.	<b>ROOM 1</b> USA, South Africa, Thailand, Colombia, Macedonia

# Workshop: Barriers to access



## 1. Barrier Identification

- What's the **most significant access barrier** in your region?
- Who is most affected?
- What part of the care pathway is blocked (diagnosis → treatment → follow-up)?

## 2. Root Causes

- What systemic, geographic, policy, or socioeconomic factors drive this?
- Is it due to awareness? Infrastructure? Cost? Eligibility criteria?

## 3. Tangible Solution Creation

- What is **one realistic, actionable solution** for this barrier?
- Could it be piloted or advocated for in 6–12 months?
- Who would be involved in implementing it (government, hospitals, NGOs, patients)?

# TOMORROW'S AGENDA



**8.15 AM**

**Breathing / Mindfulness**

**8.30 AM**

**Access – Global Realities and Solutions**

**9.30 AM**

**Power in Partnership**

**10.30 AM**

**Buddy Check in**

**11 AM**

**Workshop: What to Advocate for Locally?**

**11.45 AM**

**Closing and goodbye**

**12.30 PM**

**Lunch and departures**



## **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



# Time for yoga !

- Remove your shoes (if you want)
- Get comfy
- Breathe
- Smile
- Enjoy !

