

CML Advocates Network

Activity Update

Denis Costello – Director, CML Horizons 2023

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CMLAN Activities 2023

Highlights

01

**CMLAN
Academy**

02

Surveys

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CAB

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**Know your
CML App**

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CML Life

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Congresses

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**World CML
Day**

CMLAN Online Academy

Launched in 2023

- Online eLearning platform for CML patient advocates
- Courses created with patients and experts to help you be a better patient advocate
- Visit it at **academy.cmladvocates.net**



CMLAN Online Academy

First online course for CMLAN members - Building relationship with hematologists

Course features:

- 6 week online course
- Seven steps to connect patient associations with hematologists
- SMART goal, need based negotiation with hematologists
- Problem solving in communication with hematologists
- Role play, assignments, resource materials and live webinars plus continuous support



Gianantonio Rosti, MD, PhD

University of Bologna, Italy;
Scientific Direction
IRCCS Istituto Romagnolo per lo Studio dei Tumori (IRST) "Dino Amadori"



Jeffrey H Lipton, PhD, MD, FRCPC

Professor of Medicine at the University of Toronto and Staff Physician on the Leukemia and Allogeneic Blood and Marrow Transplant Services at the Princess Margaret Hospital



François-Xavier Mahon, MD, PhD

Director of the Cancer Center of Bordeaux (Bergonie Institute)

CMLAN Online Academy

What's next

- **Next courses:**
- Learn more about pediatric CML
- How to deal with newly diagnosed CML patients who come to your patient group

- Look out for the repeat of the learning to build relationships with hematologists course and please enroll!
- Also planning new courses for blood cancer patient advocates with CLL Advocates Network and Acute Leukemia Advocates Network in 2024



Global Leukemia Survey 2023

Survey is being run by the Acute Leukemia Advocates Network (ALAN), CLL Advocates Network (CLLAN) and CML Advocates Network (CMLAN), aims to collect key data on important areas such as diagnosis, treatment and quality of life.

- 837 patients who responded to the survey
- 169 carers

Top countries:

- UK
- Netherlands
- Czech Republic
- USA



Global Leukemia Experience Survey 2023

Share your experience

The Acute Leukemia Advocates Network, CLL Advocates Network, and CML Advocates Network are running a survey on the diagnosis, care, and treatment for leukemia. The purpose of the questionnaire is to provide information to help understand the key issues, experiences, and unmet needs for leukemia patients.

Scan to go to the survey



Who should complete the questionnaire?

This questionnaire can be answered by anyone aged 18 and above directly or indirectly affected by a diagnosis of leukemia, whether this is somebody who has received a diagnosis or who is / has been a carer to someone with a diagnosis. Two question sets have been designed, one for patients, and one for carers. Each of these surveys will take 20 to 30 minutes to complete.

What you tell us is confidential and taking part is voluntary.

 CML ADVOCATES NETWORK

 CLLAN

 ALAN

 Picker

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CMLAN feedback to SUN Survey

CMLAN members participated in and collectively gave feedback on Novartis SUN Survey

- Survey of Unmet Needs in chronic myeloid leukemia (CML SUN) data shows a greater need for the patient voice during treatment discussions that balance quality of life (QoL), efficacy, and tolerability goals across all lines of therapy
- Data reveal necessity for **greater communication** and **shared decision-making** between patients and physicians, as well as more tolerable therapy options that do not sacrifice QoL for efficacy
- CML SUN highlights an opportunity for physicians, patients, and other stakeholders to collaborate and better meet expectations for CML

“People living with chronic myeloid leukemia must be able to have open and honest conversations with their doctors about their treatment goals, how medication side effects impact their lives, as well as their emotional and mental well-being,”

Lisa Machado, CML SUN Steering Committee member, founder of the Canadian CML Network and executive producer of Healthing.ca



CML Community Advisory Board

New Co-Chairs



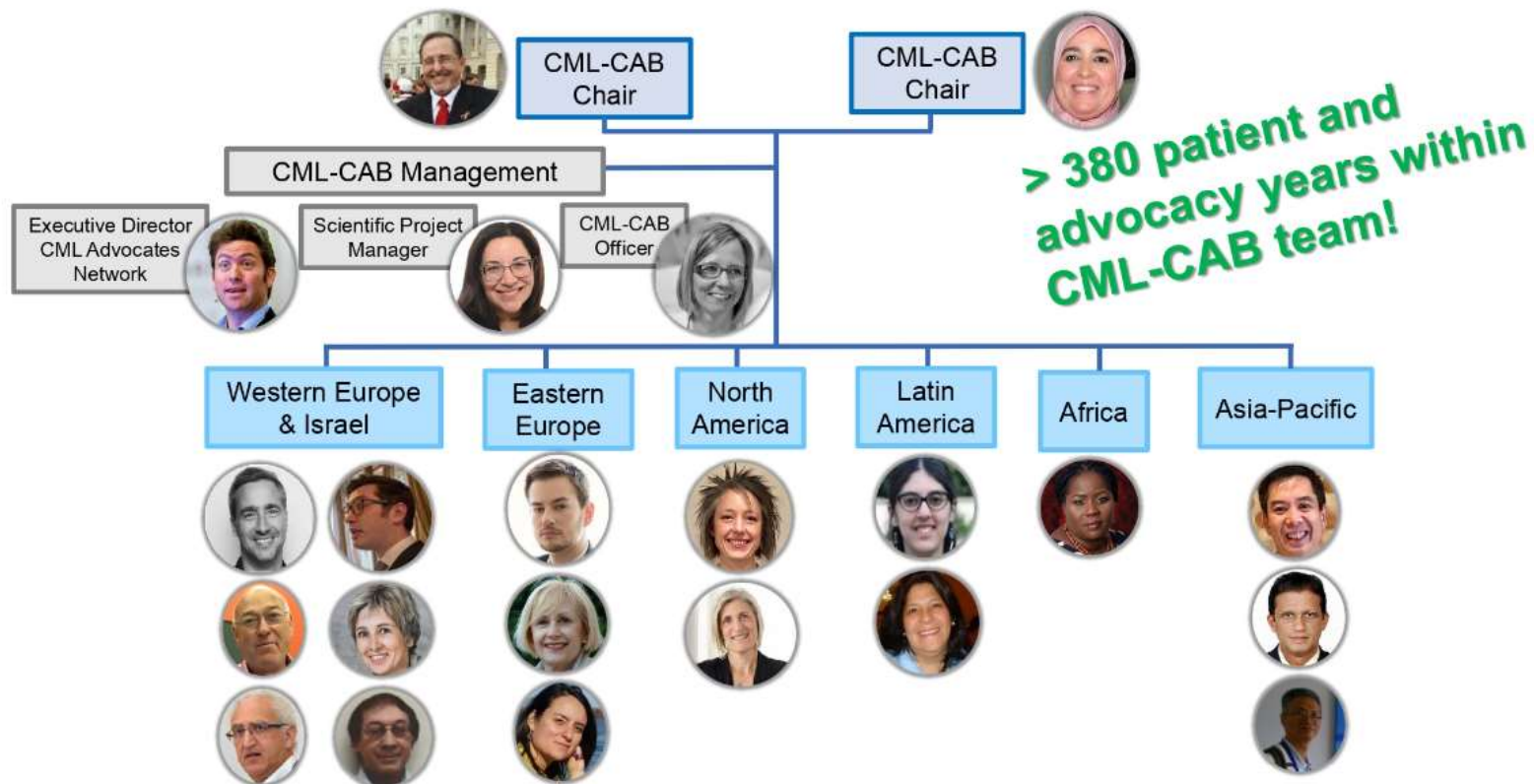
Gerald Clements (USA)



Bahija Gouimi (Morocco)

CML Community Advisory Board

19 Members



2nd Academic Community Advisory Board

During EHA in Frankfurt June 2023

Meeting of 16 CAB members and 9 CML academic researchers

- What is the researchers' approach and contribution towards CML cure beyond TFR?
- Do they understand the needs and expectations of patients?
- What are the barriers to move research forward?
- How can the patient community and researchers support each other and collaborate?



2nd Academic CML-CAB

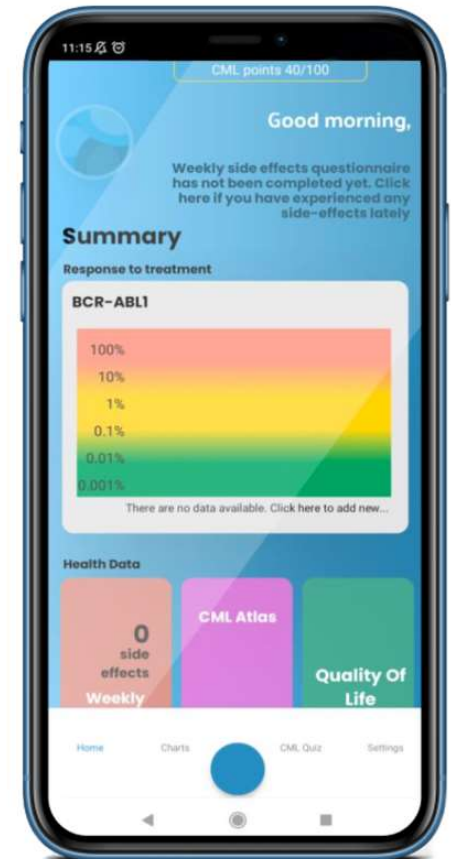
Next Steps

Taken from the discussions in the meeting

- Identifying candidates for targets and mechanisms/ looking more closely at translational research/ bench to bedside.
- Identifying the right patient populations for research and cure, (e.g., multi-resistant or multi-intolerant patients; patients with needs in underserved countries with no clinical trials).
- Identifying funding/funders, perhaps get involved with philanthropic funders.
- Identifying and creating incentives: for researchers and for pharmaceutical companies.
- Building a research platform with pragmatic trials, basket trials, platform trials.
- Enabling data sharing whilst addressing data protection and drawing conclusions from data that are already available.
- There is a need for a bone marrow (CML and other blood cancers) global research biobank which does not exist today.

Know your CML App

- Now available in 9 languages
- Promotion videos available to help you spread the word & social media pack
- In 2024: Feedback survey planned & investment in technology stability and new features



CML Life

CML Life is a unique support program for people with CML. In addition to offering support to patients and caregivers, this tool offers a wealth of information.

- Available in 5 languages (EN, ES, IT, DE, FR)
- Articles, podcasts, infographics and resources for people living with CML

Topics include:

- Mental health (Mindfulness)
- Nutrition
- Explaining CML to a child



Congresses

CML Advocates Network presence

- ASH2022 New Orleans
- EHA2023 Frankfurt
- ESMO2023 Madrid
- ESH2023
- WECAN Academy
- APPIS (Asia-Pacific Patient innovation summit)



ASH report

Latest advances in the treatment of chronic myeloid leukemia (CML) - What does this mean for patients?

This educational webinar will give an overview of how CML is treated today and the significance of 'hot topics' and key treatment development advances published and discussed at 2022 international hematology conferences.



MODERATOR

Charlotte Martin

Patient Advocacy Manager,
Leukaemia Care (UK)



SPEAKER

Prof Andreas Hochhaus

Consultant Hematologist, Director
Department of Hematology and
Internal Oncology
University Hospital Jena (DE)



SPEAKER

Lisa Machado

Patient Advocate,
CML Advocates Network (CA)



Tuesday, 28 March 2023

6:00 pm - 7:00 pm BST

7:00 pm - 8:00 pm CEST

1:00 pm - 2:00 pm EDT



Online / Zoom Webinar

REGISTER NOW



World CML Day 2023 – Campaign

September 22nd

- For World CML Day 2023, patient groups from around 40 countries united to raise awareness of Chronic Myeloid Leukemia (CML).
- We prepared campaign materials for social media in 12 different languages: Arabic, English, French, German, Hebrew, Italian, Macedonian, Polish, Russian, Serbian, Spanish and Ukrainian.
- Reach of 2million and 3million on Facebook and Twitter respectively

CML Advocates Network
Published by Marja Stefkova · August 17 at 5:22 PM ·

Help us leave **NO CML Patient** behind this World CML Day! 🙏
Join our fundraising campaign this year & make a difference in the lives of CML patients. United, we can create a better future for those affected by CML. 🙏
Donate NOW: <https://www.worldcmlday.org/projects/>
#WCMLD23 #CML #Unitedtogether #LeaveNoOneBehind

Help us leave NO CML patient behind!

This year with one small gift you can help CML patients in Africa, Latin-America and Asia.

DONATE NOW

www.worldcmlday.org

WORLDCLMDDAY.ORG
Projects - World CML Day
This year help us leave no CML patient behind! Brinqing Hope to Low- and ...

Learn more

World CML Day
22 SEPTEMBER

9/22
Putting a spotlight on CML

leaving no one behind

HELP US LEAVE NO ONE BEHIND THIS WORLD CML DAY

#WCMLD23 #CureCML

CML Advocates Network
Published by Marja Stefkova · 4d ·

This year for #WCMLD23 join us in our fundraising campaign and help us leave no CML patient behind! 🙏
Learn more: <https://www.worldcmlday.org/projects/>
Don't forget to also share your story, image or video and let the world know what does putting a spotlight on CML mean to you? 🙏

This year help us leave no CML patient behind!

Bringing Hope to Low- and Middle-Income Countries (LMIC) through FUNDRAISING.

Donate Now!

World CML Day

WORLDCLMDDAY.ORG
Bringing Hope to Low- and Middle-Income Countries (LMIC) through FUNDRAISING

Learn more

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Putting a spotlight on CML, leaving no one behind

Join us as we unite for World CML Day

#WCMLD23
#CureCML



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Our members activities

So many organisations had events dedicated for raising awareness



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WCMLD – Leaving no one behind!

Projects from around the world – Fundraising campaign



Donate!

Make a Life-Saving Difference: Donate Now to Empower CML Patients in Latin America!

Help us provide essential care to leukemia patients with CML in Latin America. Your donation ensures access to necessary tests and transportation, saving lives. Support our fundraising for testing in Bolivia, making a difference in their lives.



Donate!

Changing Lives: Your Donation Makes a Difference for CML Patients in India

In India, many leukemia patients with CML lack access to essential tests and treatments. Your donation directly supports these patients and together, we can create a brighter future for these individuals and ensure they receive the support they deserve.



Donate!

Transform Lives: Support CML Patients in Nigeria - Donate Today!

Help us break barriers for leukemia patients with CML in Nigeria and across Africa by supporting access to vital treatment and transportation. Your donation can provide the care, compassion, and life-saving resources needed to overcome challenges. Donate today for positive change.

WCMLD – Leaving no one behind!

Announcement of fundraising campaign

Total: \$21,553

Thanks to the generosity of the public and our partner for their generosity



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 **CML** ADVOCATES
NETWORK

CMLAN Team

A huge thanks!



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CMLAN Strategic Planning

Changing environment

01

More and more
CML treatments
becoming generic

02

More and more
difficult to get
funding for global
and local CML-
specific patient
groups

03

CML is still
considered a “done
deal” by many in
spite of access and
quality of life issues

CMLAN

Strategic Planning Exercise



Denis Costello



Hayley Chapman

Senior Program Director at the Synergist



The **Synergist**

Strategic Planning Exercise Objectives

From current success to NEXT LEVEL



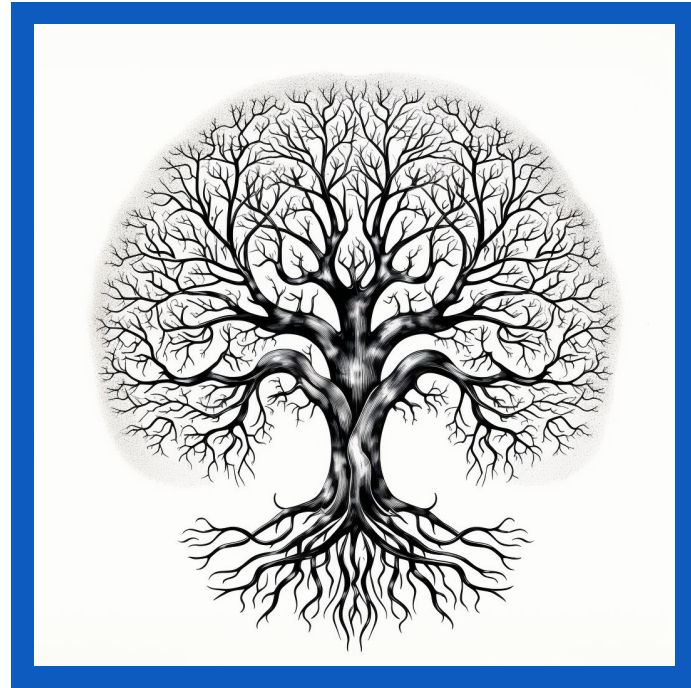
At a *pivotal point* in organizational maturity and evolution

Taking CMLAN to the next level through *co-owned mission and values*

To collaboratively develop a *strategic plan* that provides clarity and direction

To drive organisational progression evolving to meet *future challenges* and *sustainable delivery* of programs

The Synergist is a non-profit social venture, that believes the world's most important and complex societal issues are **best solved** when we address them **collectively**.



Why The Synergist?

01. | **Well-respected, neutral, thought-leader** amongst other key multi-sectoral stakeholders
02. | Extensive **global network of collaborators and project contributors** with wide representation of stakeholders
03. | Demonstrated **knowledge and understanding** to successfully plan, coordinate, implement and execute a range of potential outcomes
04. | **Contribution to many global initiatives** and advisory councils

These initiatives include work with:



Meet the Experts: Mastering Strategy & Organisational Design

Synergist team:

- Experts in *complex organisation design & strategy* shaping
- *Project team* to leverage expertise, facilitate discussions, prepare for execution of co-created actions



Nicholas Brooke

Executive Director



Amanda Bok

Chief Strategy Officer



Hayley Chapman

Senior Program Director



Nicola Bedlington

Strategic Advisor



Tony Hoos

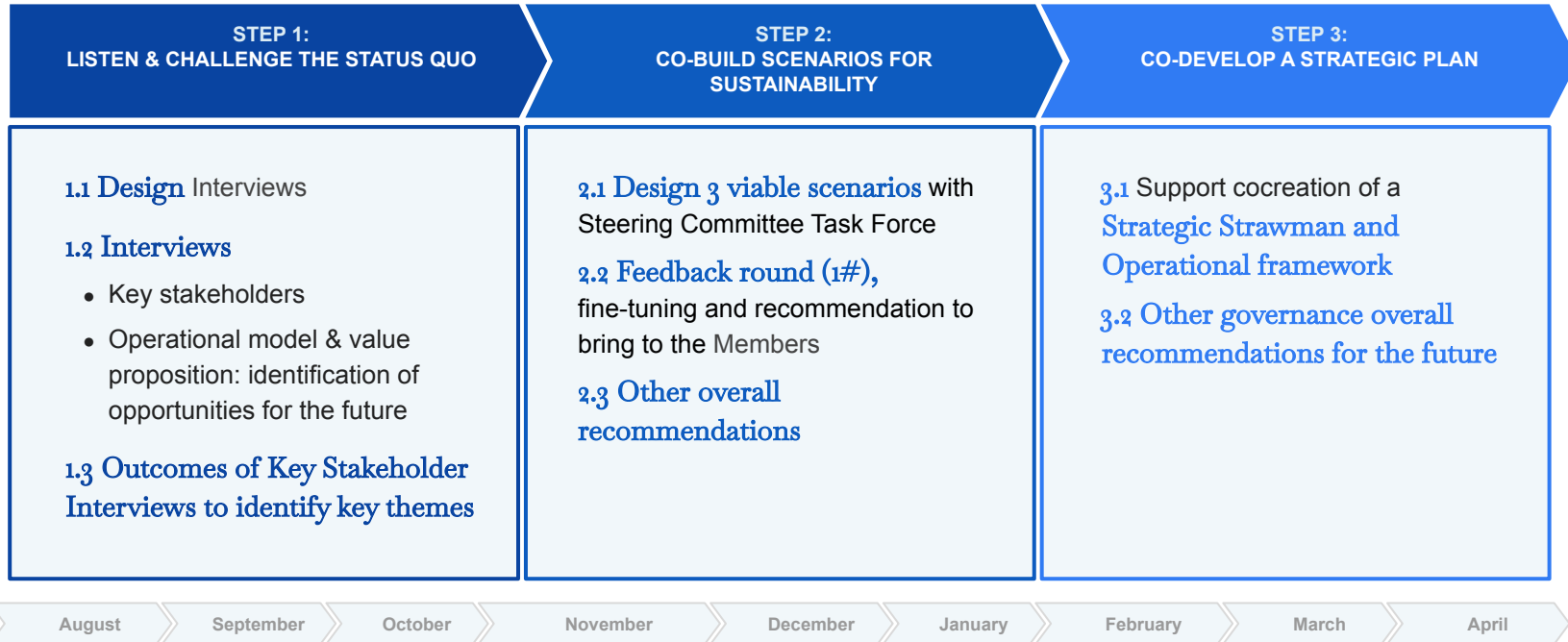
Strategic Advisor



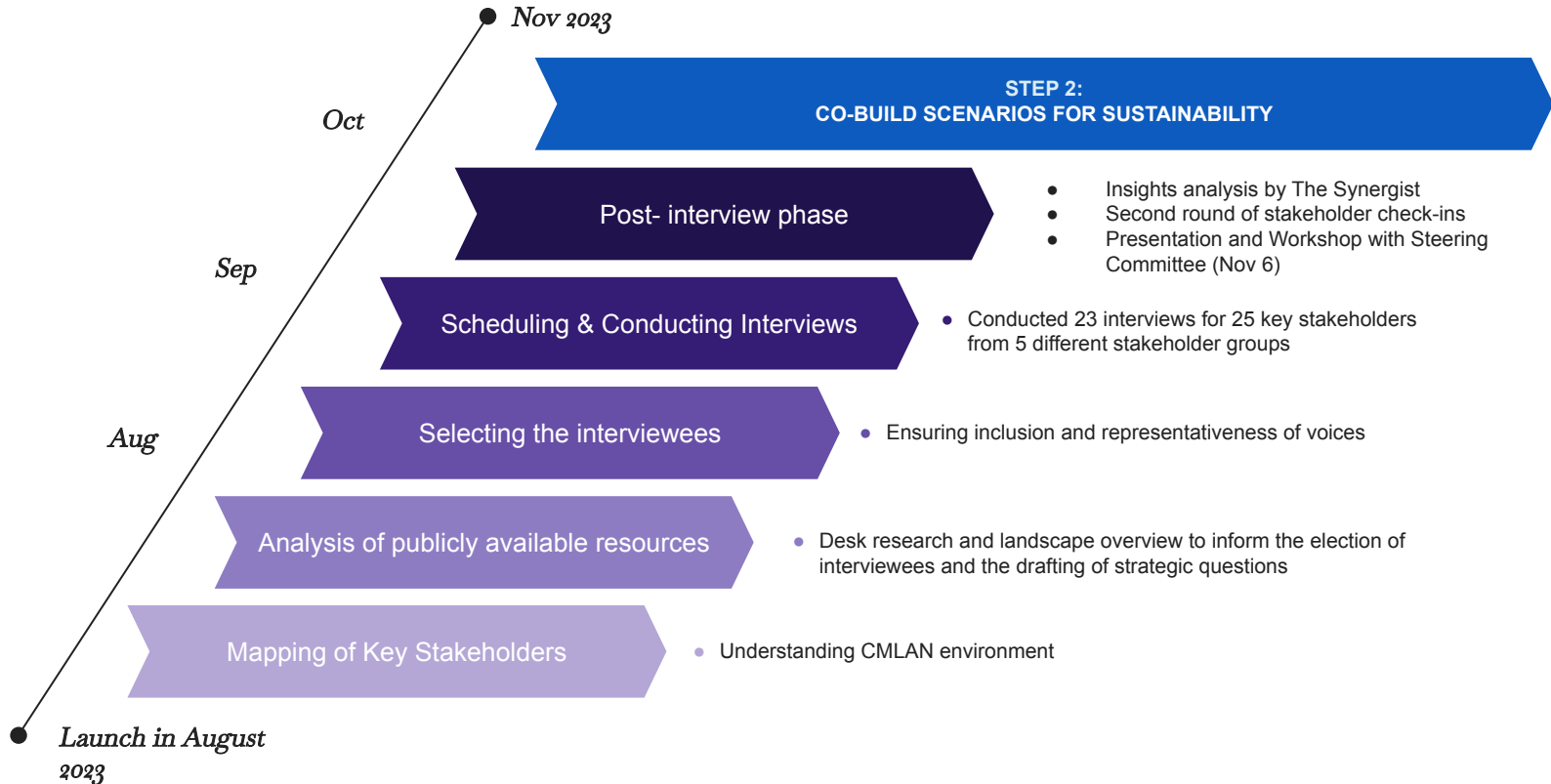
Aurora Lancha

Associate Program Manager

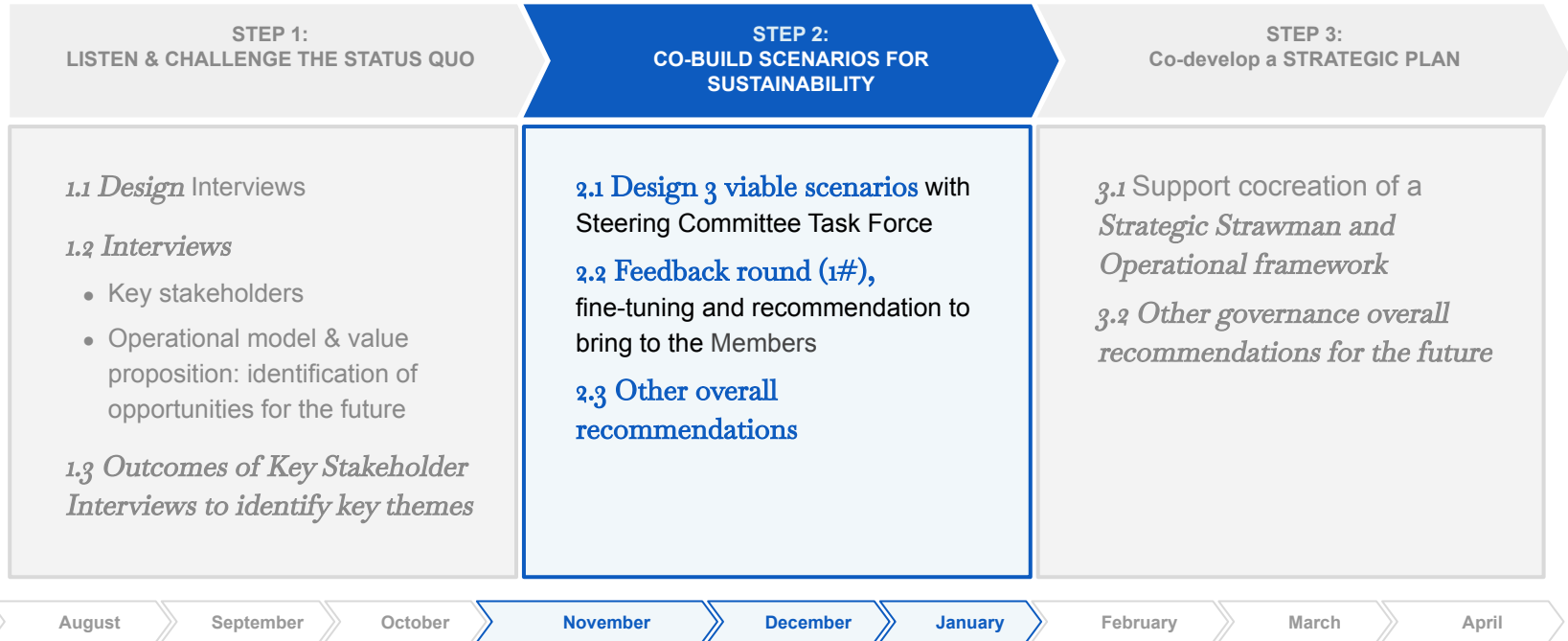
3-Step approach to guide CMLAN to the Next Step



Step 1: Listen & Challenge The Status Quo



3-Step approach: Coming Next



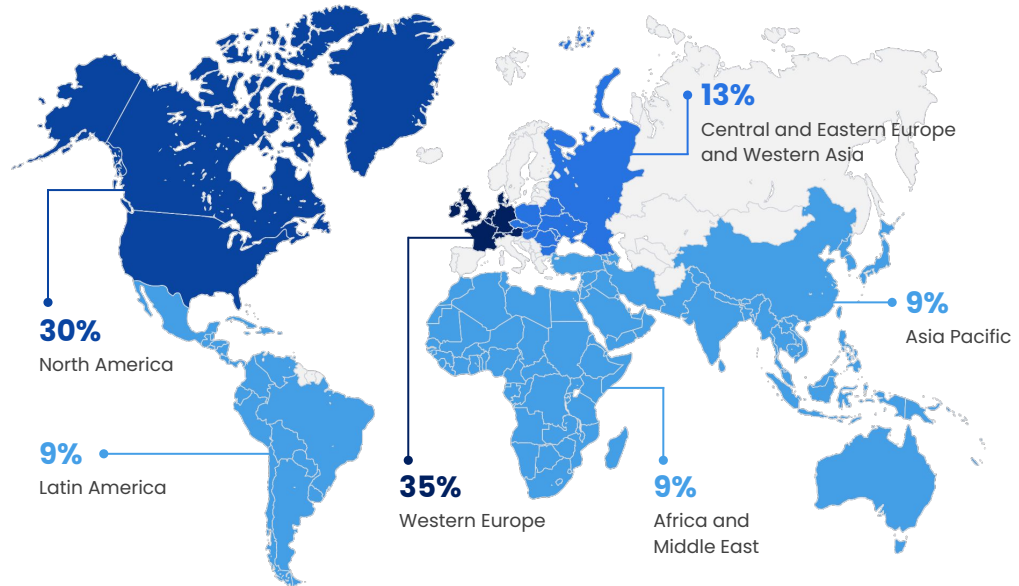
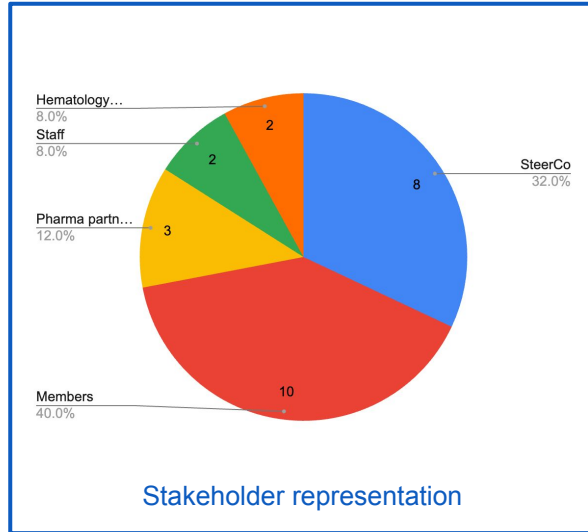


The Synergist

Partner for greater societal impact

Ensuring Inclusive Representation of CMLAN

23 interviews → Insights from 25 people from 5 key stakeholder groups with global reach



Feedback exercise

4 breakout groups + 1 online

1

World CML Day

- *Thoughts on 2024?*

2

CML Horizons &
Academy

- *Fresh ideas?*

3

Know Your CML
App

- *How to improve?*