



# CML Patient Advocates Network implementation of the Community Advisory Board (CAB) model.



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## DEFINITION AND BACKGROUND TO THE CML CAB

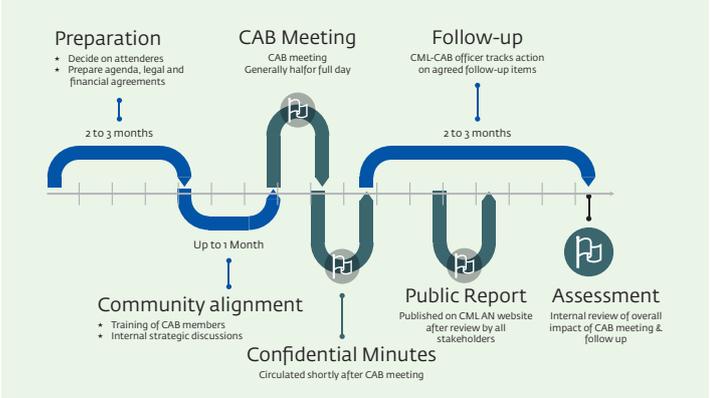
The CML Advocates Network (CML AN) is an active network specifically for leaders of Chronic Myeloid Leukemia (CML) patient groups, connecting 123 patient organisations in 93 countries on all continents. It was set-up and is run by CML patients and carers. Its aim is to facilitate and support best practice sharing among patient advocates across the world.

The CML Community Advisory Board (CML-CAB) is a working group of the CML Advocates Network. Since its inception the CML-CAB has met on nineteen occasions with five different sponsors.

## WHY CML-CABS?

- **Research** is key towards better outcomes, but often the trials are done without patient input, do not deliver on unmet needs, do not deliver patient-relevant data (e.g. PRO, QoL), are run in the wrong countries, do not recruit
- **Care** pathways are often not reflecting true patients' needs' and real-life situations
- **Access** to treatment and monitoring is often suboptimal or non-existent – focus on the “most attractive big markets”, not on hugest unmet need
- Pharma's **patient information** often doesn't answer our questions, is sometimes inappropriate (“smiling happy people riding a bike at the beach in the sunset”)
- **Pharma advisory boards** are often not meaningful, have little impact, provide no reports or follow-up

## HOW DOES CML-CAB WORK



## OUTCOMES

The main impact of the CML-CAB can be summarized as follows:

- **Discussed drug development pipeline of the companies**
- **Addressed access issues to drugs & monitoring**
- **Addressed collaboration issues**
- **Contributed to design of company-led patient services**
- **Trained CML-CAB members**

## STRUCTURE, MANAGEMENT AND INTERNAL TOOLS

The CML-CAB is comprised of two chairs + CAB-members (currently 17 members). CML-CAB organisation, sustainability and follow-up is supported by a part-time CML-CAB Officer and the CML-AN Executive Director.

CML-CAB developed several tools as an internal management and measurement framework for CAB implementation, follow-up and evaluation:

- **CML-CAB Protocol.** This document defines the strategic objectives of the CML-CAB as well as defining roles and responsibilities for each CAB participant.
- **Confidentiality agreement and Conflict of Interest templates.**
- **Follow-up Tracker.** Allows CML-CAB and sponsor to mutually nominate responsibility for follow-up action
- **Confidential minutes & Public Report.** Confidential record of the meeting plus a non-confidential public report published on the CML-AN website.
- **Score card.** Mechanism whereby CML-CAB members can score the performance of the sponsor.
- **Skills Matrix.** Evaluation of the skills of CML-CAB members under the following domains: Research, Access, Collaboration, Drug Expertise and English language skills.

## How We Handle Confidentiality?

| Considered confidential   | Non-confidential / public information  |
|---|--|
| <ul style="list-style-type: none"> <li>• Corporate strategies</li> <li>• Development pipelines</li> <li>• Unpublished data</li> <li>• Commercially sensitive information</li> <li>• Discussions at the CML-CAB</li> </ul> | <ul style="list-style-type: none"> <li>• Concepts of treatment and care</li> <li>• Advocacy strategies</li> <li>• Patient information</li> <li>• Positions and decisions taken by CML-CAB</li> </ul> |

## RESOURCES

- CML AN Website:  
<https://www.cmladvocates.net/cml-cab>
- Reasonable agreements between patient advocates and pharmaceutical companies:  
<https://wecanadvocate.eu/rapp/>

## ACKNOWLEDGEMENTS

The CML Advocates Network would like to thank the CML-CAB members, both two co-chairs and the seventeen patient advocates from all regions, for their participation and development of the CML-CAB and all partners for their assistance and support in the last five years.