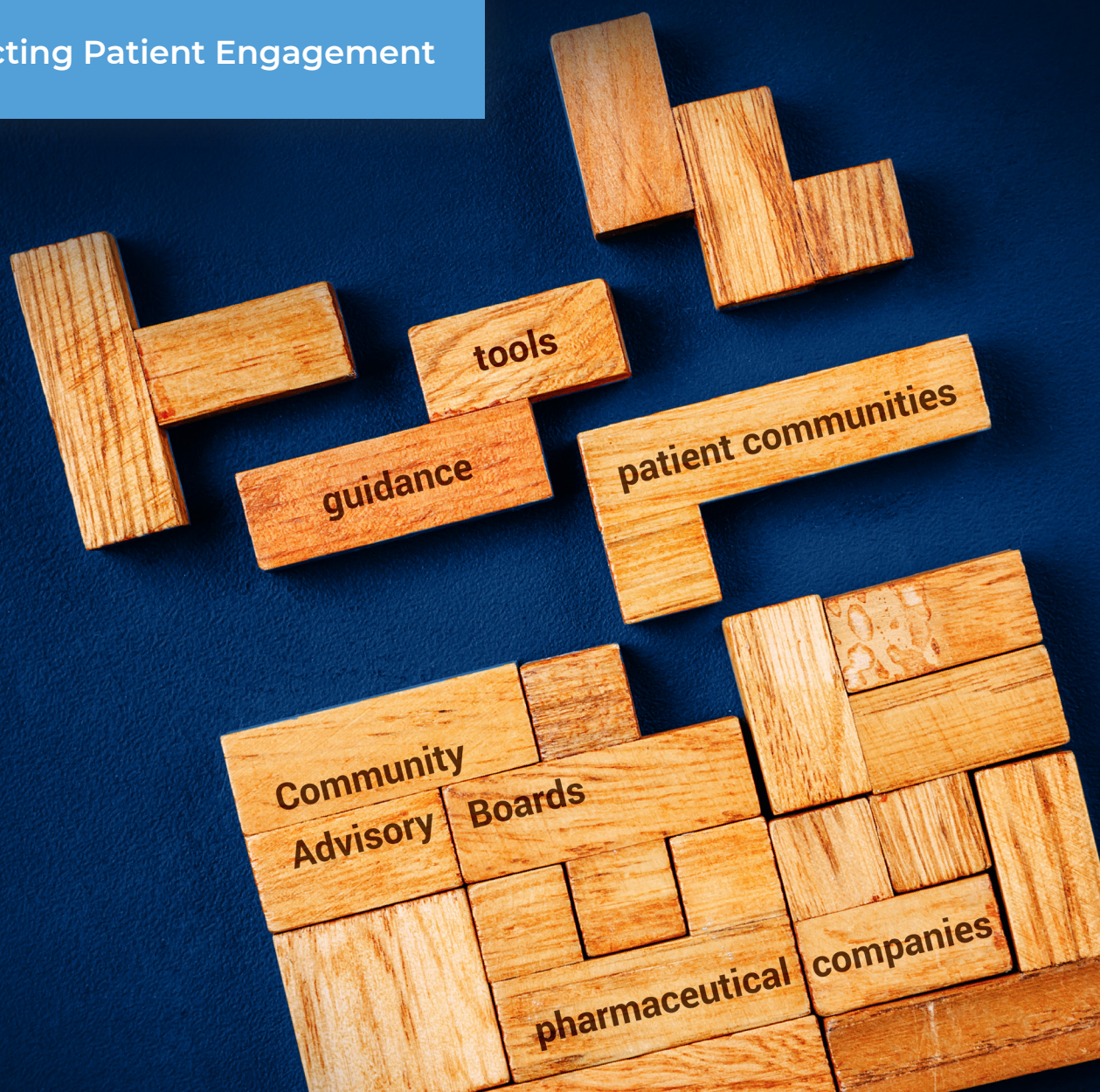




## Conducting Patient Engagement



# Community Advisory Boards

## Tool 3: Comparative table

## Introduction to the CAB toolkit

Comparative Table. **Different CAB approaches**

	<b>ECAB</b> (led by the European AIDS Treatment Group, EATG )	<b>Chronic Myeloid Leukemia (CML) CAB</b> (led by CML Advocates Network)	<b>EuroCAB Programme</b> (led by EURORDIS, Rare Diseases Europe)
<b>Scope</b>	Networks of activists from the HIV-affected community in Europe (as defined by WHO)	Leading patient advocates from all world regions, many living with CML	Trained patient / carer/ patient representatives in the field of rare diseases
<b>Aim</b>	To promote the best available clinical practices, standards of care and access to the latest and best available therapies and diagnostic tools for HIV and related co-infections throughout WHO Europe	To promote best-in class research in CML, harmonisation of good clinical practices and access to treatment and diagnosis	The particular aims of the collaboration between CAB and each company are defined in the Memorandum of Understanding (MOU)
<b>Resources</b>	<ul style="list-style-type: none"> <li>Support provided by Scientific Officer and EATG secretariat</li> <li>Elected Chair (sometimes co-chair) and steering committee (3-5 members)</li> <li>One CAB member is appointed and contracted (i.e. paid) to take minutes (via a yearly call to members)</li> </ul>	<ul style="list-style-type: none"> <li>CML Advocates Network Steering Committee and CML CAB Chair(s) guides the CAB's work</li> <li>Management: CML CAB officer + CML Advocates Executive Director (ED)</li> <li>1-2 Chairs</li> <li>Companies working with the CAB need to appoint a company liaison</li> </ul>	<ul style="list-style-type: none"> <li>CAB secretariat: CAB chair+ EURORDIS mentor</li> <li>Recommended a professional note taker and facilitator (meeting manager)</li> </ul>
<b>Membership</b>	<ul style="list-style-type: none"> <li>In 2016, 112 members from 38 countries</li> <li>On average 15-20 members invited to the meeting</li> <li>Members interested in participating in a meeting complete a selecting process</li> <li>Final decision about who will participate is made by Chair/ co-Chairs.</li> </ul>	<ul style="list-style-type: none"> <li>Membership come from members of CML advocates network. In 2017, 2 chairs and 17 members</li> <li>Members complete a self-assessment survey with their skills</li> <li>Names of members are publicly disclosed</li> <li>The decision about which members will attend a particular CAB meeting is made by the Chair(s) based on skills, representation and other predefined criteria</li> </ul>	<ul style="list-style-type: none"> <li>A time commitment for membership of 2 years is suggested</li> <li>CABs include 7-16 trained patients</li> <li>Names of CAB members are publicly available</li> <li>Members receive online training, as well as face-to-face (when appropriate) training</li> </ul>



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	<b>ECAB</b> (led by the European AIDS Treatment Group, EATG )	<b>Chronic Myeloid Leukemia (CML) CAB</b> (led by CML Advocates Network)	<b>EuroCAB Programme</b> (led by EURORDIS, Rare Diseases Europe)
<b>Meetings</b>	<ul style="list-style-type: none"> <li>The agenda is drafted by the EATG staff, Chair and steering committee based on follow-up points from previous meeting with company, questions from CAB members and information in recent developments. The company can also include points to address</li> <li>Meetings are over weekends. On average 2-3 companies are met at each meeting</li> <li>Members have “internal briefing” meeting before and after meeting each company.</li> <li>Meeting with a company lasts around 3.5h</li> <li>The overall event is chaired by the CAB Chair, and each company meeting is chaired/ facilitated by a member of the CAB</li> <li>Internal rules: minute of silence, the community speaks with one voice</li> <li>Last day (Sunday) is a community-only meeting</li> </ul>	<ul style="list-style-type: none"> <li>The agenda is decided by CAB chair(s), CAB officer and CML Advocates network Executive Director (ED). Companies also suggest points of interest to them</li> <li>A CAB meeting lasts 1-3 days and includes internal training sessions and meeting with companies</li> <li>Meeting with a company can last half a day or a full day</li> <li>Meetings are recorded for purpose of minute taking</li> <li>The minute taker is chosen by the Chair(s) and contracted</li> </ul>	<ul style="list-style-type: none"> <li>Meetings start mid-week and continue until Saturday. There is preparatory work with members prior to meeting each company. Meetings can last half day or a full day</li> <li>A professional note taker and external facilitator are recommended</li> <li>Members meet without the company before and after each meeting</li> <li>Last day is dedicated to training and organisational issues</li> </ul>
<b>Funding</b>	<ul style="list-style-type: none"> <li>Companies can contribute to the ECAB funding in different ways (examples include core funding e.g. unrestricted grants; sponsoring specific projects; support of a specific ECAB meeting)</li> <li>Main costs include administrative work, venue and members' expenses</li> </ul>	<ul style="list-style-type: none"> <li>Companies contribute to funding of the CAB activities. Main costs include administrative work, venue, members' expenses and members' compensation</li> <li>All members of the CAB are compensated for their time</li> </ul>	<ul style="list-style-type: none"> <li>An amount is charged to the company per full or half day. Main costs include administrative work, venue, members' expenses, members' compensation, and EuroCAB programme costs</li> <li>Members of the CAB are compensated for their time (different amounts apply to different CABs)</li> </ul>

## Comparative Table. **Different CAB approaches**

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<b>Legal agreements</b>	<ul style="list-style-type: none"> <li>CAB members sign a confidentiality agreement with EATG when they join</li> <li>Information disclosed to ECAB members is considered “not confidential” unless explicitly stated otherwise</li> </ul>	<ul style="list-style-type: none"> <li>The CML CAB operates under confidentiality, however companies must clearly state when information is confidential</li> <li>All members of CAB and members of the CML advocates network steering committee have to sign a confidentiality agreement</li> </ul>	<ul style="list-style-type: none"> <li>Members of the CAB can be asked to sign confidentiality agreement or declaration of interest with the companies</li> </ul>
<b>Post meeting</b>	<ul style="list-style-type: none"> <li>Minutes are prepared by the minute taker and approved by EATG staff and sent to company for comments</li> <li>Minutes are confidential and are only shared internally and with company</li> <li>A follow-up list of points is prepared by the minute taker and scientific officer and sent to the company within a few days of the meeting</li> <li>An evaluation form is used to collect feedback from ECAB members about the ECAB meeting and meetings with each company</li> </ul>	<ul style="list-style-type: none"> <li>The CAB work is evaluated on an ongoing basis. Once a year the chair must update the CML advocates network and CAB members of activities</li> <li>The minute taker prepares a confidential and a non-confidential version of the minutes. Both versions are approved by all parties. The confidential version is shared with members who have signed a confidentiality agreement and people who attended the meeting, the non-confidential version is shared with all membership of the CML advocates network</li> <li>Both set of minutes should be shared within 10 weeks of the meeting. The confidential minutes are made available in a password protected online site</li> </ul>	<ul style="list-style-type: none"> <li>The minutes are written by a professional minute taker and reviewed by the CAB members and the company representatives</li> <li>The minutes are accompanied by a letter which includes the “next steps” from the CAB perspective</li> <li>After the CAB meeting an online survey is sent to CAB members and sponsors to assess success and satisfaction</li> <li>CAB follow progress with companies with a Tracker</li> </ul>