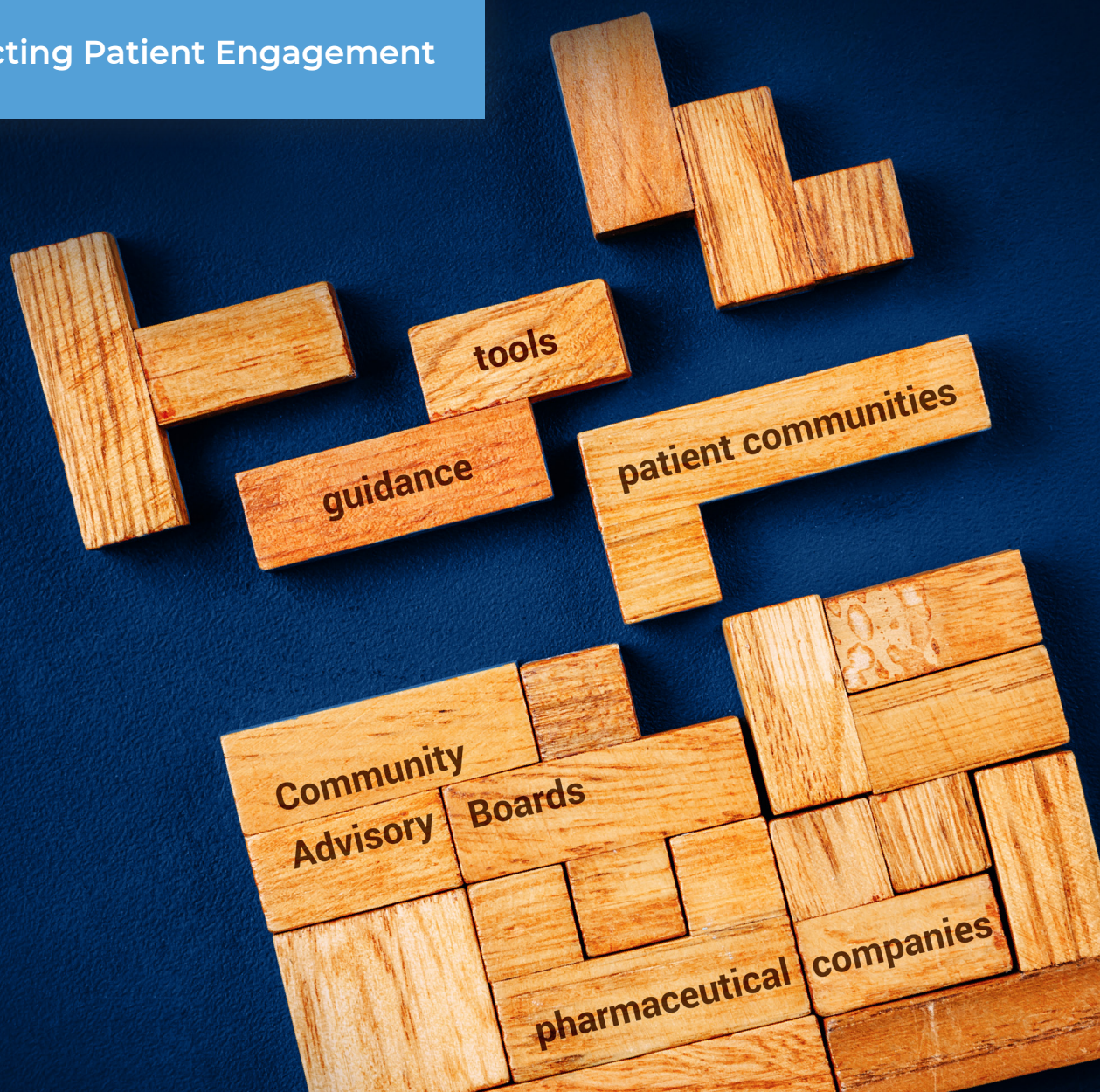




## Conducting Patient Engagement



# Community Advisory Boards

## Tool 5: Reflective questions & tracking tool

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# Introduction to the CAB toolkit

## Introduction

- This tool contains a set of “reflective questions” and a “tracking table”. It aims to stimulate reflection about different aspects to consider when setting up or running a Community Advisory Board (CAB) from the perspective of the different stakeholders involved.
- The reflective questions are organised around six different topics which coincide with the sections of the Guidance Document.
- This tool can be used in combination with the [Guidance document](#) and [the comparative table of CABs](#).
- It is possible to select from each topic the sections and questions which are relevant to the CAB at a particular point in time. Other questions can also be added. If there are plans to set up a CAB, it is recommended to consider all the questions.
- To follow up the progress of plans, it is possible to use the “tracking table” at the end of this document.



## Area 1: **Aim and scope of the CAB**

### Patient Community

|                         |  |
|-------------------------|--|
| <b>Aim</b>              | <ol style="list-style-type: none"> <li>1. Why is it important to establish a CAB for this patient community?</li> <li>2. What will the aim of the CAB be?</li> </ol>   |
| <b>Scope</b>            | <ol style="list-style-type: none"> <li>3. What will the geographical scope of the CAB be?</li> <li>4. How diverse is the patient community and what type of people will the CAB include (e.g. people living with the condition, at risk of acquiring the condition, carers, patient advocates)?</li> <li>5. What will the main scientific priorities of the CAB be?</li> <li>6. What does “success” look like? What (external) factors may influence or inhibit “success”?</li> </ol>  |
| <b>Horizon scanning</b> | <ol style="list-style-type: none"> <li>7. Which are the key pharmaceutical companies and other stakeholders with whom the patient community should interact (e.g. around research and development, pipeline/ clinical trials, access to diagnostics and treatment)? <ul style="list-style-type: none"> <li>• Does the PO/network have a relationship with any of them?</li> <li>• Do these companies have experience in working with CABs?</li> <li>• What interest could these companies have in participating in the CAB and why would they join/fund the CAB?</li> </ul> </li> <li>8. Has the PO/network done a horizon scanning to know what exists already and the gaps which need to be addressed? Are there other existing CABs in the same or similar disease/condition to learn from and collaborate with?</li> </ol> |

### Industry

1. Has the company previously engaged with CABs or is this a new concept?
2. Is the CAB engagement in-line with the overarching project/disease area strategy (long-term vs. short-term engagement)?
3. How can the company and CAB collaborate to help the company to better engage with patients and their representatives to create better solutions?
4. What does “success” look like? What (external) factors may influence or inhibit “success”?

## Area 2: **Human and financial resources**

### Patient Community

#### Administration

1. What resources are required for preparing and implementing the CAB and follow-up on the actions?
2. What are the roles, responsibilities and skills required for the Secretariat? How many hours of work will be required?

#### Roles in CAB

3. What are the roles and responsibilities of the Chair and other CAB members?
4. How will the Chair and other members work with the Secretariat?
5. Within the CAB, will there be a scientific steering committee or other bodies related to specific aspects (e.g. an access group)?

#### Timelines

6. What is the planned timeline and the main milestones for setting-up the CAB?

### Industry

1. What resources are needed for the CAB (including preparing for the CAB meeting and follow-up actions)
2. Does the company have the human and financial resources to support the CAB on a long-term basis?
3. Who can become the relationship owner, company representative, project lead and coordination within the company?
4. Is the engagement process clearly organised to have the company adapt their strategy and activities based on input received and commitments made to the patient community during a CAB?

## Area 3: **Membership**

### Patient Community

#### Recruitment of members

1. How will members of the CAB be recruited and retained, and which procedures will be used (e.g. potential collaborations/outreach for membership recruitment - organisations, fora, working groups etc.)?
2. How is it planned to promote balanced representation (diversity) in the composition of the CAB?
3. How will the ongoing recruitment of members be ensured?

#### Requirements & training

4. What are the requirements to become a CAB member? What type of knowledge, skills and experience do you expect to have from members?
5. What kind of training will CAB members need in relation to the agenda of the CAB and processes (confidentiality, conflict of interest, compensation etc.)?
6. What is the ongoing plan for training and development of the CAB? How will you develop CAB members in new potential fields of interest which may form part of the CAB Agenda?
7. How will you help further develop your members' non-technical skills (e.g. communication, etc.)?
8. How will you mentor and train new members?
9. How will you fund the training of the CAB members?

#### Rules

10. Which rules of conduct will be applied to CAB members?
11. Will CAB members be asked to have their names publicly available (e.g. for transparency)?

### Industry

1. What expertise and experience are required for CAB participants representing the company?
2. What level of training or mentoring will need to be provided to CAB participants in preparation of CABs?
3. How will it be ensured that representatives from industry attending the CAB meeting have an understanding of the roles and functions of the CAB?

## Area 4: **CAB meetings**

### Patient Community

#### Meetings

1. How will it be ensured that the meeting is meaningful for all involved and aligned with the aims and priorities of the CAB?
2. How will the CAB work with each company to organise the meeting and to ensure a two-way dialogue in all relevant issues?
3. How and where will the meetings be organised (e.g. face-to-face, virtual meetings? If face-to-face, same country for all meetings, rotating system etc.)?
4. How long and on which day(s) should a CAB be planned? How can this respect the need of participants (e.g. over weekends for those attending on a voluntary basis, in the first half of the day for those with fatiguing conditions, etc.)
5. How many participants should be invited from both community and industry?
6. Who will moderate the CAB meeting? Who will take the minutes?
7. Will there be a briefing session with members before the meeting and a debriefing afterwards?
8. Which pre-meeting materials need to be received from industry, and by when, to allow sufficient time for CAB members to prepare?

#### Members attending meetings

9. Which procedure and selection criteria may work best for your patient community to decide which members will attend the meeting? Who will be in charge of these procedures and decisions?
10. Which needs of the patient community should be considered when planning the meeting (e.g. mobility problems, fatigue, cognitive problems)? Which type of support will you provide to CAB members?
11. Which pre-meeting material do you plan to share in advance of meetings? What should be considered when preparing this material? What timelines will be required for the pre-meeting material (e.g. not to receive materials the day before of meeting so conversations can be as rich as necessary)

### Industry

1. How will the company representatives attending the CAB be optimally prepared?
2. Which pre-meeting materials need to be sent, and by when, to allow sufficient time for CAB members to prepare?
3. Have all relevant company functions such as Legal, Compliance, Finance, been engaged early on to ensure full compliance with laws and regulations and review and approval processes?

## Area 5: **Funding models and official/legal documents**

### Patient Community

#### Funding

1. What are the plans to fund the CAB and which actions are needed (e.g. contacting the funder, preparing a formal letter, etc.)?
2. What costs would be included in the funding request for a CAB?
3. What financial documents are needed to get funds for CABs? (e.g. financial agreement or sponsorship arrangement). What other documentation may funders need?
4. Who will be the recipient of the funds (e.g. is the CAB a legal entity and can the CAB receive the funds?)?
5. Will the funding be on an annual basis or are longer-term contracts possible? What type of contract needs to be used?

#### Cost (members)

6. Will any member of the CAB be remunerated for a particular task?
7. Will CAB members be compensated for the time spent at the meeting, trainings and/or other preparations?

#### Documents

8. What are the terms and conditions of confidentiality and other compliance measures that could be in place for the CAB?
9. Do CAB members need any support, information or training to understand concepts such as confidentiality, conflict of interest or the possible consequences of receiving compensation?
10. Is legal support needed to assist the patient community with the processes and documentation associated with organising a CAB?

### Industry

1. What documentation is required to set up a contract?
2. What type of funding models exist within the company?
3. Will the funding be on an annual basis or can you commit for more than one consecutive year? If so, who would need to be involved in such discussions (e.g. finance)?
4. What contract and confidentiality agreement will be used?



## Area 6: **Impact and follow-up activities**

### Patient Community

#### Follow up

1. How will a long-term relationship with each company be developed and sustained in line with the CAB's objectives? Which tools will the CAB use to keep track of the agreed actions?
2. Which channels and tools will the CAB use to maintain a constructive and timely communication after and between meetings with industry (and other constitutional stakeholders) and with CAB members.
3. How will the report/minutes be structured? Who will be responsible for preparing the minutes (e.g. a member, professional minute taker, etc.) and how will this person be selected? With whom and how would you share these documents?

#### Impact

4. How is the impact and quality of the CAB monitored and evaluated?
5. How is whether the CAB has been meaningful, productive and impactful assessed?

### Industry

1. How will timely follow-up on open requests from CABs be ensured?
2. How will follow-up activities be evaluated and sufficient resources to meet the agreed milestones identified and secured?
3. How does the company maintain timely and constructive communication and dialogue with the CAB?
4. How will the company measure impact of the CAB?

## Tracking - Stakeholder:

| Area & question number | Actions | Challenges | Follow-up |       | Achievements |
|------------------------|---------|------------|-----------|-------|--------------|
|                        |         |            | Who?      | When? |              |
|                        |         |            |           |       |              |
|                        |         |            |           |       |              |
|                        |         |            |           |       |              |