Community Advisory Boards

Working with Community Advisory Boards: Guidance and tools for patient communities and pharmaceutical companies

Background/Rationale for the document
Community Advisory Boards (CABs) can improve research by providing direct and independent advice from the community of patients about different aspects of a clinical trial in ways that are more inclusive from the perspective of patients. Setting up and running a CAB requires careful planning, organisation, follow-up, monitoring and evaluation.

Objective of the tool
The objective of this toolkit is to offer information, material and references that can support patient communities and pharmaceutical companies with different backgrounds (such as different levels of expertise, or from different disease areas) interested in setting up, running or engaging with CABs.

Summary of the content
The toolkit on Community Advisory Boards (CABs) contains 8 different documents (1 guidance and 7 other tools):

1. The CAB Guidance contains three different sections. Readers can consult the entire guidance document as a general guiding tool for CABs or use the separate sections according to their needs and specific focus in engaging with patient communities.
2. CABs at a “glance”: This tool is a brief summary providing a high-level overview of how a CAB operates.
3. Comparative tables for three existing CABs: This table provides information about three different approaches for setting up or running a CAB.
4. Checklist of tools and resources: This tool includes a list of templates and documents which can be useful when

working with CABs.

5. Reflective questions and tracking tool: 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/running or collaborating with CABs.
6. Value-adding factors of a CAB from a pharmaceutical company perspective: while CABs are established to encourage patient engagement, they also offer a unique way to provide input in the development process for companies. This tool gives an overview of what CABs can deliver and how from an industry perspective.
7. Practical briefing guidance for industry: This tool refers to what company representatives need to consider and how to get prepared for participating in a CAB meeting.
8. Examples of successful outcomes of CABs and industry interaction: This tool describes three case examples of how CABs have been instrumental to provide timely patient input to change the course of the studies leading to successful outcomes.

Key message

This toolkit intends to provide a basic set of instruments for the initiation and development of CABs. Representatives of patient organisations and pharmaceutical companies (as well as other stakeholders) are invited to consult and use this toolkit as a whole or consider its individual elements according to their needs and interests.

Methodology

Overall approach

The Community Advisory Boards (CABs) toolkit has been developed in the context of the PARADIGM project. The work has been led in a collaborative style by an authoring group

composed of four people from the patient community and industry. Ongoing input was sought from other patient groups, companies and academia within the scope of PARADIGM. In addition, when appropriate, other relevant organisations outside of the PARADIGM consortium were invited to collaborate and provide information and feedback.

The development of the tools involved:

• Online searches for publicly available information and materials. A short questionnaire was sent to members of the PARADIGM consortium (patient groups, industry, academia) to gain broad understanding of existing initiatives and approaches.

• Discussions with representatives of three patient groups (i.e. HIV/AIDS, rare diseases and oncology) with experience in CABs to gather further information and insight not publicly available. Each patient group decided which CAB to showcase as an example of working on each of the topics. In the case of rare diseases, it was decided to refer to the work of their CAB-related programme (EuroCAB) rather than to one specific CAB within the programme.

• Iterative drafting, writing and revision of the tools. The main text was written by the members of the working group who led this work. The examples from CABs were each written by the respective patient community. In the case of HIV, as the patient organisation EATG was part of the working group, they were involved in the writing process of both the main text and in the specific information about their CAB.

• Ongoing feedback and validation process from different organisations /stakeholders with and without experience of working with CABs. The list of people and organisations involved in this work is available in the list of authors and contributors.

Basis of the work

The information gathered suggested that:

• There is still often a lack of information or

misunderstanding about CABs and their role.
• Different approaches and needs exist (e.g. communities or companies starting their work with CABs and others with several years of experience). Tools could be very important for both, those starting their work with CABs but also for those who have been working with CABs for a long time and should be flexible to adapt to new needs, priorities and ways of working of different patient communities
• The tools should include tailored information for each stakeholder (i.e. patient community and industry) and be developed to address their specific needs, but all tools should be developed together in a collaborative manner and reflect the collaboration between patient communities and industry.

The tools were developed with these principles in mind and aimed at providing information of CABs (tools 1, 2, 6 and 8) and providing support for planning /working with CABs (tools 1,3,4, 5 and 7).

Development of tools
The Guidance document (tool 1) was initially developed based on the expertise from members of the working group, existing information about CABs and the specific information provided by each patient community about their CABs. Early drafts were shared with representatives of the three patient groups and industry and their feedback incorporated in the document. Several rounds of feedback were organized at different points during the development of this tool.
Tools 2, 3, 4 and 8 were developed after this, focusing on specific aspects of the Guidance document (tool 1) with the aim to present some of the relevant information in a more simplified and straightforward manner (e.g. comparative table, checklist).

Tools 5, 6 and 7 were co-developed as part of a PARADIGM workshop in March 2020. Ideas to improve tool 5 and the need for and contents to develop tools 6 and 7 were discussed

during the workshop. After this, the working group developed the tools based on the discussions.

The final validation process involved a task force composed of a mixed-group of representatives of patient organizations and industry, which provided final input on the eight CAB tools. In addition to the specific ongoing feedback from patient communities with experience in CABs and industry, the tools have received feedback from two internal consultations within the consortium and the PARADIGM public consultation. The feedback received from organisations and individuals with expertise and interest in CAB has been assessed by the authors and appropriately integrated in the final version of the tools.

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Download the Guidance

- **Printable tools**

Download CABs toolkit

CAB tool 1

CAB tool 2

CAB tool 3

CAB tool 4

CAB tool 5

CAB tool 6

CAB tool 7

CAB tool 8

- **Black and white version**

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- **Russian language version**

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CAB tool 1

CAB tool 2

CAB tool 3

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CAB tool 5

CAB tool 6

CAB tool 7

CAB tool 8