



Conducting Patient Engagement



Community Advisory Boards

Tool 2: CABS “At a Glance”

Introduction to the CAB toolkit

Community Advisory Boards (CABs) At a Glance

- CABs are a way of fostering long-term collaboration between the patient community and pharmaceutical industry with regard to research, development and access to medicines. CABs are initiated and driven by the patient community.
- CAB members and industry representatives meet on regular basis. The preparation of a CAB meeting starts well before the meeting and involves close collaboration between the designated representatives of the CAB and industry. The agenda is proposed by the CAB and discussed with the invited company. Additional topics of mutual interest can be agreed and added to the agenda. In most cases, a patient organisation/network acts as a Secretariat for the CAB and provides support for the administration of the CAB and the travel, training and support to members. The Secretariat works closely with the CAB Chair.
- The number of CAB members attending a CAB meeting varies. On average 8-10 members of the CAB participate in the face-to-face meeting. A selection process can be organized to decide which members will attend the meeting.
- A CAB face-to-face meeting is organised over 2-3 days (often weekends) and members meet with several pharmaceutical companies. Each company meets separately with the CAB members under confidential terms. However, in some cases several companies can be invited to attend a CAB meeting simultaneously to discuss relevant cross-company advocacy issues.
- After the meeting, the minutes and a list of follow-up actions are produced by the CAB and shared with the industry representatives for review and agreement. Follow-up actions are discussed in the following meeting in order to discuss progress on the company's commitments. Between CAB meetings, the CAB Secretariat should ensure monitoring of progress whenever possible. There are different ways of approaching the evaluation and monitoring of the work of a CAB. PARADIGM developed a monitor and evaluation framework for PE.
- Organising and conducting a CAB requires adequate financial and human resources. Industry partners attending the meeting are expected to support the costs associated with the organization of the CAB. Different funding models exists. All CABs require that costs of travel and accommodation of members are covered. Some members of the CAB can be contracted (i.e. paid) for undertaking particular tasks (e.g. chairing the meeting, minute taking etc.). In some cases, members of the CAB participate on a voluntary basis (e.g. they are not paid for their time), in others, all members of the CAB are expected to be receive remuneration in line with the principle of Fair Market Value.
- Legal agreements between the CAB and the company are necessary and should include relevant points such as the purpose of the collaboration, confidentiality and any other consideration for members. These agreements are often different for each company. There are recent efforts to standardise these agreements and make them more accessible (see the Reasonable Agreements between Patient Advocates and Pharmaceutical Companies (RAPP) project <https://wecanadvocate.eu/rapp/>).