



Participation of Patient Advocates in Community Advisory Boards

A case-study: the European Community Advisory Board

What is the European Community Advisory Board



- The European Community Advisory Board (ECAB) was established in 1997 as a forum for interaction between the community of people living with HIV and AIDS (PLWHA) and the pharmaceutical industry.
- ECAB operates as a working group of the European AIDS Treatment Group (EATG), a European voluntary patient organisation for PLWHA.
- At the end of 2016 ECAB had 112 members. The membership covers a total of approximately 38 countries.

ECAB achievements – 1



Key achievements and milestones include:

- Putting a lower limit of CD4 cell count to one important trial in treatment naïve patients.
- Working out and maintaining an access template for all drugs of the companies working in the field. The database informs about the registration status, availability and reimbursement of drugs in every European country.
- Participation of ECAB members in different data safety monitoring boards (DSMB) attached to clinical trials.
- Achieving amendments to protocols that were not in the best interests of study participants.
- Formal cooperation and communication with the European Medicines Agency.

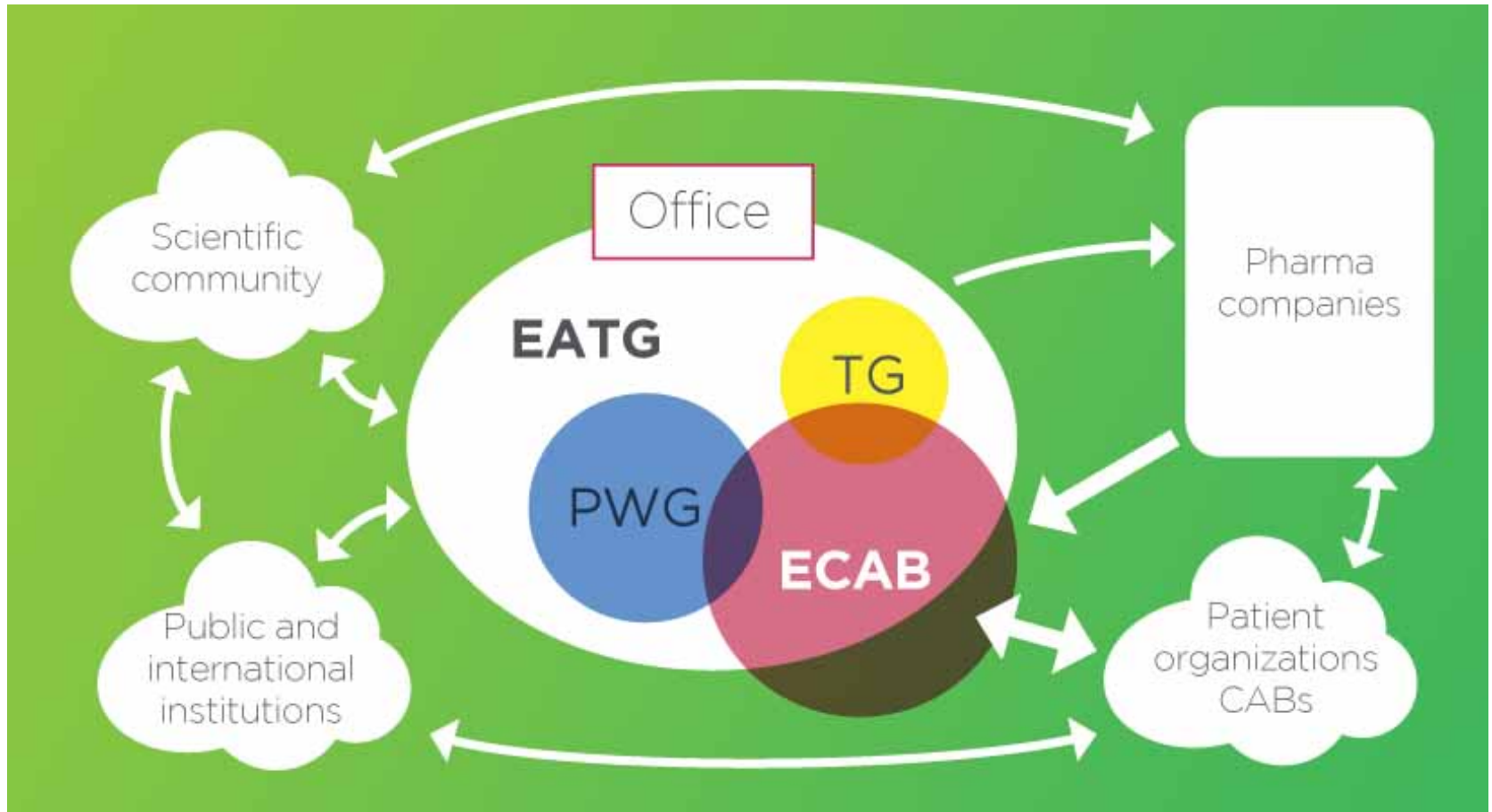
ECAB achievements – 2



Key achievements and milestones include:

- Voice of patients in the EU with several formally held positions in institutions.
- ECAB as a part of EATG is collaborative organisation to WHO Europe.
- Maintaining close relationships with important research groups and consortia.
- Recognised and involved in pan-European structures – European conferences, guideline panels, EU panels and conferences.
- Leading role in helping promote ECAB-like working models in different European countries, and strengthening the empowerment of PLWHA in the field of treatment and research.

ECAB structural mapping



ECAB: European Community Advisory Board
EATG: European AIDS Treatment Group

TG: Training Group (within EATG)
PWG: Policy Working Group (within EATG)

The funding structure of ECAB



- Being part of the EATG, ECAB is integrated into its budget.
- Pharmaceutical companies contribute to the funding of ECAB in different forms:
 - Through core funding in the form of unrestricted grants,
 - through support for ECAB meetings, and
 - through sponsoring specific projects (conferences, information campaigns etc.).
- With the changing legislative environment in the European Union and a ban on direct to consumer advertising of pharmaceuticals, this form of funding has become a matter of controversy.

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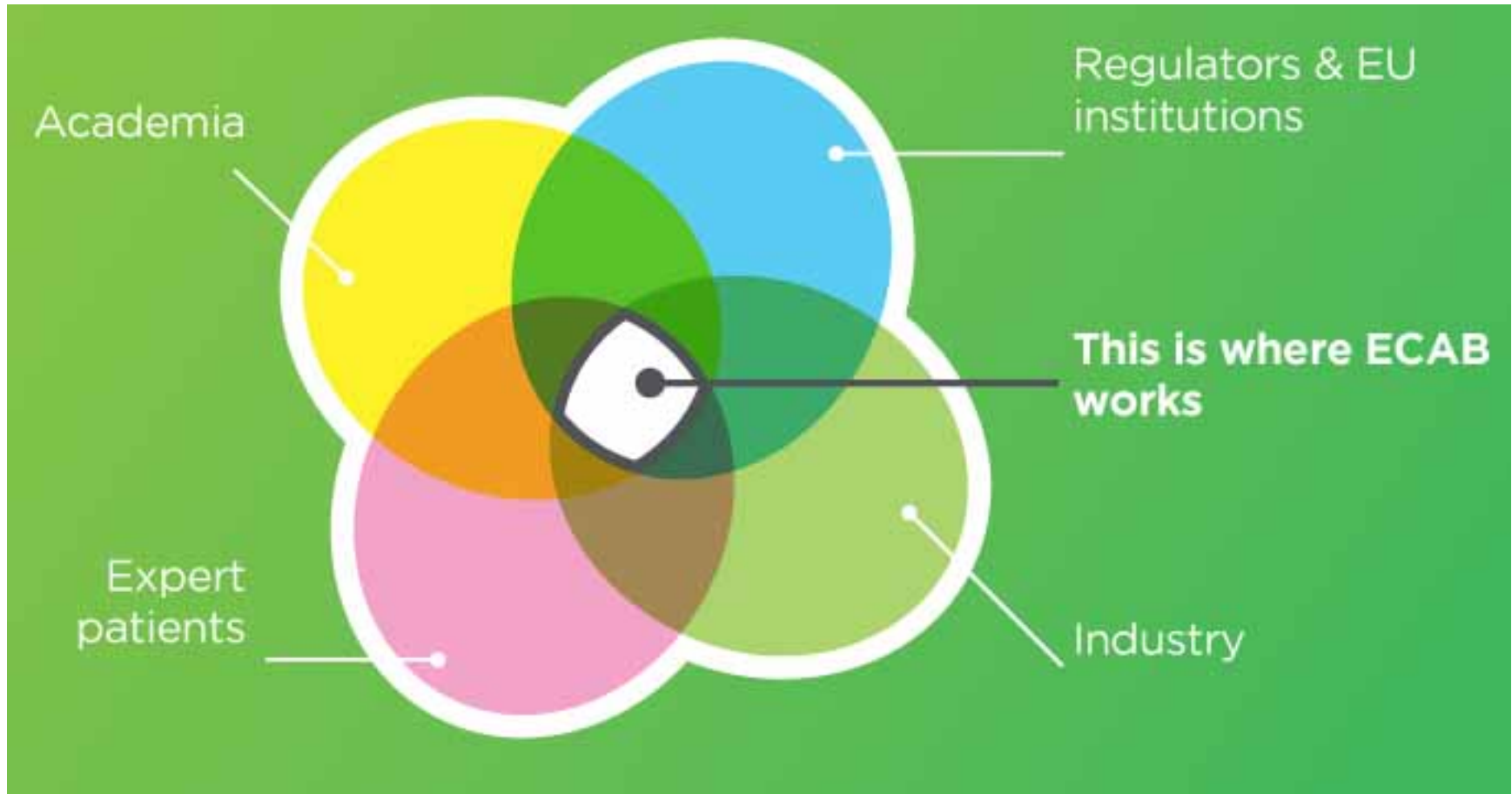
EATG and ECAB stand firm in saying that interaction with the pharmaceutical industry in ECAB meetings is:

- rigorously scientific;
- confidential;
- targeted at information exchange between the community and industry;
- organised on the highest possible level between patient advocates and researchers;
- outside of the scope of usual interactions between industry and consumers;

and therefore cannot be seen as direct to consumer marketing of drugs.

Nevertheless, there has been intensive work done at EATG/ECAB to ensure diversification of funding, especially through the involvement of non-pharmaceutical and public funders.

General working model



Wienold, M., Community Participation in Clinical Research, Hanover, 1997 and Derbyshire, J., *Patient groups - Do they have anything to say?*, in: European AIDS Treatment News, Spring 2011, 8-9

ECAB work



The work of ECAB is composed of several elements:

- regular meetings,
- substantial back-office work by the Scientific Officer and the Hepatitis Officer,
- and several lively e-mail lists keep the daily work of the organisation going.

ECAB meetings



- Most ECAB meetings are held over week-ends; they are usually divided into five units, app. 3.5 hours each, and companies and other presenters can reserve one or two units (which means either a half or a full day).
- Meetings with companies are conducted under strict confidentiality.
- Sunday morning meetings are reserved for the discussion of internal ECAB. Training sessions cover current or general scientific and policy related topics.
- A full-time staff of the EATG, the Scientific Officer has the task of supporting the development and strengthening of EATG's activities in the key area of science and research.

ECAB meetings agenda



- ECAB, i.e. the community sets the agenda of the meetings. Setting the agenda and taking the initiative in the community's own hands are cornerstones of the organisation's work and success.
- ECAB includes clinical trials and compounds in its agenda from phase II trials upwards to phase IV.
- Topics suggested by the companies are completed with the proposals and questions of the community, which are collected and collated by the company liaisons and the Scientific Officer.
- The company liaison responsible for the company invited will start working with the representative of the company several weeks ahead of the meeting.
- A pre-meeting precedes the company meeting, which is confidential and private to ECAB members and EATG staff. New or inexperienced members are briefed in the pre-meeting, but questions are always welcome also during the meeting.
- All meetings are minuted, and the minutes are shared with the companies concerned.

References



- EATG ECAB, “The impatient Patient - From Anger to Activism”
A systematic review of the history, working models, relevance and perspectives of the European Community Advisory Board
<http://www.eatg.org/wp-content/uploads/2016/05/The-impatient-patient.pdf>