



European
AIDS Treatment
Group

The impatient patient - From anger to activism

A systematic review of the history, working models, relevance and perspectives of the EATG – European Community Advisory Board to provide guidance and best practices for a possible model of interaction between patient organisations, industry, academia and regulators.

Download full report:

www.eatg.org/gallery/168463/The%20impatient%20patient.pdf

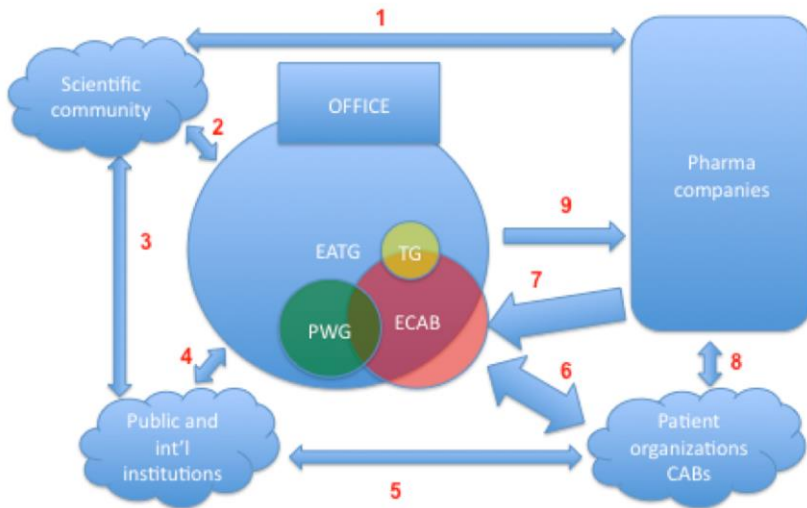
David H.-U. Haerry, EATG
david@eatg.org

Background + Methodology

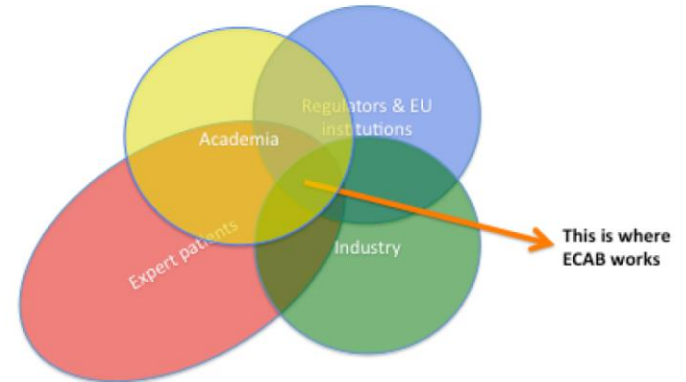
- The **European Community Advisory Board (ECAB)** – 15 years in the forefront of patient advocacy and scientific research.
- ECAB established in 1997 – **forum for confidential interaction about drug development between PLHIV and industry.**
- **Objective:** To support the organisation's work in promotion of biomedical research & pharmaceutical development in HIV/AIDS and related co-infections.
- Mixed-method **quantitative and qualitative research** was conducted with organisation members, stakeholders, and pharmaceutical industry representatives.
- Members of the organisation (n=36) and industry representatives (n=13) polled through questionnaires. SWOT analysis of functioning of ECAB followed up by semi-structured interviews with members (n=27). Interviews analysed for meaning and key concepts, contrasted against the questionnaires.

ECAB – Crossroads between patient organisations, industry, academia and regulators

The current structure of ECAB in relation to relevant stakeholders



The quadruple helix of ECAB



ECAB can be seen, and positioned as, a novel vehicle of innovation.

Wienold, M., Community Participation in Clinical Research, Hanover, 1997 and Darbyshire, J., Patient Groups - Do they have anything to say?, in: European AIDS Treatment News, Spring 2001, 8-9.

ECAB – Crossroads between patient organisations, industry, academia and regulators

RECOMMENDATIONS

- **ECAB** working model transferable to PO, civil sector - knowledge transfer methodologies
- Mapping, monitoring member skills, knowledge
- T & E programme for **ECAB** members
- ‘School of excellence’ concept for HIV patients proposed
- Discovery, institutionalisation informal existing knowledge
- Proactive new member recruitment (special skills)

KEY FINDINGS

- **ECAB** = model for meaningful & useful interaction across all stakeholders.
- Peculiar dynamics, roots in activism call for forward looking management & clear vision.
- Anger based activism no longer suffices – strength in knowledge base and member commitment.
- **ECAB** = tool of innovation, vehicle of patient empowerment.