

# THE IMPATIENT PATIENT

A DISCUSSION OF PATIENT INVOLVEMENT IN NOVEL FORMS OF KNOWLEDGE PRODUCTION  
— A CASE STUDY OF THE EUROPEAN COMMUNITY ADVISORY BOARD ON HIV/AIDS

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## ABSTRACT

Novel forms of knowledge production and dissemination increasingly extend to the involvement of civil society. This research looks at the role of the community of people living with HIV (PLH) in biomedical research and pharmaceutical development by tracing the evolution of such involvement from anger to activism to scientific contributions. The institutional review of the European Community Advisory Board (ECAB)<sup>2</sup> has examined the history, working models, relevance, and future perspectives of the organisation. Semi-structured interviews have been conducted with organisation members and stakeholders to explore the history of ECAB and its role in scientific research. The concept and role of the “expert patient” are discussed. This paper emphasises the role of expert patients and their organisations in the production of knowledge with recommendations to ease the burden on health care institutions, reduce stigmatisation and discrimination, and to add aspects of the ‘consumers’ of knowledge to the process of knowledge production. The triple-helix model of knowledge production is revisited, and the adoption of a quadruple-helix model is proposed that includes civil society (the patient community) in the process of knowledge production and distribution. On a more general level, some conclusions are drawn as to how the empowerment of patients may in turn lead to a deepening and widening of democratic processes through increased awareness of citizens of their rights. A model of transition from expert patient to empowered citizen is proposed.

## KEYWORDS

HIV, HIV/AIDS, HIV activism, sociology of knowledge, patient involvement, patient empowerment, Triple Helix, EATG, ECAB

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## INTRODUCTION

In 2011, the WHO estimated the number of people living with HIV in Europe to be around 2,300,000.<sup>3</sup> Even if it has become a manageable disease, HIV infection remains incurable, and leads to AIDS-related illnesses and death, if left untreated. Although the spreading of the disease has slowed globally, there is a clear increase in the number of new infections, especially in the East European region, with almost 30,000 new diagnoses in 2012,<sup>4</sup> as shown by recent data from the European Centre for Disease Control. The key affected populations include men having sex with other men, young adults of all sexual preferences, and injecting drug users. Some of these groups qualify as difficult to reach, either because of their socio-economic status (e.g. sex workers, injecting drug users) or because of stigmatisation and discrimination that isolate them from mainstream information sources. Although antiretroviral therapy (ART) is relatively widely available in the European region, there are serious gaps in access to treatment even in high-income countries.<sup>5</sup>

The dissemination of relevant information on treatment and prevention is the responsibility of health-care systems; however, involvement of the community of people living with HIV (PLH) in this process has been paramount for more than two decades simply because of the sheer size of the task. Wienold (1997: 21) provides a thorough description of the early history of HIV/AIDS activism and patient involvement in Europe “[f]rom the streets and from public action, patient pressure has over time been transferred to the meeting rooms of Community Advisory Boards in numerous forms”. Wienold outlines the process of how the (initially) politically motivated process of activism transgressed into, pressurized and then infiltrated the world of pharmaceutical research.

## FROM PATIENT TO EXPERT PATIENT TO CONSUMER

Anderson *et al.* (2010) point out that receiving a HIV diagnosis causes shock and stress and leads to a “biographical disruption” for most persons. In their thorough and in-depth analysis, Tsarenko and Polonsky highlight that any life-changing illness, such as HIV, is an undesired “possession” that “people accept to varying degrees”, i.e. integrate into their identities (2011: 465). They describe that, while identity transitions can be very different from person to person, the positive framing of the experience is also important for health outcomes, and they recommend focusing on the “new life” rather than aspects of loss (Tsarenko and Polonsky, *ibid*).

Becoming a treatment activist (or expert patient) takes time (Wienold, 2003) and effort, and one part of this process is intra-psychic elaboration of stigmatisation and discrimination, which often turns into anger, and then into determined effort. In a former research, this author interviewed several peer helpers and treatment activists living with HIV (Bereczky, 2011, in publication). One of the key findings documented was how internalised fear and frustration caused by the disease and stigma could be turned around into positive, productive work. Patient organisations epitomise this process of “positive transition,” as also suggested by Tsarenko and Polonsky.

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<sup>3</sup> <http://www.euro.who.int/en/health-topics/communicable-diseases/hivaids/data-and-statistics>, last accessed on 25.11.2013.

<sup>4</sup> <http://ecdc.europa.eu/en/healthtopics/aids/Pages/infographics.aspx>, last accessed on 30.11.2013.

<sup>5</sup> <http://www.who.int/hiv/data/ARTmap2013.png>, last accessed on 25.11.2013.

Consequently, there may be different pathways towards integrating HIV into one's identity. One of the alternatives is the way of the "expert patient" (Kielmann and Cataldo, 2010). Expert patients are people living with a medical condition who become highly educated about their disease and work as active contributors to the provision of health-care services, psychosocial support, advocacy and policy services to other patients. More and more patients in different disease areas organise themselves into patient organisations: the European Patients' Forum, the umbrella organisation for patient organisations in the EU currently includes 61 patient organisations representing 150 million patients from different disease areas.<sup>6</sup>

Tsigas and Magee describe three typical forms of patient organisation:

- (1) providing emotional support and information to patients;
- (2) collective work to influence public policy through advocacy;
- (3) medical research organisations by patients focusing on translational research and research gaps (2011: 524).

Tsigas and Magee also identify the following areas for the meaningful intervention of patient organisations (patient advisory boards) in the biomedical research and regulatory (political) processes (2011: 527):

- enhancing patient awareness;
- enhancing the provision of education and training;
- supporting research, building the science base and accelerating knowledge translation;
- overcoming barriers to accessing care and high-quality care;
- changing perceptions of the disease;
- influencing public policy;
- increasing collaborations within and between the public and private sectors.

Henderson and Henderson point out the importance of recognising patients as informed consumers of health-care services – a concept that is increasingly present in health-care approaches in the West. They also point to the importance of admitting the 'everyday knowledge' of patients into the process of consideration about biomedical research (2010: 613). They highlight the fact that "the addition of everyday knowledge to the communication process between patients and health professionals would contribute to [...] a more informed decision-making process" (2010: 615). Discussing the balance of power between patients and health professionals (2010: 614), they also emphasise that the knowledge of the patient is not considered when making decisions about their health care, which may lead to dissatisfaction, and ultimately, weaker results.

The European Medicines Agency (EMA) has already recognised the importance of involving patients and consumers of medicines and medicinal products in the regulatory process. The EMA very consciously also tries to become and remain a driver of innovation, this being one of its declared objectives.<sup>7</sup> The Committee for Medicinal Products for Human Use (CHMP) of the

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<sup>6</sup> <http://www.eu-patient.eu/Members/>, last accessed on 25/11/2013.

<sup>7</sup> <http://goo.gl/5UzesQ>, last accessed on 25 September 2013.

EMA includes an important vehicle of patient involvement: the Patients' and Consumers' Working Party<sup>8</sup> (PCWP), which currently works with representatives from 19 patient organisations.

Caldon *et al.* discuss the involvement of 'consumer groups' (where they also include patient groups/organisations) in cancer research in the UK (2010: 547). They admit that: "Consumers should be regarded as an expert resource and equal members of the research team [...] [this would add] depth to data interpretation" (2010: 550). However, the literature on patient involvement in biomedical research and treatment activism in Europe is scarce. The compilation of a relevant bibliography with a broader perspective could be of interest for further research.

#### THE TRIPLE- AND QUADRUPLE-HELIX MODELS OF KNOWLEDGE PRODUCTION

Leydesdorff and Zawdie (2010) give a detailed description of the triple-helix model of innovation and knowledge production. Contrasting with national innovation systems, they describe the triple helix of interaction between government, university and industry as "a recursive interaction system underlying the knowledge-based economy" (2010: 789). They point out that the triple helix provides a model that can explain the dynamics underpinning innovation systems in a geographically less constrained and more competitive global economic environment.

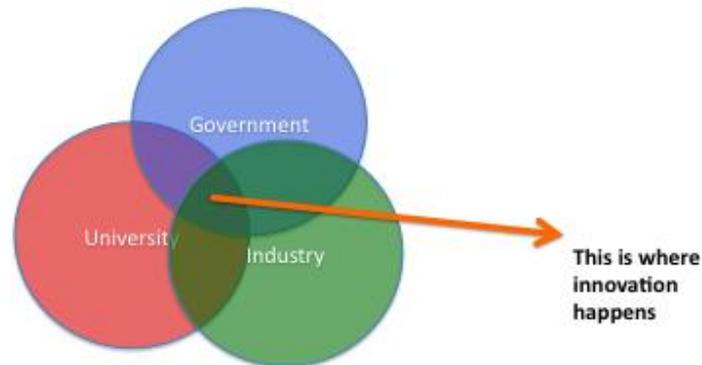
Discussing the triple-helix model as described by Etkowitz and Leydesdorff, Kotsis and Nagy underline how the closeness and intensity of the cooperation between these three institutions define the dynamics of the innovation systems of a country, region or industry. The triple helix is at once an analytic and normative model. Kotsis and Nagy also refer to it as a tool that helps describe the relationship of governments to universities and industries (2009: 123).

Oberman Peterka *et al.* include the civil society in the triple-helix model, albeit in parentheses and as part or constituent of the 'industry' arm of the model (2012: 869). The discussion of the possible implications of cultural differences between the partners involved does refer to the social development implications of the triple-helix model, but completely ignores the possible role of the civil sector in this process.

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<sup>8</sup> <http://goo.gl/9mEq85>, last accessed on 25 September 2013.

## The triple helix model



When discussing Mode 3 Knowledge Production Systems, Carayannis and Campbell describe knowledge production as both a top-down process through government, university and industry policies, and a bottom-up process stemming from civil society (2012: 3). By adding civil society to the classical model, they introduce the concept of a 'quadruple helix' (2012:13) that includes the media- and culture-based public, and the civil society. This implies a higher level of integration of the public into advanced innovation systems.

Lindberg *et al.* (2012) use the example of Women Resource Centres in Sweden and Europe to demonstrate the expansion of the triple-helix model by adding another helix of the civil society (women's groups, in their case). They refer back to the theoretical frame of Creative Knowledge Environments as work settings in which people generate new knowledge on the basis of the causality between creativity, knowledge development and innovation (2012: 46). They conclude that the WRC model is a practical implementation, or rather manifestation of the theoretical quadruple helix model described by Carayannis and Campbell (2012: 47). They also refer back to MacDonald and Maldonado (*ibid.*) to state that the inclusion of NGOs, citizen groups, associations and think tanks in the 'helix model' is essential in order to make it complete.

### PURPOSE

The original terms of reference defined two key purposes of this study:

(1) to map out and describe the history and evolution of the European Community Advisory Board; and

(2) to explore its contribution to biomedical research, pharmaceutical development, and knowledge production in the field of HIV/AIDS.

This paper discusses the outcomes of the second part of the study, with a brief description of ECAB's history where relevant. The study aims to enrich the discussion about current models of knowledge production, with particular regard to the triple-helix

model. Qualitative interviews were used to explore the experience of participants in the work of this organisation about its contributions to knowledge production processes. The more conscious use of patient organisations and civil involvement in translational biomedical research promises more patient-centred and health-focused outcomes, which in turn lead to better health outcomes, and the empowerment of the patient community. ECAB and its work provide a unique example for this type of involvement. Another distinct aim of the study is to improve the processes and work of ECAB in the longer term.

## METHODS

The study was carried out between June 2012 and May 2013. The sampling frame was defined by the terms of reference. Participants were selected on the basis of their involvement in ECAB's history and work. Former chairpersons of the organisation, founding members and the Scientific Officer of EATG were included. Care was taken to ensure a good geographical distribution of the sample, however, this was not always successful. Countries covered included Bulgaria, Croatia, Denmark, France, Germany, Greece, Italy, Israel, Netherlands, Portugal, Russia, Switzerland, and the United Kingdom. Members from other countries have not usually been involved in the work of ECAB long enough to be able to reflect on the historical evolution or achievements of the organisation.

Semi-structured interviews were requested from 27 participants. Two requests were declined; four participants did not provide answers or a formal refusal to participate. In total, 11 interviews were conducted, while 10 participants opted to reply to the interview questions in writing. Out of 21 respondents of the completed interviews, 19 were living with HIV, and all have been working in the field of HIV/AIDS activism and/or research for at least five years. The socio-economic status of the respondents was not captured. Interviews were about 60–90 minutes long, conducted over the telephone and/or Skype (VoIP) and recorded, transcribed, and edited for grammar and clarity. Transcripts were anonymised, names changed and all personal details were removed that would allow identification.

Written responses and interview transcripts were collated into a unified corpus and transformed into a codebook along key common topics. No specific quantitative analysis was applied to the dataset; rather the researcher looked at the contents of the interviews and the meanings represented. The coding was conducted by a team of two researchers. Key common elements of the narratives provided by the participants were filtered and interpreted, then combined into a common narrative. No software tool was used for the analysis; however, basic considerations for a standard manual discursive analytical approach were applied following guidelines described by Potter and Wetherell (1987). Cases of ambiguity or doubt were resolved by the researchers through discussion; and in one particular case, triangulation with a third researcher was used to elicit the meaning of a particular segment.

There were several shortcomings of the interview process. Interviews conducted over the telephone or VoIP lack the personal intimacy and directness of personal meetings; however, the geographical diversity of the sample of participants and budget limitations forced the researcher to conduct interviews over telecommunication media. All interviews were conducted in English, while most participants were not native English speakers. The research team had to pay special attention to the interpretation of fragments and grammatically ambiguous utterances.

A set of 14 questions was used with all participants. The questions covered the history of ECAB, a short SWOT analysis, vision and recommendations for the future of the organisation, and the personal experience of being involved in ECAB's work. Questions were sent to the participants by email in advance with ample time allowed for them to prepare.

The interviews also included specific questions on the strengths, weaknesses, opportunities and threats (SWOT analysis) of ECAB and its work. Analysed in a separate paper, the statistical evaluation of the SWOT analysis is therefore also informed by the responses of interview participants.

## ETHICAL CONSIDERATIONS

Informed consent was obtained from all participants: they were specifically asked at the beginning of the interview to give their consent to participation. The Board of Directors of the EATG passed a separate resolution, approving the conduct of the study within the organisation on the basis of its terms of reference. Participants were thoroughly briefed and debriefed about the nature of the study, its purpose and the methods used. Participants were allowed to withdraw from the study any time they wished. The name and email address of the supervisor (EATG Scientific Officer) was provided to the participants. One's membership in a voluntary HIV organisation can be a sensitive issue, as HIV is still associated with stigmatisation and discrimination. Therefore, no demographic data were captured, to avoid any possibility of identification, and different participants are numbered when quoted from their interviews (P1-21). Most of the selected participants are 'out' about their HIV status and have been working in the HIV field as peer helpers for several years. The researcher also works as a peer helper in the same organisation, which created a sense of solidarity and confidence. All data were anonymised. Analysis of the data and quotations from the interviews were edited so that the identity of the respondents cannot be discerned. Original recordings of the interviews were stored in password-protected files after transcription. Personal details that allow identification were not recorded or divulged. Transcripts are kept on a separate storage device where only the researcher can access them. The researcher prepared transcripts of the interviews; no outside person was involved at that stage.

The Code of Ethics and Conduct of the British Psychological Society<sup>9</sup> was respected.

## Disclosure

The author of this paper worked under contract as an independent researcher for the duration of the project, while also participating in the work of ECAB as a member. During the research project, the author was required to regularly consult the project supervisor, and external referees were involved to make sure that the viewpoint of the researcher was not biased.

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<sup>9</sup> <http://www.bps.org.uk/what-we-do/ethics-standards/ethics-standards>, last accessed on 23.12.2012.

## RESULTS

### From anger to activism

One of the key findings of this research is how the history of ECAB and patient involvement is rooted in anger and frustration caused by sluggish drug development, and the lack of political will to tackle the HIV epidemic, even in developed countries. This factor of anger renders the entire process 'politically' motivated, but it also points out another important factor: the will to survive as an essential drive behind the birth and then continued work of patient involvement and empowerment.

Discussing this phenomenon, one respondent said: "The will to survive definitely helps with the motivation of getting people involved. I think it's more on the personal level and less on the institutional level that you would have it. Maybe in the beginning, when EATG was started, it was more [...] the death threat was so pervasive. It is still a good motivator for individual members to get involved. I think in regions where access is less than optimal, like in the East, this can still be a good motivator. But in Western Europe, it is probably a mixture, it is a lot less important I guess." (P12)

From the earliest days of treatment activism fuelled by frustration and anger and the unethical conduct of clinical trials (where patients were encouraged not to take their drugs, to find out whether they were in the placebo arm), incensed by neglect from the federal government of the US (Wienold 1997: 18), there is a clear line of history explaining how activism crossed from the US to the UK, and then to the European continent.

A rudimentary form of patient meetings was instituted by the EATG before 1997. One founding member remembers: "Since its implementation in 1992, EATG has had meetings with pharmaceutical companies to receive information on research/drugs in the pipeline, discuss trial designs, and (partially) also marketing strategies. [...] This happened mostly when a problem came up [...]." (P2)

"ECAB was created by a new generation of HIV activists who 'came into power' in 1996 at the time of the arrival of protease inhibitors, with people such as François Houÿez, Raffi Babakhanian, Emmanuel Trenado, Simon Collins, Filippo von Schlösser and many others ..." (P2, pointing out one of the founding members). Spilling over from the United States to Europe, this politically motivated push was largely rooted in the gay civil-rights movement. "This is linked to the fact that it was mostly the gay community in the USA – layers of society where people were educated in and related to the civil-rights movements and trained in politics" (P5, pointing out that the original movement was motivated by gender and class inequalities). "We were at a time of crisis, and people were dying" (P6, recalling a former chair of the organisation – a point that is stressed by several respondents). The "will to survive" is recognised as one of the key drivers behind the establishment and operation of the organisation.

There is tension between the original drive and mission behind ECAB (the will of patients to survive), and the current societal environment (discourse) that ECAB has to work in. This phenomenon is exacerbated by more conscious and target-oriented communication strategies of pharmaceutical companies, which are in search of more lucrative areas of development than HIV/AIDS. Nevertheless, the benefits have an effect in the background – they need to be brought to the surface and made conscious to all stakeholders through targeted communication strategies. Even if weakened, the original concept of Thorne (in

Wienold 1977: 45) about “aggressive patient involvement” remains key, and a factor that ECAB and other patient organisations can and should foster as a living tradition.

### Knowledge and experience

Another key topic featured in the respondents’ narratives was about the wealth of knowledge and experience concerning HIV/AIDS accumulated in and embodied by the organisation. “ECAB has a collective knowledge and memory which far surpasses many of those doctors who come and meet with us. That’s why ECAB can be very useful to them. This is what [pharmaceutical companies] benefit from. They also want to meet the people who take their drugs!” (P12, a former ECAB chair).

Another member recalls:<sup>10</sup> “What was quite new and unusually effective in HIV advocacy, however, was its engagement with science. We’re not unique in this: the environmental movement and some other areas of health activism also depend on activists who are either activist-researchers or who, more often, teach themselves science in order to use it as a campaigning weapon and to debunk bullshit [*sic*]. What distinguished AIDS activism from these others has been the intensity of its urgency – it has been a movement of dying people – and the relative speed and success with which its most urgent aim was achieved, namely drugs for HIV.” (P9)

A former chair of the organisation describes how the initial political motivation led to the conscious accumulation of relevant knowledge: “Initially it was about speed, that the drugs are registered as fast as possible. At one point, more members, more issues, more drugs [were there] as well; we could look into ethics, the representation of specific populations in clinical trials, inclusion of IDUs, human-rights issues ...” (P5). This process of self-education remains key in the work of the organisation, and it is in line with the concept of self-organising ‘user communities’ as described by Carayannis and Campbell (2012: 37).

### Pride in work and achievement

The third most prevalent topic was the pride associated with the results and achievements of the organisation.

The original roots of the European Community Advisory Board are in the so-called Community Constituency Groups (also referred to as Community Clinical Consultancy Groups [CCCCG]), which were mostly established or called forth by pharmaceutical companies or national regulatory agencies. Sometimes also referred to as community advisory boards (CABs), these entities were “attached to a trial<sup>11</sup> site, or a specific study, or a specific company” (P20), as one respondent recalls. These groups were not without their problems: “At the time, the pharma industry used to pick and select members from diverse European HIV groups to attend meetings where industry was setting the agenda and presenting its data. We did not like the fact that we were their ‘guests’ [...] some people were receiving fees [...] but the [whole] process had no transparency.” (P20) Another long-standing member recalls: “[we] used to have these meetings organised by companies, they set the agenda, cherry-picked the people, defined the venue” (P5). Being able to move away from these initial structures and setting up an independent and autonomous organisation are a source of pride: “The core values [of ECAB], to me, became a need to ensure better

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<sup>10</sup> Private correspondence concerning issues around the social science of HIV, 31.12.2012.

<sup>11</sup> Trial = clinical trial or study.

treatment options, better care, faster delivery, equal access irrespective of groups of countries. There are still many unmet medical needs. [We are] bringing forward good standards of care” (P10), states one member.

### Unified community

According to a recent report by the WHO,<sup>12</sup> HIV remains highly concentrated among some key subpopulations: men who have sex with other men; people coming from countries with generalised HIV epidemics; and injecting drug users. This means that the PLH community is far from homogenous. It seems, therefore, understandable that the theme of representativeness stands out in the interview narratives. In Europe, “ECAB tries to make sure that the community speaks in one voice” (P1), according to one ECAB member. Another member points out: “Being united makes you stronger as advocates” (P5, 6, 17).

Representativeness is combined with a strong sense of a united community. One member remembers what happened in early meetings: “[pharmaceutical company representatives] used to sit amongst us, which was a way for them ‘to study and evaluate us’. Very soon, we had a procedure where they had to sit on one side of the table, while the community sat on the other side.” (P17) Another respondent stresses that it took several years and a lot of targeted work to find unity and dispel feuds amongst different subgroups of the community: “The gays said they did not want to work with the junkies. The drug users said they did not want the gays at the table. But finally, we all had to realise that we were all in the same boat.” (P6)

One particular story was recalled by five different respondents. Here is a quotation from one of them: “The formal story [from industry] was ‘we want to share information with you so that we can get your honest opinion because your point is worthwhile’. But it was a little bit of a marketing exercise. In reality, these would typically be presentations that you see in conferences with the results. Occasionally, we would look at the protocols, but then they would come and say ‘it’s already been decided, and we cannot do much to change it, the researchers wanted this way’. So initially, [our involvement] would only be rubber-stamping.” However, this attitude changed rapidly, partly due to a mishap at one of the first meetings: “It was in a meeting where there was a trial of a drug against CMV retinitis. And we were very critical about this, it was very invasive, and they came to the meeting and made the huge strategic mistake of bringing bodyguards with them. You know, we went into the room, and it was 1996–97, people were sick, people were very thin, and you had these GI Joes, these American bodyguards saying that they were from [company name] security to see that we were well taken care of. It was a very delicate double entendre.” (P4)

“All that stuff went into the papers, and the moment was all right as they were fragile enough to say: ‘Okay, let’s do it your way’.” (P4) Recalled by several interview respondents, the ‘bodyguard incident’ remains a vivid element of the institutional mythology of ECAB. It is also often seen as an original source of anti-industry sentiments by some members, although the relationship between EATG and the pharmaceutical industry has evolved tremendously and in very complex ways over the last

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<sup>12</sup> <http://www.euro.who.int/en/health-topics/communicable-diseases/hiv/aids/news/news/2013/11/hiv-aids-in-the-european-region>, last accessed on 25.11.2013.

15 years. When asked about key milestones in the history of ECAB, respondents consistently mentioned some important trials and protocols, access,<sup>13</sup> and policy-related projects.

Before the actual content part of ECAB meetings starts, there is a minute of silence held “to remember those who were not born in those parts of the world where treatment is available, and those who did not live long enough to benefit from the advances of science” (P1). Observing the minute’s silence remains a powerful and important rule. Despite major advances in treatment, the PLH community keeps losing members at a higher rate than a random group of the general population.<sup>14</sup> There is almost always someone that members will actually grieve for during the minute. For others, it is a moment of reflection and contemplation. Its ritual and symbolic value radiates a sense of serenity and elation to the entire meeting. It is a ritual that distinguishes ECAB meetings from an everyday business interaction among professionals. “A lot of my friends died because of AIDS, and I found the minute’s silence an important way to remember and respect them and to focus on the meeting goals” (P15), one member pointed out.

## DISCUSSION

### A short history of ECAB

The European AIDS Treatment Group (EATG) was established in Berlin, Germany in 1992. One aim of the mission of the EATG is: “To achieve the fastest possible access to state-of-the-art medical products and devices, and diagnostic tests that prevent or treat HIV infection or improve the quality of life for people living with HIV, or are at risk of HIV infection,”<sup>15</sup> which it has been pursuing since its establishment.

The European Community Advisory Board (ECAB) was established five years later (in 1997), as the scientific working group of the EATG, although it has always retained a certain degree of independence. The task of the ECAB is to monitor pharmaceutical developments in the field of HIV/AIDS through active and targeted interaction and long-term cooperation with pharmaceutical manufacturers, regulators, and the scientific community working in the field. Pursuing this mission, ECAB builds on the work of volunteer expert patients in liaising with the pharmaceutical industry and other stakeholders.

An important milestone in the establishment of ECAB was the meeting held in Bergen, Norway during 11–13 April, 1997. When laying down the principles for work, the *Bergen Report on a workshop on Community Advisory Boards* started out from an ethical research stance. It describes the different types of community advisory entities existing at the time, making specific reference to an example from the public sector in the USA (CCG), one stemming from the PLH community in France (TRT-5), and one from the industry sector in Europe (Glaxo-Wellcome). The report also specifically refers to the EATG as “the main group involved with setting up Community Advisory Boards with various pharmaceutical companies”.

From the early stages, the EATG distributed treatment-related news and information to its members and other treatment activists. Initially, before email and the internet became widespread, the European AIDS Treatment News was

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<sup>13</sup> ‘Access’ means access to treatment for people living with HIV. ‘Treatment’ refers to the complex concept of a standardised form or care including biomedical and psychosocial care, treatment, and prevention.

<sup>14</sup> [http://www.aidsmeds.com/articles/mortality\\_rate\\_1667\\_23424.shtml](http://www.aidsmeds.com/articles/mortality_rate_1667_23424.shtml), last accessed 26.11.2013.

<sup>15</sup> <http://goo.gl/sCSjKO>, last accessed on 01.01.2013.

distributed via fax. Edited by an informal group of members, the EATN was first published around 1997 and lasted until about 2002.

An essential change in the operation of the ECAB was achieved with the installation of the position of Scientific Officer, working as a full-time employee at the office of the European AIDS Treatment Group in Brussels in 2008. Hepatitis C (HCV) co-infection is one of the leading causes of death for PLH in Europe.<sup>16</sup> After an extensive consultation with the community and scientific advisors, the ECAB decided in 2007 to add HCV to its portfolio, and its work now extends to the monitoring and scrutiny of the development and research of HCV drugs. In 2012, the EATG/ECAB also created the position of Hepatitis Consultant, responsible for coordinating the work of the organisation around viral hepatitis.

Similar work started around tuberculosis (TB) in 2010, with a dedicated ECAB meeting organised around TB in 2013. Other areas of interest or importance are also covered in thematic multi-stakeholder meetings such as the Vaccine Meeting in 2008 or the Pre-exposure Prophylaxis (PrEP) Meeting in 2011.

At the end of 2012, the ECAB had 101 regular members, of whom 70 are EATG members, two are list-only members (participating with varied frequency in discussions and communication on the organisation's mailing list), and 29 are guests/candidate members. The membership covers a total of approximately 30 countries in Europe. While the ECAB is a membership-based organisation with individuals joining as members, there are certain rules for the selection of members: "ECAB members are chosen so as to represent the diverse needs, interests, and concerns of the entire spectrum of the European HIV patient community (women, men, IDUs,<sup>17</sup> ethnic minorities, people in detention, vulnerable groups, etc.). In terms of membership, priority is given to people living with HIV", provides the working protocol of the organisation.

Setting the agenda and placing the initiative into the community's own hands are cornerstones of the organisation's work and success. The ECAB reviews clinical trials and compounds from phase II trials upwards to phase IV, and the post-marketing efforts of companies. This is especially important for the novel model of knowledge production. The patient organisation is not only involved in the process, but actively steers and arranges it.

Recapping the description of patient organisations by Tsigas and Magee (2011: 524), the European AIDS Treatment Group is a patient organisation that actively covers all three key areas described here, while the ECAB focuses on the biomedical research process by exerting pressure on industry and regulators to shape the research and pharmaceutical development agendas. Tsigas and Magee also state that the aim of advocacy is to create social pressure, political accountability, and policy change. "Advocacy requires a specific expertise that is not always present or even desired by scientists. Thus, it is recommended that the scientific community build alliances with advocacy organisations to affect change" (2011: 525).

In his yet unpublished thesis,<sup>18</sup> James describes how "HIV activists have become knowledgeable negotiators invited and expected to effectively contribute to the determination of strategy whether in health governance, clinical guidelines or determining state policy". Community advisory boards like the ECAB have been successful in bringing together all of these different aspects of patient involvement, and have practically and successfully integrated them into the process of biomedical

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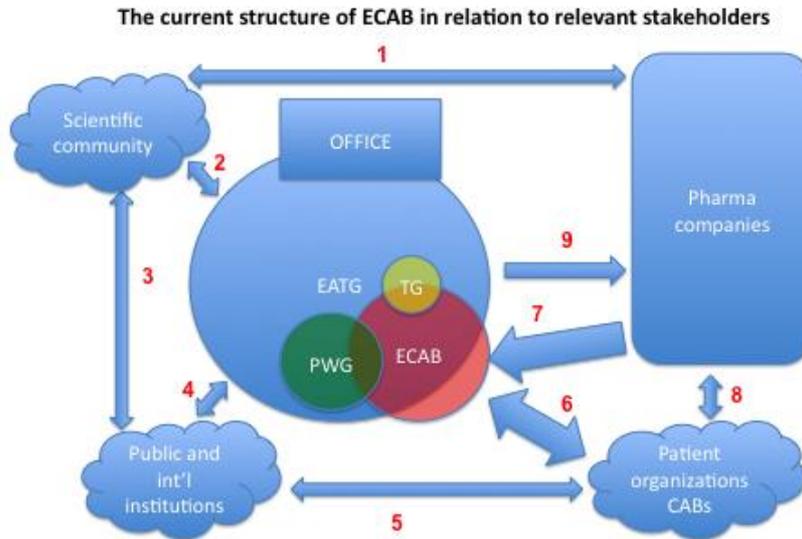
<sup>16</sup> [http://www.aidsmeds.com/articles/hiv\\_hcv\\_deaths\\_1667\\_21929.shtml](http://www.aidsmeds.com/articles/hiv_hcv_deaths_1667_21929.shtml), accessed on 20.12.2012.

<sup>17</sup> Injecting drug user.

<sup>18</sup> James, R., *Keep taking the tablets*, courtesy M. Wienold, 2012.

research; cooperation with other stakeholders such as industry, academia and public regulators were also launched and pursued productively.

Current working structures and stakeholders of the ECAB



**EATG** = European AIDS Treatment Group

**ECAB** = European Community Advisory Board

**Office** = The office of EATG located in Brussels, Belgium

**PWG** = Policy Working Group of EATG

**TG** = Training Working Group of EATG

**Scientific community** = Different stakeholders from the science/academic community including research institutions, networks

**International institutions** = Regulators and institutions at the national and European levels

**Patient organisations and CABs** = Patient and treatment/advocacy organisations in the field of HIV/AIDS and other disease areas

**Pharma companies** = Pharmaceutical companies involved in the research, development, manufacturing and distribution of compounds intended to treat HIV, HCV, HBV and other co-infections.

Based on this structural map of ECAB and the relevant stakeholders around it, the following relations can be described. Numbers correspond to the numbers of relationships in the diagram above.

The relationship between the scientific community and the pharmaceutical industry is beyond the control, but not necessarily beyond the scope of the ECAB.

Currently there is no formal relationship between the EATG/ECAB and the scientific community.

The ECAB does not control the relationship between the scientific community and public and international institutions, but it can influence that relationship indirectly. Treatment activists can exert pressure on governments and international institutions to achieve universal access to treatment.

Relationships between public and international institutions and the EATG are partly formalised. These relations contain a lot of potential that can be exploited through the more conscious involvement of the ECAB and its members.

The relationship between public and international institutions and patient organisations is not within the scope of control of the ECAB. However, it is capable of exerting some influence through lobbying and spreading the know-how amassed in the EATG/ECAB over the years.

The relationship between patient organisations (CABs) and the ECAB is partly formalised. The ECAB has assisted in the establishment of several country- and disease-specific community advisory boards.

The relationship between the ECAB and the pharmaceutical industry is strong. This particular aspect of the relationship involves not only the flow of support and information from industry to the ECAB, but also a reciprocal flow of information, skills and know-how.

The relationship of patient organisations and pharmaceutical companies can be strongly influenced by the ECAB, and in a concerted way through lobbying and leveraging on the role of the EATG/ECAB as a leading patient and advocacy organisation in Europe.

The reverse relationship between the ECAB and the pharmaceutical industry entails the flow of information from the ECAB to the companies, and is currently seen as being weaker than it could or should be.

### The quadruple helix of the ECAB

Wienold describes community advisory boards as “quadrilateral structures” with community representatives, clinical researchers (“university”), pharmaceutical industry (“industry”) and drug-regulatory authorities (“government”) participating (2002: 4). He does not mention the concepts of innovation or knowledge production; however, he does point out that information and communication are important in this process of collaboration among the four stakeholders.

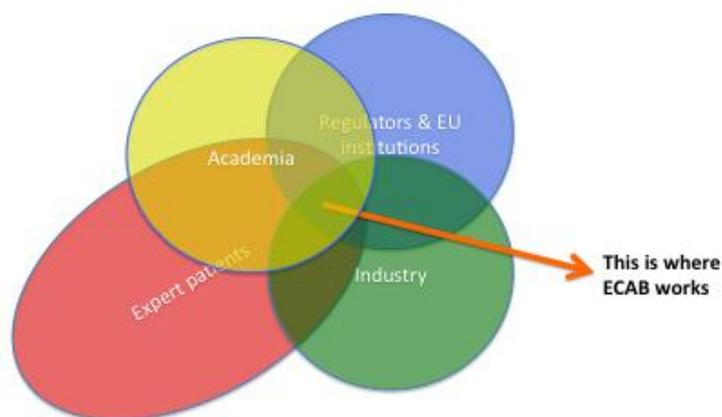
Recapitulating Leydesdorff and Etzkowitz’s triple-helix model (Leydesdorff 2011: 26), and the extended proposal by Leydesdorff adding “an alphabet of 20+ helices” to the model (2011: 32), and also taking into consideration the “quadruple

helix” described by Carayannis and Campbell (2012), this paper proposes a revised quadruple helix model for the operation of the ECAB and similar organisations. In this case, the new dimension of “expert patients” or “civil society” is added to the model. The simplified diagram below shows the ideal state of the system, which is conceived here as dynamic and in constant flux.

The relationships of the different stakeholders is characterised by an interplay of interests, thus it is also reflective of the actual state of play in the given environment. This environment is “global” or “international” *per se* in the case of ECAB, as the organisation itself is pan-European; it acts on a European, and to a certain extent global level, and the stakeholders on the industry side are typically multinational companies. This fact partly removes the work of ECAB from national economies, but also creates a dynamic tension. Primary policy objectives, based on knowledge production in the quadruple helix, often need to be implemented on the national level (e.g. making sure that proper health-care standards are realised for all people living with HIV in a given country).

Kotsis and Nagy mention that the triple helix is both an analytical and a normative model (2010:123). It helps not only to understand how innovation comes about in the interaction of the three (or in this case four) helices, but also may help steer the organisation towards a more conscious use of its resources and networks.

## 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.

## CONCLUSIONS

The informal structures of advocacy work in the civil sector (or in the intersection of the civil and public sectors) allow for flexibility, speed and non-conventional tools in the implementation of interests. However, the professionalisation and standardisation of certain knowledge elements and procedures are inevitable. The particular dynamism and, sometimes, radical thinking of the civil sector add new momentum to the approaches of the other stakeholders.

One of the key achievements of this politically highly motivated HIV/AIDS treatment activism was the introduction of the accelerated registration process of pharmaceuticals at the relevant supervisory bodies in the USA and the EU, which led to an unprecedented development in the research and treatment of the HIV infection. With almost 30 different compounds and the successful paradigm of combination antiretroviral therapy (cART or HAART), PLH can now live in good health for almost as long as their “healthy” counterparts.

Wienold refers to certain limitations of the community advisory board model (2002: 6 pp). There is a certain opportunity for the ECAB to consciously spread the know-how of community involvement to other disease areas, or even the generalised model of civil involvement to the NGO sector at large. For example, the EATG/ECAB is currently engaged in developing the concept of a ‘school of excellence’ for HIV patients (‘Patient Academy’), supporters and other patient organisations in different disease areas, in order to allow for the mapping and institutionalisation of the immense informal knowledge that exists within the organisation.

Wienold points out that working as a community representative on a CAB “requires a lot of time and effort from the individual participant” (2002: 6); and underlines the importance of continuous education and capacity building. Formalised structures and a rigorous documentation of institutional memory is even more important for the reasons of what he calls ‘attrition’ (i.e. the death or otherwise disappearance of an experienced expert patient from the organisation). This process can and should be countered by a more conscious and targeted cooperation across all stakeholders as reasonable and long-term patient involvement in the innovation process yields clear benefits to all parties concerned.

“I think the industry is getting less and less interested, they don’t see the importance today as much as they did in the past [...] They can sell the products to any country without going to any NGO. They don’t need the stamp of approval as they did in the past” (P2, to one ECAB member during interview). This reality of the market calls for additional efforts and a conscious stride towards excellence in the work of patient organisations. The organisation’s relevance can only be ascertained if its professional stance is consistently supported by content.

Therefore, political advocacy and work become more and more important in the process of integrating patient organisations, and civil society in general, into the knowledge production and distribution process. For example, the EATG co-drafted the resolution of the European Parliament on HIV/AIDS in 2009–2010, calling for the Member States of the EU to promote research in the field of HIV/AIDS (EP 2010). The PLH community has demonstrated many times how political pressure can influence the industry, the state and also academia to take a different course of action. With the establishment of reliable and easy-to-manage treatment options for PLH, the will to survive has become a less pressing objective, at least in the parts of the world that are not resource-limited.

It is also assumed here that peer helpers can (and should) play an important role in providing support to other PLH. Through shared and similar experiences, peer helpers and expert patients bring to the equation the added value of credibility and authenticity towards other PLH. Their involvement in the provision of psychosocial services could ease the increasing burden on health-care systems. Also, their visibility and work can implicitly contribute to the erosion of stigmatisation and discrimination against HIV/AIDS and people living with HIV. Eatough and Smith, quoting Riessman, point out that “sense making is always both an individual and social product” (2006: 115). Expert patients are the focal point of this process.

In her essay, Decoteau describes a “shift in both the discursive construction of AIDS and the material symptoms of the disease”. She assumes that this has caused a disconnect between the signified of AIDS and its signification in the public sphere (2008: 230). Treatment activists, prevention advocates and expert patients in fact work in the “grey zone” between the dominant and hidden, spectral frames of HIV/AIDS.

While mostly firmly rooted in the highly medicalised and rational tradition of scientific research and reliable treatment, expert patients who live with HIV are also the embodiment of the disease, and the success of their work is often dependent on how far they are able to balance between the strategy of calm and composed “survivorhood” and “haunting” the audience in order to get the message across (Decoteau 2008: 232). Thereby, expert patients, through their presence, become active vehicles of the fight against stigma and discrimination, and also actively, even if not consciously, use their empowerment to overcome the “victim-blaming” frames in the discourse of HIV/AIDS. The risks are mainly associated with stigma and the fear from disease; while the benefits with perceptions in society that frame PLH as victims and/or terminally ill patients who are bound to die within short, hence induce pity.

The emancipation of the “patient” (the person living with HIV/AIDS) is thus key. It implies the recognition of the fact that the person living with HIV is more than the patient sufferer of their disease and medical interventions. ‘Patients’ become ‘consumers’ (i.e. active participants, conscious partners in the construction of their disease and its progression). Empowerment yields more conscious citizens who will be able to take better care of themselves and their peers.

This research argues for more inclusive scientific projects where PLH are not only the subjects of research but also active participants involved from the stage of study design, through assessment to evaluation. As demonstrated through the example of ECAB, this concept has been working very well in biomedical research for many years – and it is spreading to the field of social sciences.

Some limitations of this study must be recognised. The geographical dispersion of the participants and the fact that English is used as a common language while it is not the native tongue of the majority of the participants are key factors that needed to be controlled for. Also, more focused exploration of the experience of the participants about their personal involvement in knowledge production could shed more light on the possibilities to improve the working model described here. Participants usually took great pride in their involvement in ECAB, which sometimes ‘carried them away’ during the interviews.

The author believes that the example of the EATG/ECAB argues for the use of the potentials offered by the patient community and peer helpers in areas like prevention, adherence, psychosocial support to other patients, outreach to hidden and difficult-to-reach populations, education and training for the medical profession, or study design. A more conscious use of these resources is also empowering for the patients. “Getting more involved with the scientific community, and initiating research – to the extent that our expertise allows, the ECAB should be more involved in proposing research questions that are interesting for the community”, argues one ECAB member. The bottom-up process of innovation from the civil society as described by Carayannis and Campbell (2012: 3) is realised intuitively.

Adding a fourth dimension to the triple helix of knowledge production, that of the civil society, in a conscious and planned way, will make sure that an arch can be drawn from the expert patient to the empowered citizen. People who are

aware of their choices and know the limits and expanse of their freedom of action can also contribute more actively and meaningfully to the functioning of democracy.

The exploration of the directions, depth and outcomes of such patient involvement remain subjects to further observation and research. Additional research could also shed light on how far and in which directions the triple/quadruple-helix model can be expanded, and whether or not the helix model is tenable at all for the description of the changing landscape of innovation and knowledge production with the involvement of patient communities. Thereby, 'patients' and 'subjects' of research can and should become active 'participants'. As evidenced by the example of the European Community Advisory Board, and demonstrated by this case study, the structured and systematic involvement of patient organisations and the civil society seems to be a reasonable and feasible step in the design of future research.

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The European Community Advisory Board (ECAB) was established in 1997 as a forum for interaction between the community of people living with HIV ("patients", "PLH") and the pharmaceutical industry. Currently ECAB operates as a working group of the European AIDS Treatment Group (EATG), a European voluntary patient organisation for PLH that covers the WHO Europe region.<sup>19</sup> The EATG works to improve the daily lives of people living with HIV/AIDS covering three key activity areas: scientific research in the field of HIV/AIDS and relevant co-infections (HCV, TB etc.); policy and advocacy to facilitate better access to vital medication for PLH including pricing issues; and capacity building that includes organising training courses internally and externally on treatment literacy and advocacy, the medical, social and political aspects of living with HIV/AIDS.<sup>20</sup> The ECAB is the working group responsible for the scientific research related activity of the EATG.

The European AIDS Treatment Network (NEAT) was established in 2007 with the objective to "create a durable European collaboration for clinical Research in HIV/AIDS therapeutic approaches towards the goal of defining optimal strategies for the management of HIV infection in adults and children. NEAT is designed to exploit and capitalise on the wealth of existing but dispersed European expertise, resources and capacities in order to make concerted efforts which will have a decisive impact in the fight against AIDS."<sup>21</sup>

*Budapest/Brussels, September 2013*

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<sup>19</sup> <http://www.euro.who.int/en/where-we-work>, accessed on 22.12.2012

<sup>20</sup> <http://www.eatg.org>, accessed on 22.12.2012

<sup>21</sup> <http://www.neat-noe.org/?q=content/about-neat>, accessed on 23.12.2012

## LIST OF ABBREVIATIONS

AIDS	Acquired Immunodeficiency Syndrome
CAB	Community Advisory Board
CCCG	Community Clinical Consultancy Group
DSMB	Data Safety Monitoring Board
EACS	European AIDS Clinical Society
EASL	European Association for the Study of the Liver
EATG	European AIDS Treatment Group
EATN	European AIDS Treatment News
ECAB	European Community Advisory Board
EMA	European Medicines Agency
EU	European Union
HCV	Hepatitis C Virus
HIV	Human Immunodeficiency Virus
IAS	International AIDS Society
IDU	Injecting Drug Users
NEAT	European AIDS Treatment Network (FP 7 project)
NGO	Non-Governmental Organisation
PLH	People Living With HIV and AIDS
WHO	World Health Organization

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