

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)² 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 2,300,000.³ 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 2012,⁴ 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.⁵

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.

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

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

⁵ <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.⁶

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.⁷ The Committee for Medicinal Products for Human Use (CHMP) of the

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

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

EMA includes an important vehicle of patient involvement: the Patients' and Consumers' Working Party⁸ (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

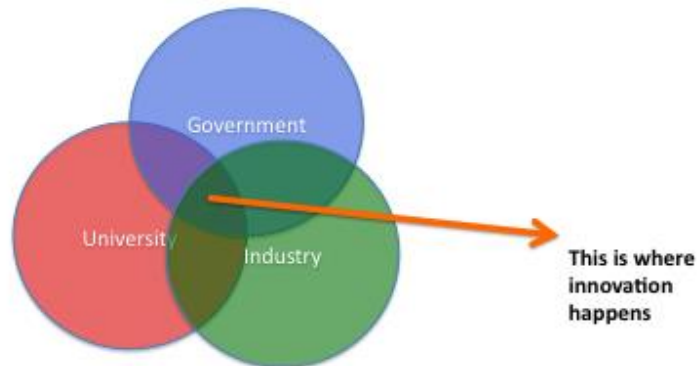
Leydesdorff and Zawdie (2010) give a detailed description of the triple-helix model of innovation and knowledge production. Contrasting with national innovation systems, they describe the triple helix of interaction between government, university and industry as "a recursive interaction system underlying 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.

⁸ <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 Society⁹ 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.

⁹ <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:¹⁰ “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 trial¹¹ 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

¹⁰ Private correspondence concerning issues around the social science of HIV, 31.12.2012.

¹¹ 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,¹² 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

¹² <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,¹³ 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.¹⁴ 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,”¹⁵ 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

¹³ ‘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.

¹⁴ http://www.aidsmeds.com/articles/mortality_rate_1667_23424.shtml, last accessed 26.11.2013.

¹⁵ <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.¹⁶ 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,¹⁷ 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,¹⁸ 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

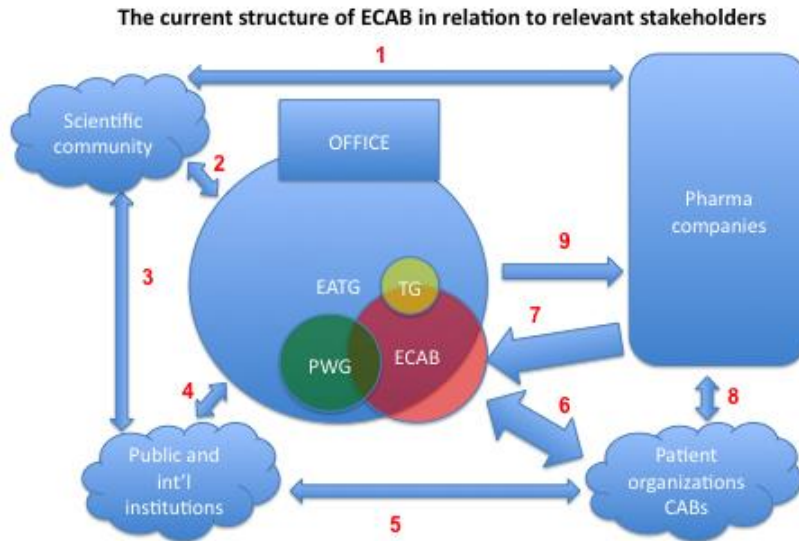
¹⁶ http://www.aidsmeds.com/articles/hiv_hcv_deaths_1667_21929.shtml, accessed on 20.12.2012.

¹⁷ Injecting drug user.

¹⁸ 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.

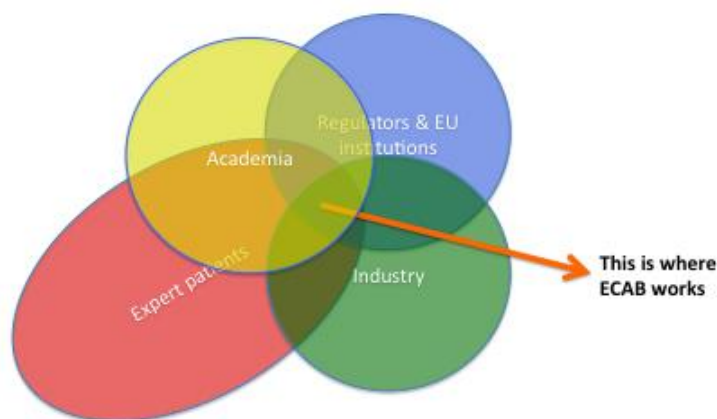
Recapitulating Leydesdorff and Etzkowitz’s triple-helix model (Leydesdorff 2011: 26), and the extended proposal by Leydesdorff adding “an alphabet of 20+ helices” to the model (2011: 32), and also taking into consideration the “quadruple

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 author would like to express his sincere thanks to everybody who provided help, attention, and support. I owe thanks to them for their time and patience, and especially for the work they have done to support and improve the lives of people living HIV/AIDS in Europe and around the world. I also thank all members of the European Community Advisory Board and of the European AIDS Treatment Group for their contributions and support.

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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.¹⁹ 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.²⁰ 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."²¹

Budapest/Brussels, September 2013

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

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

²¹ <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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ABSTRACT

The paper investigates the phenomenon of multiple discrimination and the quality of jobs available on the labour market in the European Union. Numerous studies have demonstrated the negative impact of discrimination on employment prospects; however, only a very few have investigated how discrimination relates to overall job quality. The paper analyses the significance of discrimination on multiple grounds; the grounds of discrimination that are most likely to be combined, and finally, whether there is a significant difference in the employment rate and job quality among victims of single or multiple-grounds discrimination. The research tested the hypothesis that victims of multiple discrimination have both a lower employment rate and, when employed, a lower overall job quality compared to those affected by no or single-grounds discrimination at the same educational level. To measure the overall job quality of respondents, a complex index has been designed. The research evaluates data from the fifth round of the European Social Survey (ESS) conducted in 2010. The findings reinforced the view that victims of multiple discrimination had a lower job-quality level compared to those not discriminated against, or discriminated on a single ground, especially at the lower and higher ends of the educational continuum. Furthermore, the research revealed important methodological implications concerning the measurement of discrimination.

KEYWORDS

Multiple discrimination, job quality, social exclusion

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Discrimination in employment or in access to services such as education, health care, social protection, or others, is a widespread phenomenon in most countries, despite the presence of laws prohibiting discrimination and the legal requirement of equal treatment. Discrimination and exclusion are self-sustaining social mechanisms that in the longer run become a dimension of the social structure. The unequal treatment linked to both structural/institutional and personal/cognitive factors result in tensions and conflicts among the majority and minority society, and forms a major source of social disintegration. The majority of studies linked to the topic of discrimination focus on the so-called single-ground discrimination, namely considering the grounds and cases of discrimination separately and independently from each other. However, in the last few years, there has been a growing awareness of the importance of tackling the issue of multiple discrimination both in the European Union and elsewhere (European Agency for Fundamental Rights, 2011; Ontario Human Rights Commission, 2001).

This paper examines the phenomenon of multiple discrimination in relation to the quality of jobs available on the labour market across Europe. For this purpose, data arising from the fifth round of the European Social Survey have been used, representing the state of affairs in 2010. The research aims to identify the scope of multiple discrimination and the occurrences of various grounds of discrimination leading to multiple discrimination across European countries. Using additional data, methodological issues will also be raised about the difficulties of measuring multiple discrimination. Numerous studies have demonstrated the negative impact of discrimination on employment prospects (Helps & Skitmore, 1975; Conway & Roberts, 1994; Ravaud, Madiot & Ville, 1992); however, only a very few have investigated how discrimination affects overall job quality. This paper aims to identify whether there is a significant difference in terms of job quality among those who have not been subject to any form of discrimination, those who have been discriminated on a single ground, and those who were subject to discrimination on multiple grounds. The study also aims to analyse which elements of job quality are most likely to be at a lower level in cases of previous experience with multiple discrimination. For this purpose, eight dimensions of job quality have been identified: compensation; working hours; opportunities for participation; self-actualisation; satisfaction of social and self-esteem needs; work-life balance; and issues of workload.

The research aims to test the following hypotheses.

- Multiple discrimination is an important aspect of discriminatory processes across Europe.
- Discrimination on multiple grounds has an aggravated impact on employment prospects, compared to discrimination on a single ground or no discrimination.
- When employed, victims of multiple discrimination have a lower overall job quality compared to those previously affected by no discrimination or by discrimination on a single ground among equally qualified people.

LITERATURE REVIEW

A study published by the European Commission in 2007 entitled *Tackling Multiple Discrimination* (European Commission, 2007: 5) summarises the problem as follows.

Multiple Discrimination happens in all spheres of social life. The labour market, however, appears to be the sector where Multiple Discrimination occurs most often. In many Member States, the scope of anti-discrimination legislation outside employment and occupation is limited to only gender and race/ethnic origin. This could be the reason for the lack of visibility of Multiple Discrimination in sectors such as education, access to goods and services, social protection, etc. Lack of data again adds to an incomplete picture of which intersectional groups are vulnerable and in which sectors Multiple Discrimination occurs. Lack of data also means insufficient knowledge about the extent of Multiple Discrimination.”

Historically, the term “multiple discrimination” appeared in the United States in the late 1980s to describe the specific situation when a person belonged to more than one disadvantaged group and thus experienced forms of discrimination of a more complex and severe nature than those subject to discrimination on a single ground. (ENAR, 2007). People affected by discrimination on the basis of multiple grounds can be subject to three distinct types of discrimination: *multiple discrimination* (two or more grounds operating separately); *compound* or *additive discrimination* (a person discriminated on the basis of two or more grounds at the same time); and finally, *intersectional discrimination* (in this case, several grounds of discrimination operating simultaneously and interacting in an indivisible way) (Danish Institute for Human Rights, 2007).

According to the above-mentioned study from the European Commission (2007), most National Equality Bodies and organisations concerned with anti-discrimination *legislation* and policy are still focused on the single-ground approach to discrimination; thus, the concept and the reality of multiple discrimination remains unclear. Recent research carried out by the European Agency for Fundamental Rights (2011) published comparative European findings on the extent of multiple discrimination in European countries. In the fifth European Union Minorities and Discrimination (EU-MIDIS) survey carried out in 2008, 23,500 immigrant and ethnic minority people were surveyed from 27 EU countries. The survey revealed that every fourth (23%) ethnic minority or immigrant respondent interviewed in the EU-MIDIS indicated that they had felt discriminated against on at least one ground, and every seventh respondent (14%) on two or more grounds in the last 12 months. Interestingly, comparing EU-MIDIS and Special Eurobarometer 296 on Discrimination in the European Union, the results of the EU-MIDIS survey showed that the majority population in EU Member States felt discriminated against less often across a range of grounds than ethnic minority and immigrant persons surveyed in EU-MIDIS. According to the Eurobarometer 296, the occurrence of discrimination on a single ground affected 12% of the European population in 2008, whereas the incidence of multiple discrimination was not higher than 3% (European Agency for Fundamental Rights, 2011; European Commission, 2009). Therefore, the authors of the report concluded that ethnicity or immigrant origin consistently emerged as the most significant reason for experiencing discrimination on more than one ground. The EU-MIDIS survey (2011) also

proved that “visible” minorities – those who generally look different to the majority population – felt discriminated against more often and across a wider range of grounds than other minorities.

Concerning the link between discrimination and job quality, most of the literature deals with the impact of gender and race on wage differentials (Bodvarsson & Sessions, 2011; Carnoy, 2010; Petersen & Togstad, 2006; Eckstein & Wolpin, 1999). Pinkston (2003), for instance, assumes that observable wage differences among men and women are tied to the weaker performance signals of women during the selection process. Research more specifically on the impact of discrimination, especially that of multiple discrimination, on overall job quality, could not be found. Research was more developed on the issue of how experience with discrimination influences job satisfaction, and furthermore the subjective perception of job quality. Goldsmith *et al.* (2004) revealed that jobseekers who had previously been victims of discrimination either tended to target lower level jobs; or on the contrary, would be motivated to develop their competencies and level of qualifications, which was apparent from their CVs. Poggi (2010) claimed, based on research evidence, that job satisfaction was not an objective indicator of working conditions, because previously experienced good or bad instances of working conditions had influenced the level of personal aspirations for job quality. Using data from the 1997 *International Social Survey Program*, Llorente & Macias (2005) investigated whether job satisfaction was a fair indicator of job quality, and concluded that in most cases it was not. The above research results reinforce the methodological consideration that job quality needs to be studied through objective figures and not indirectly by using the indicator of job satisfaction. Moreover, one also needs to give due consideration to the statement that perceptions of job quality are influenced by subjective personal aspirations, as well as previous experience with discrimination.

MULTIPLE DISCRIMINATION ACROSS EUROPE

It is important to note that the European Social Survey (ESS) database does not make it possible to differentiate between the different types of multiple discrimination (*multiple discrimination* (two or more grounds operating separately); *compound* or *additive discrimination* (a person discriminated on the basis of two or more grounds at the same time); and *intersectional discrimination* (several grounds of discrimination operating simultaneously and interacting in an indivisible way), as discussed in the literature review. Therefore, we used the broadest term of *multiple discrimination*, keeping in mind that the ESS data might include all three types of multiple discrimination. The core ESS questionnaire included a question on whether the respondent would describe her/himself as a member of a group that was being discriminated against. In the case of a positive response, respondents were given nine grounds of discrimination to choose from: colour or race; nationality; religion; language; ethnic group; age; gender; sexuality; and disability.² Please note that the survey method assesses the respondents’ personal, subjective perception of discrimination.

According to the ESS 2010 data from 17 European Union countries, an average of 94.9% of the respondents were not subject to discrimination; 4% experienced discrimination on a single-ground basis;

² ESS round 5, core questionnaire, questions C24 and C25.

whereas 1.1% of the population were hit by discrimination on multiple grounds. Overall, the level of discrimination on multiple grounds varies across European countries. Hungary and Estonia represent the higher end of the scale with a 2.6% ratio of multiple discrimination in absolute terms, while respondents of Poland, Portugal and Slovenia reported the lowest ratio of discrimination on multiple grounds (0.1 and 0.2%). The data show a relatively high variance by countries in respect to what share of the victims of discrimination were due to a disadvantage on a single or on multiple grounds. According to the ESS 2010 data of 17 European Union countries, on average, approximately one-quarter (22%) of the victims of discrimination are subject to discrimination on multiple grounds. In this respect, too, Hungary and Estonia have the largest proportion of people hit by multiple discrimination among those discriminated (52 and 49% respectively); whereas in Poland, Portugal and Slovenia, multiple discrimination is least probable amongst victims of discrimination (Table 1).

To gain a better understanding of the nature of discrimination on multiple grounds, we investigated the occurrence of the different grounds of discrimination amongst those affected by multiple discrimination. The frequency of the various grounds of discrimination varies to a great extent among the European countries. One could say that each country has its own pattern for multiple discrimination. In Belgium, the most frequent grounds of multiple discrimination were related to colour and religion. In the Czech Republic, age and gender were the basis for typical combination of discrimination grounds. In Hungary, ethnic origin and colour were the most frequent grounds, while in Estonia it was nationality and language (Table 2).

To sum up the European trends of multiple discrimination, we can conclude that colour and race, nationality, ethnic origin, religion and language constitute the most frequent grounds of discrimination amongst those discriminated on multiple grounds, which are clearly closely linked to ethnicity. In this respect, the results of the ESS and those of EU-MIDIS (European Union Agency For Fundamental Rights, 2011) strongly converge. Conducting the principal component analysis for the entire sample of 17 EU countries led to two principal factors of discrimination: that of *Ethnicity-related* and *Non-ethnicity-related factors*. This result underlines the major role ethnicity plays in multiple discrimination (Table 3). To further study the linkages amongst grounds of discrimination, we conducted a principal component analysis among the victims of multiple discrimination and found three factors explaining 55% of the variance. The first factor, labelled *Demographic factors*, integrates grounds of discrimination based on age and gender. The second factor was entitled *Ethnicity factors*, as it comprised grounds of discrimination such as colour or race, nationality, language and ethnic group. Finally, the third factor was labelled *Physical and spiritual difference factors*, as it mostly integrated sexuality, disability and religion as grounds for discrimination (Table 4).

A few methodological notes need to be made at this point. First of all, being discriminated against leads to sensitive data. The extent to which respondents will reveal previous incidents of discrimination strongly depends on the phrasing of the question, the context in which the question is embedded, and how the questionnaire is administered. Comparing the incidence of discrimination on both single and multiple grounds of the European Social Survey (ESS, 2010), the Special Eurobarometer on Discrimination in Europe (European Commission, 2009) and the EU-MIDIS (European Union Agency For Fundamental Rights, 2011), one can detect

that the ESS had the lowest rate of discrimination reported by respondents. This is surely due to the fact that the question on discrimination was integrated into a set of questions that included a wide range of different topics, compared to the focused nature of both the Eurobarometer and the EU-MIDIS surveys. Another important aspect of the extent to which people reveal previous discrimination incidents is related to whether the questionnaire is a face-to-face interview or a self-completed one. In Hungary, the ESS 2010 survey had a supplement on discrimination administered in a self-completed manner (enquiring about 19 grounds of discrimination listed in the Hungarian law on Equal Treatment) in addition to the core face-to-face questionnaire. While the occurrence of discrimination was 5%, based on the nine grounds of discrimination in the core ESS questionnaire, 47% of exactly the same sample reported incidences of discrimination in the self-completed questionnaire. Similarly, the ratio of reported multiple discrimination was higher both in absolute and relative terms in the self-completed ESS questionnaire.³ The huge difference in reported discrimination rates among the same population may be the result of a combination of factors: the wording of the question; the context in which the question on discrimination is embedded; the overall focus of the questionnaire; the method of administering the questionnaire itself (face-to-face or self-completed). Also, one has to keep in mind that we are measuring the respondents' subjective perception of their previous discrimination experience. Some respondents might not be aware of the exact meaning of this discrimination, or did not recognise a disadvantageous incident as discrimination, or simply were not able to recall the experience on the spot. On the other hand, others might not want to admit to belonging to a group of discriminated people or having been discriminated against, and there might also be cases in which respondents classify their negative experiences as discrimination, while legally they would not be qualified as such. Levels of awareness and respondent strategies to hide or uncover discriminatory experiences might differ significantly from one country to the other, and different social groups within countries. In the special case of the ESS 2010 Hungary, the huge differences based on the core and the supplementary questionnaire in terms of discrimination rates (5 versus 47%), were most probably also due to a combination of the above-mentioned factors, accentuated by the fact that the questions on discrimination in the supplementary questionnaire appeared for the second time. Also, respondents had no time constraints during the self-completion of the questionnaire, could recall more experiences under less stressful circumstances, and might have decided to change their strategy from hiding to reporting personal discrimination incidents due to the non-verbal nature of the communication. Previous research conducted on discrimination (Tardos, 2005) revealed similar discrepancies between reported discrimination rates among the same population: in the first phase, respondents answered a non-discrimination-focused questionnaire, then in the second phase a smaller subsample participated in a discrimination-focused face-to face, indepth interview. Reported discrimination rates increased from 17% in the first phase to 80% in the second phase. Furthermore, only half of those who reported an incident in the

³ The wording of the question in the core and the self-completed supplementary ESS questionnaire was somewhat different. In the ESS core questionnaire, it was first asked: "Would you describe yourself as being a member of a group that is discriminated against in this country?" If the response was positive, a second question was raised: "On what grounds is your group discriminated against?" In the Hungarian self-completed questionnaire, the grounds for discrimination were asked about separately, one after the other: "Have you ever been discriminated on the ground of" Obviously, in the core questionnaire, there was much less time for the respondent to reflect on any previous experience linked to discrimination. Furthermore, if the first response was negative, no further questions followed.

interview had previously reported discrimination in the questionnaire. In this particular research, the face-to-face indepth interview was a more effective method for revealing exposure to discrimination than the non-focused questionnaire. Related to the sensitive and hidden nature of discrimination data, researchers have to be very careful in designing the methodology for discrimination-related data-collection circumstances and methodology, as reported discrimination will particularly be influenced by these factors.

DISCRIMINATION AND LABOUR MARKET STATUS

In 11 of the 17 European Union countries, the ratio of those in paid employment, but previously discriminated against,⁴ was lower than those who were not discriminated against. Within the group of those subject to discrimination, the lowest employments rates were reported from Bulgaria (22%), Hungary (35%), the Czech Republic (40%) and Portugal (40%). To investigate the relative chances of finding employment, we compared the employment rates of those discriminated against to those not discriminated against, and to the general employment rates in the respective countries. The ratios of the employment rate of the two groups were also the lowest in Bulgaria (0.53), Hungary (0.71) and the Czech Republic (0.72). Similarly, the ratio of country-level employment rates of the discriminated group and that of the whole population put Bulgaria (0.55), Hungary (0.71) and the Czech Republic (0.74) to the lower end of the scale (Table 5). Hence, according to the results, we can state that people discriminated against in Eastern-Central Europe are more likely to be in a disadvantageous position for finding employment than in other parts of Europe. The statement is especially true for discriminated people with a secondary or higher education, as employment opportunities for people with primary education are limited for both groups in these countries.

It is also important to find out whether discrimination on multiple grounds has an aggravated impact on employment prospects, compared to single-ground discrimination. However, because of the low case numbers for multiple discrimination, we eliminated the country-level analysis. Taking a glance at the average employment rate in Europe of those not being discriminated against (51.7%), those who were discriminated against on a single ground (50.6%), and those discriminated against on multiple grounds (50.0%), we could not identify, as assumed, a significant reverse linear relationship between the number of grounds of discrimination and the employment rate. In fact, there seems to be a more important demarcation line in terms of the employment rate among those not discriminated against at all, and those discriminated against on single grounds. One might assume that, bearing in mind employers' hiring decisions, the dominant factor considered is whether the jobseeker has any characteristics considered to be risky for the employer or not, while the actual number of risky characteristics might be of secondary importance. Nevertheless, this issue needs further investigation with a larger sample size.

⁴ People having paid work in the seven days prior to the completion of the questionnaire were considered "employed" in our analysis.

JOB QUALITY AND MULTIPLE DISCRIMINATION

In the framework of the research, a Job Quality Index has been created, composed of 23 variables. Eight dimensions of job quality have been identified: compensation; working hours; opportunities for participation; self-actualisation; satisfaction of social and self-esteem needs; work-life balance; and issues of workload. These eight dimensions have been weighted with a point value of 10 or 15. A higher weighting has been assigned to factors of job security, workload, social and self-esteem needs, and compensation based on expert decision. Correspondingly, variables have been weighted, too. As a result, the point values of the Job Quality Index can range from 0 to 100.

The Job Quality Index has been calculated for all 17 European Union countries, restricting the sample to those who were employed (i.e. had a paid job in the last seven days). The average score of the Job Quality Index across Europe was 59.18 out of 100 points. The highest levels of job quality were measured in Norway, Sweden, and France (64.2, 63.6 and 62.3 respectively). East and South European countries mostly scored the lowest on job quality (Hungary: 57.5; Czech Republic: 55.6; Poland: 55.4; Spain: 56.6; Portugal: 55.5) (Table 6).

According to the ESS 2010 data, on an aggregated level, there was a significant reverse relationship between the number of grounds of discrimination and the average score of the Job Quality Index. The score amongst those who were not victims of discrimination was the highest (59.30); among people discriminated against on a single ground, the score was somewhat lower (57.31); while the score was the lowest amongst those hit by discrimination on multiple grounds (55.32). The two variables are therefore inversely proportional. Overall, the relationship was rather weak between the number of grounds of discrimination and the average score of the index. Moreover, not all dimensions of the Job Quality Index have a significant relationship with the fact of discrimination, especially discrimination on multiple grounds. There was no significant correlation between the fact of being a victim of discrimination and the quality of working hours, the extent of workload, or the opportunities for self-actualisation. On the contrary, multiple discrimination had a significant correlation with the level of wages and job security (Table 7).

To look at the influence of education levels, we differentiated between people with primary, secondary and higher level education. The aim was to examine whether multiple discrimination could be associated with lower levels of job quality than single ground or no discrimination on any educational level, or not. To measure the level of education, the years spent in full-time education were used.⁵ According to our findings, multiple discrimination at all educational levels could be linked with lower job quality, but to different degrees. The largest differences of job quality could be observed among people with primary education (maximum eight years of full-time education). In their case, employed people who had previously experienced multiple discrimination had a job quality index of approximately 10 points lower, compared to those people with primary education who had never been subject to discrimination (54.5 and 45.08 points). Interestingly, the

⁵ We coded 0–8 years of full-time education as “primary education”, 9–14 years of full-time education as “secondary education” level, and 15 years or more of full-time education as “higher education”.

relationship of multiple discrimination and job quality was the weakest in the case of people with a secondary-level education. In this category of people, the Job Quality Index of those with experience of discrimination based on multiple grounds was only three points lower than those without any experience of discrimination (58.33 and 55.65 points respectively). Employees with higher education (at least 15 years in full-time education) have a medium position in this respect: the gap between the non-discriminated and those discriminated against on multiple grounds was half as large as in the case of people with primary education (61.31 and 56.78 points respectively) (Table 8). Additionally, the relationship between job quality and discrimination has been controlled for gender, age, and ethnic minority membership. Gender does not influence job quality levels, whereas age does. In general, younger and older age groups have a lower level of job quality on average. However, in all age groups, the number of discrimination grounds shows an inversely proportional relationship to job quality levels. Similarly, these levels vary according to the presence or absence of ethnic minority membership but in both groups, the average level of job quality shows an inversely proportional trend related to the number of discrimination grounds.

As stated above, multiple discrimination and a lower level of job quality will most probably be linked, in the case of jobs at the lower and higher ends of the job market. One could rephrase the relationship between labour-market competition and discrimination as “those who are at the bottom of the hierarchy and subject to discrimination will probably get the worst jobs among the bad ones, while those who do not have to fear discrimination will get the best jobs among the better ones”. However, multiple discrimination does not equally affect all components of job quality at each educational level. In the case of people with a primary or lower level of education, being subject to multiple discrimination will most probably be connected to lower levels of participation opportunities (2.51 vs. 4.84 points), work-life balance (4.19 vs. 6.03 points) and job security (7.55 vs. 10.13 points) compared to others with the same level of education. For people with a secondary education, multiple discrimination might be linked to lower levels of compensation (7.27 vs. 8.93 points) and job security (9.68 vs. 10.67 points) in their job compared to others with similar qualifications. Whereas, for people with a higher education diploma, discrimination on multiple grounds will most typically be associated with lower levels of job security (9.38 vs. 10.97 points) and work-life balance (5.50 vs. 6.09 points) (Table 9). To sum up, the number of discrimination grounds and various components of the job quality indicator are in most cases inversely proportionate at different educational levels. Nevertheless, one dimension of job quality (namely, the job security level) is more likely to be endangered in the case of multiple discrimination, no matter what the level of education is.

CONCLUSIONS

In the first section of this paper, we elaborated on the significance of discrimination on multiple grounds across Europe, and revealed that only 1.1% of the population actually reported any previous experience of multiple discrimination. It has also been stated that the level of multiple discrimination varies across European countries, based on the ESS 2010 data. In relative terms, approximately one quarter (22%) of the victims of discrimination were subject to discrimination on multiple grounds; this ratio could be considered important,

but in absolute terms, the observed occurrence of 1.1% of the population certainly cannot be evaluated as a significant level postulated in the first hypothesis. Hence, the first hypothesis was only partially true, if we only consider ESS data. However, comparing the results of the ESS 2010 survey data with other European surveys (Special Eurobarometer 296, EU-MIDIS), which were more focused on the topic of discrimination, it can be revealed that the methodology used was probably responsible for a high latency rate in surfacing incidents of discrimination by the European Social Survey core questionnaire.

Concerning the European trends of multiple discrimination, we concluded that colour and race, nationality, ethnic origin, religion and language constituted the most frequent grounds of discrimination amongst those discriminated on multiple grounds, and these were all clearly closely linked to *ethnicity*. The principal component analysis carried out for the entire European population of 17 countries also identified two major factors among the grounds for discrimination: these were linked to *ethnicity* and integrated all the other *non-ethnicity* factors such as gender, age, sexuality and disability. The primordial role of ethnicity in multiple discrimination was identified by the EU-MIDIS (2011) survey as well. At this point, in relation to the results of the factor analysis, we could ask about the extent to which we are measuring cases of genuine multiple discrimination. We have to acknowledge that separate grounds of discrimination might overlap in certain cases. A person living somewhere other than their country of origin might be recorded as being discriminated against on multiple grounds (linked to nationality, language, and colour) though the major reason for unequal treatment has the same root cause: being born in another country. This differs from the classical case of multiple discrimination, where colour and gender, or age and gender are associated in an inseparable way and called intersectionality. Nevertheless, seemingly overlapping grounds of discrimination can also come into action separately, thus aggravating the outcomes for the victim of unequal treatment. In most large-scale surveys, as in the ESS, the method of data collection does not make it possible to clearly identify the exact type of multiple discrimination, but using the legally defined grounds of discrimination, it is still the best way forward.

The second hypothesis of the paper assumed that discrimination on multiple grounds had an aggravated impact on employment prospects, compared to discrimination on a single ground. Based on the ESS 2010 data, we had to reject this hypothesis, as we could not identify a significant reverse linear relationship between the number of grounds of discrimination and the employment rate at the European level. As a matter of fact, there seems to be a more important demarcation line in terms of the employment rate among those not discriminated against at all, and those discriminated against on single grounds in a higher number of European countries. An explanation offered for this trend was that employers' hiring decisions were influenced by whether the jobseeker displayed any characteristics considered to be risky by the employer or not, while the number of risky characteristics might have been of secondary importance in hiring decisions.

In the literature review section, it was shown that the quality of jobs could not be assessed indirectly through the indicator of job satisfaction (Poggi, 2010; Llorente & Macias, 2005). These research results reinforced our adopted methodological approach to measure job quality by a complex indicator composed of

23 variables. Our third hypothesis stated that victims of multiple discrimination, when employed, have a lower overall job quality compared to those previously affected by no discrimination, or by discrimination on a single ground among people of equal qualification. The hypothetical relationship between multiple discrimination and lower-level job quality among people with equal educational levels was accepted. Statistical data from ESS 2010 reinforced the assumption that experiences of multiple discrimination could more likely be associated with lower-level job quality, be it at the primary, secondary or higher education level. These research results were in line with the findings of Goldsmith et al. (2004), who identified accepting a lower-quality job as one of the possible jobseeker strategies in view of employers' discriminatory practices. The analysis of the ESS 2010 data also revealed that at each educational level, different dimensions of job quality were at stake in the case of multiple discrimination. The most "sensitive" dimensions of job quality to multiple discrimination were participation opportunities, work-life balance, job security, and lower levels of compensation. However, there was one single job quality dimension that was significantly lower for all levels of education: job security.

Finally, it is crucial to insist on the necessity of further investigating the multiple-discrimination phenomenon. It would be of the utmost importance to develop research into the more specific types of multiple discrimination (namely, compound and intersectional discrimination), in order to be able to better understand the forms of discrimination of a more complex and severe nature, and the combination of various grounds of discrimination inseparable from each other. Also, the research has important policy implications with respect to raising awareness about the more complex nature of discrimination, especially multiple ground discrimination, and how it is connected to job-quality dimensions and social well-being in general.

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APPENDIXES

Table 1: Distribution of the population by the number of grounds of discrimination and the rate of multiple discrimination among the discriminated in the European Union in 2010 (%)

	No discrimination	Discrimination on one ground	Discrimination on two or more grounds	Total	Rate of multiple discrimination among the discriminated
Hungary	95.0	2.4	2.6	100.0	52
Estonia	94.7	2.7	2.6	100.0	49
Bulgaria	91.1	6.9	2.0	100.0	31
United Kingdom	90.1	8.3	1.6	100.0	29
Netherlands	93.4	5.0	1.5	100.0	24
France	94.1	4.5	1.4	100.0	24
Sweden	94.7	4.1	1.3	100.0	24
Czech Republic	94.6	4.1	1.3	100.0	24
Germany	96.8	2.2	1.1	100.0	22
Denmark	96.5	2.5	1.0	100.0	20
Belgium	96.5	2.8	.8	100.0	16
Spain	96.3	3.1	.6	100.0	16
Finland	95.2	4.2	.6	100.0	14
Norway	96.5	3.0	.5	100.0	12
Slovenia	97.9	1.9	.2	100.0	10
Portugal	97.6	2.2	.2	100.0	8
Poland	97.4	2.5	.1	100.0	4
EU average (17 countries)	94.9	4.0	1.1	100.0	22

Source: ESS 2010

Table 2:

Frequency of different grounds of discrimination among those affected by multiple discrimination (two or more grounds) in the European Union countries, in 2010 (%)

	Colour or race	Nationality	Religion	Language	Ethnic group	Age	Gender	Sexuality	Disability	Total
Belgium	84.6	38.5	61.5	15.4	15.4	15.4	7.7	0.0	7.7	100.0 N=13
Bulgaria	56.0	8.0	34.0	26.0	76.0	20.0	8.0	0.0	6.0	100.0 N=50
Czech Republic	42.4	21.2	15.2	9.1	36.4	63.6	45.5	12.1	27.3	100.0 N=33
Denmark	50.0	50.0	43.8	37.5	43.8	12.5	12.5	0.0	12.5	100.0 N=16
United Kingdom	59.0	31.6	34.2	10.5	18.4	36.8	31.6	5.1	10.3	100.0 N=38
Estonia	0.0	82.6	2.2	91.3	19.6	15.2	10.9	2.2	10.9	100.0 N=46
Finland	27.3	27.3	18.2	18.2	45.5	36.4	9.1	18.2	9.1	100.0 N=11
France	73.9	56.5	34.8	21.7	39.1	17.4	30.4	26.1	21.7	100.0 N=23
Netherlands	48.1	55.6	48.1	11.1	48.1	18.5	18.5	7.4	3.7	100.0 N=27
Poland	0.0	0.0	100.0	0.0	50.0	0.0	50.0	0.0	0.0	100.0 N=2
Hungary	75.0	47.2	8.1	5.6	66.7	13.9	8.3	0.0	8.1	100.0 N=36
Germany	25.6	74.4	35.9	51.3	25.6	5.3	7.7	10.3	10.3	100.0 N=39
Norway	42.9	28.6	42.9	14.3	28.6	14.3	28.6	14.3	0.0	100.0 N=7

Portugal	100.0	75.0	50.0	0.0	0.0	0.0	0.0	0.0	0.0	100.0 N=4
Spain	46.2	38.5	23.1	30.8	15.4	25.0	33.3	25.0	0.0	100.0 N=13
Sweden	10.5	26.3	15.8	26.3	42.1	36.8	57.9	5.3	31.6	100.0 N=19
Slovenia	33.3	100.0	100.0	33.3	33.3	66.7	33.1	33.3	33.3	100.0 N=3
EU average (17 countries)	50.3	48.9	32.9	25.6	32.7	21.1	23.2	11.6	12.1	100.0 N=380

Table 3: Principal components of grounds of discrimination across Europe (17 countries)

	Component	
	1 Ethnicity related factors	2 Non-ethnicity related factors
Discrimination of respondent's group: colour or race	.613	-4.174E-02
Discrimination of respondent's group: nationality	.726	-.135
Discrimination of respondent's group: religion	.654	-.137
Discrimination of respondent's group: language	.748	-.137
Discrimination of respondent's group: ethnic group	.666	-7.522E-02
Discrimination of respondent's group: age	.152	.628
Discrimination of respondent's group: gender	.178	.626
Discrimination of respondent's group: sexuality	.175	.461
Discrimination of respondent's group: disability	.167	.469

Extraction Method: Principal Component Analysis.

KMO=0.770, BartlettSig=0.00

a 2 components extracted.

Table 4: Principal grounds among those discriminated against on multiple grounds in the EU (17 countries)

	Component		
	1 Demographic factors (age & gender)	2 Ethnicity factors	3 Physical and spiritual difference factors (Disability, sexuality, and religion)
Discrimination of respondent's group: colour or race	-.370	-.662	.100
Discrimination of respondent's group: nationality	-.426	.636	.152
Discrimination of respondent's group: religion	-.274	-6.088E-02	.425
Discrimination of respondent's group: language	-.309	.711	8.062E-02
Discrimination of respondent's group: ethnic group	-.333	-.499	.250
Discrimination of respondent's group: age	.809	-4.887E-03	-.147
Discrimination of respondent's group: gender	.768	2.145E-02	-9.920E-02
Discrimination of respondent's group: sexuality	.374	-1.778E-02	.730
Discrimination of respondent's group: disability	.430	.133	.578

Extraction Method: Principal Component Analysis.

KMO=0.613, BartlettSig=0.00

a 3 components extracted.

Table 5: The ratio of those in paid work among those affected by discrimination and those not affected by discrimination (%)

	Rate of those in paid work across the total population	Rate of those in paid work among persons not affected by discrimination (%)	Rate of those in paid work among persons affected by discrimination (%)	Ratio of the employment rate of the discriminated and non-discriminated	Ratio of the employment rate of those discriminated against, and the total population
Bulgaria	40	42	22	0.53	0.55
Hungary	49	49	35	0.71	0.71
Czech Republic	54	55	40	0.72	0.74
Portugal	40	40	40	0.101	1.00
Poland	50	51	41	0.81	0.82
Denmark	56	56	42	0.75	0.75
Netherlands	59	60	44	0.73	0.75
Belgium	51	51	45	0.88	0.88
Sweden	57	58	46	0.81	0.81
Estonia	49	49	46	0.94	0.94
Finland	48	49	48	0.99	1.00
Slovenia	47	47	48	0.103	1.02
Germany	53	53	50	0.93	0.94
United Kingdom	53	52	54	0.104	1.02
France	52	52	55	0.106	1.06
Spain	49	49	61	0.126	1.24
Norway	62	62	66	0.106	1.06
EU average (17 countries)	52	52	50	0.96	0,96

Source: ESS 2010

Table 6: Average value of the Job Quality Index among the employed population (job-quality dimensions and countries of the European Union)

	compensation (15 points)	working hours (10 points)	participation (10 points)	social and self-esteem needs (15 points)	job security (15 points)	work-life balance (10 points)	workload (15 points)	self-actualisation (10 points)	job quality index (100 points)
Norway	9.9	5.5	7.2	10.3	11.6	6.2	6.5	7.0	64.2
Sweden	9.6	5.7	7.0	10.0	11.7	6.2	6.6	6.7	63.6
France	9.4	5.8	6.2	9.4	11.5	6.3	6.8	6.9	62.3
Denmark	9.4	5.8	6.8	10.0	11.1	6.8	5.9	6.4	62.2
Belgium	10.2	5.5	6.0	10.1	11.3	6.4	6.3	6.4	62.2
Finland	8.7	5.8	6.8	9.9	11.4	6.7	6.3	6.4	61.9
United Kingdom	9.4	5.3	6.1	9.9	10.1	6.2	6.9	6.5	60.4
Slovenia	8.7	5.5	5.4	9.4	11.4	6.1	6.7	6.9	60.2
Estonia	7.8	5.8	5.7	10.4	10.3	6.0	6.8	6.8	59.5
Germany	8.9	5.3	5.6	9.5	11.0	5.8	6.3	6.3	58.7
Bulgaria	8.8	5.8	4.8	9.3	10.7	6.2	7.0	5.7	58.1
Netherlands	9.1	5.3	6.1	9.4	10.0	6.2	5.9	6.0	58.0
Hungary	8.5	5.7	4.9	9.3	10.5	5.9	6.7	6.0	57.5
Spain	8.1	5.2	5.8	9.2	10.2	6.2	6.4	5.5	56.6
Czech Republic	8.6	5.4	4.5	8.5	10.0	5.5	6.8	6.0	55.6
Portugal	9.0	5.4	4.8	8.3	10.3	5.9	6.7	5.1	55.5
Poland	8.1	5.2	5.0	8.8	10.1	5.7	6.4	6.1	55.4
European Union average (17 countries)	8.9	5.4	5.8	9.4	10.7	6.0	6.5	6.3	59.18

Source: ESS 2010

Table 7: Average value of the Job Quality Index dimensions among the employed population by number of discrimination grounds across 17 Europe Union countries

	non-discriminated	discriminated on a single ground	discriminated on multiple grounds	total
compensation (15 points)	8.98	8.42	7.81	8.94
working hours (10 points)	5.42	5.24	5.46	5.41
participation (10 points)	5.81	5.61	5.43	5.80
social and self-esteem needs (15 points)	9.43	9.36	8.90	9.43
job security (15 points)	10.76	9.65	9.41	10.70
work-life balance (10 points)	6.08	5.83	5.47	6.07
workload (15 points)	6.51	6.90	6.73	6.53
self-actualisation (10 points)	6.30	6.29	6.11	6.30
average Job Quality Index (EU 17) (max. 100 points)	59.30 N=15960	57.31 N=670	55.32 N=184	59.18 N=16814

Source: ESS 2010

Table 8. Average Job Quality Index value by the number of discrimination grounds and level of education among working people in the 17 European Union countries

years of full-time education completed	number of grounds of discrimination	Job Quality Index average value	N	std. deviation
primary/lower level education (0-8 years)	0	54.50	898	19.036
	1	55.38	34	15.622
	2	45.08	13	16.811
	subtotal	54.40	946	18.914
secondary/vocational education/ (9-14 years)	0	58.33	8717	18.284
	1	55.31	284	16.657
	2	55.65	101	14.790
	subtotal	58.33	8717	18.284
higher education (at least 15 years full-time)	0	61.31	6345	18.046
	1	59.11	352	18.652
	2	56.78	70	15.879
	subtotal	61.15	6767	18.067
total	0	59.30	15960	18.326
	1	57.31	670	17.763
	2	55.32	184	15.546
	total	59.18	16814	18.283

Source: ESS 2010, International

JUSTICE ON THE STREETS

THE PRODUCTION OF CRITICAL KNOWLEDGE THROUGH PARTICIPATORY ACTION RESEARCH WITH HOMELESS PEOPLE IN BUDAPEST

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ABSTRACT

With knowledge and power so intimately tied together, research and documentation can easily turn into technologies of control and exclusion. While the modern state is extremely adept at counting, documenting and categorizing its residents, it is also able to enforce certain expectations towards its citizens through a request for proper documentation. In today's Hungary, the state has acquired a vast knowledge about people who are homeless through various forms of registration. At the same time, being properly documented is essential for homeless people in order to access necessary services and maintain their links to the body politic. By contrast, homeless people are rarely in a position either to get to know the state's operations in detail or set expectations towards the state and its representatives. *Justice on the Streets*, a participatory action research (PAR) project undertaken by the homeless and housed members of *The City is for All* (AVM), a homeless rights advocacy group in Budapest, represents an attempt at bridging this huge inequality in knowledge and power by documenting the behaviour of the state from the perspective of street homeless people. In this paper, I use the concept of deep participation to examine the collective process of critical reflection and knowledge production in PAR. More specifically, I analyse the unfolding of deep participation in *Justice on the Streets* from the perspective of: 1) the development of a critical consciousness; 2) the dynamics of participation in a cross-class context; and 3) the deconstruction of power and inequality at both the micro and macro levels.

KEYWORDS

Homelessness, discrimination, Participatory action research, Budapest, The City is for All

“The point is to change it” goes Marx’s famous tenet in his 1845 *Theses on Feuerbach* about the imperative for social scientists to move beyond the documentation of social life and directly contribute to efforts of social transformation. In practice, socially engaged research takes shape in many hybrid forms in between theory, practice, activism and scholarship. In the following, I explore how engaged social science can intervene into social processes through collaboration with social movements, and assess their transformative potential. First, I provide an overview of the right to research as a theoretical, ethical and political framework for engaged scholarship. Then, in order to understand how a democratic research practice takes shape on the ground, I examine the dynamics in *Justice on the Streets*, a participatory action research project with homeless people in Budapest. In the second part of the paper, I discuss the theoretical and political consequences of “deep participation” from three different perspectives: the development of critical consciousness; issues of power and control; and the possibilities of mitigating deeply engrained social inequalities.

1. THE RIGHT TO RESEARCH

The question of who has control over the production of social life is intimately tied to the ways in which social control and exclusion are negotiated and justified. This is why the production of knowledge, access to information and the power of interpretation all play a central role in struggles over citizenship. The concept of the right to research (Appadurai, 2006) is not only useful in understanding the relationship between power and knowledge but also helps to develop counter-hegemonic practices.

The right to research is based on the understanding that scientific practices are socially constructed and research is embedded in relations of power. As Latour and Woolgar (1979) observe, scientific facts are socially constructed through academic protocols, rituals, hierarchies, tenure and publications, among others. At the same time, educational institutions are structured to reproduce existing social inequalities (Bourdieu & Passeron, 1990). Today, many of the institutions that define knowledge and the appropriate ways to acquire it tend to be patronizing and hegemonic (Appadurai, 2000: 9–10).

One way to contest hegemony over the production of knowledge is to democratize research, and question the social processes that make it an exclusive privilege. To liberate research from the confines of official academic spaces, Appadurai (2006: 167) defines research as:

the capacity to make disciplined inquiries into those things we need to know, but do not know yet. All human beings are, in this sense, researchers, since all human beings make decisions that require them to make systematic forays beyond their current knowledge horizons.

Echoing Gramsci’s (1970) argument that every person is an intellectual in their own right, the right to research recognizes that both research in particular and intellectual activity in general belong to everybody and not only to a small and privileged portion of society.

In a political sense, the right to research includes the right to information and the right to experiment with new ways of knowing. From this perspective, conducting research is not a privilege but a kind of practice where the standards of rigour may be very different from those enforced in most spaces of academic knowledge production. If research can be carried out by

everyone, then anyone may be both a subject and object of inquiry. In this way, the conventional dichotomy between marginalized people who are studied, and academic researchers who study them, is seriously challenged.

2. PARTICIPATORY ACTION RESEARCH

While the need to document, understand and expose oppressive social conditions is at the heart of all efforts to reclaim the right to research, it can be exercised in many different ways. One way to subvert conventional research practice and reclaim the right to research is participatory action research (PAR), which provides “a space for questioning exclusionary practices and social inequities” (Cahill, 2004: 273) and transforms research from “the gaze of the privileged” into a tool for social change. Born out of a combination of Marxist theory, critical pedagogy, action research and feminist critique, PAR radically changes the ways in which knowledge is produced and puts research at the service of social transformation.

PAR’s philosophy of social change is rooted in Paulo Freire’s ([1970] 2007) critical pedagogy, which poses a direct challenge to the reproduction of marginalization and privilege by mainstream education as well as the hierarchical relationships embedded in conventional academic (research) practice. Defining social transformation as a pedagogical process, Freire maintained that marginalized groups have to undertake a process of radical self-humanization by understanding and subverting the structural roots of oppression. Freire’s theory of social change is important because of its focus on process and methodology – how social transformation is achieved is just as important as its outcome – and the recognition that marginalized groups have to participate actively in changing the social conditions that oppress them.

PAR aims to connect personal experiences with the broader context of structural inequalities through the co-construction of the research process and the development of critical consciousness. This:

refers to the process by which members of oppressed groups cultivate abilities to perceive and deconstruct the prevailing ideologies and practices that veil inequalities as legitimate and how they progressively work to change the conditions of their lives through action aimed at restructuring hierarchal power relations. (Guishard, 2009: 89)

In other words, critical consciousness is not a specific state of mind, but a deeply intellectual process of critical reflection and practice.

While Freire dismissed reflection for its own sake, Kurt Lewin advocated against research for purely academic purposes: “research that produces nothing but books will not suffice” (1946: 35). Looking specifically at intergroup relations between minority and majority populations, Lewin maintained that it is not enough to use research to understand social relations; it also has to contribute to improving them. For research to be an effective tool for social change, it should take place not only in the isolated setting of the university, but become embedded in the practice of social movements and organizations.

Based on these ethical and political considerations, PAR brings together the commitment of social movements, their members’ experience and expertise, and scholars skilled in the craft of research with access to the resources and privileges of academia and other dominant spaces such as the media. By establishing a democratic and critical process of knowledge production, PAR is able to produce results that are both theoretically significant and politically transformative.

Critical participatory research (see Torre et al., 2012) creates a space for theorizing by those who are dehumanized and silenced by hegemonic institutions, and plays a critical role in challenging dominant discourses of personal blame and failure. In this way, PAR can be instrumental in the creation of counter-publics, or “parallel discursive arenas where members of subordinated social groups invent and circulate counter-discourses to formulate oppositional interpretations of their identities, interests, needs” (Fraser, 1990: 67). At the same time, critical PAR also has a role in bringing these counter-publics into communication with mainstream conceptions and practices. In all, with its commitment to “speaking back to power” and its focus on the process as much as the outcome, PAR is a tool to produce the cultural and discursive power necessary for the viable political representation of groups that are marginalized (see Gramsci, 1971).

3. JUSTICE ON THE STREETS: PARTICIPATORY ACTION RESEARCH ABOUT DISCRIMINATION

A main feature of the modern state is to count, document and categorize its people, land and assets (Scott, 1998). In this way, research and documentation are important forms of state control that can also be turned into technologies of exclusion. In Hungary today, registering a permanent address or having a social security card and a tax number are not only ways for the state to document its population, but also essential links to the full exercise of citizenship. In Budapest, homeless people spend an average of almost four hours a day travelling, taking care of paperwork, or standing in line for various services (Győri, 2006: 14) in an effort to ensure their survival and keep up essential social links. Street social workers have to document each encounter they have with a homeless person, and a new regulation stipulates that every time a homeless individual uses a social service, their social security number has to be registered. Homeless people are documented not only through the registration of their personal data, but also through other means, including GIS maps compiled by the police and public space supervisors (*Rendőrök ellenőrzik*, 2011).

Through all these channels, the Hungarian state gathers a lot of information about homeless people. By contrast, the homeless know a lot less about the state. While users of social services often have an intricate knowledge about how to get things done, they rarely have a broader understanding of the state apparatus or the ways in which decisions can be officially questioned or appealed. This lack of a broader knowledge not only makes them vulnerable, but also creates a feeling of isolation as they navigate state bureaucracy and the social-services system. At the same time, the state – through its representatives such as municipal workers and police officers – sends a powerful message to homeless people about themselves, their own social position and the kinds of things they do or do not deserve.¹

Justice on the Streets, a participatory action research project undertaken by homeless and housed members of *The City is for All* (*A Város Mindenkié*, AVM), was an attempt to bridge this inequality in knowledge and power between homeless people and the state. The aim of the project was to examine the ways and extent to which street homeless people in Budapest are discriminated against by representatives of the state. Besides collecting data, the project sought to challenge the political and intellectual exclusion of homeless people from relevant public discussions by empowering them as key agents of change. Through systematic inquiry, the project aimed to: 1) raise critical consciousness; 2) produce strategic knowledge; and 3) build power for effective self-advocacy at the individual and collective levels.

¹ For more on the role of street-level bureaucrats in policy-making and interaction with citizens, see Lipsky 1980.

Justice on the Streets was coordinated by four AVM activists, two of whom are housed with training in the social sciences (the author was one of them)² and two long-time homeless members. By offering a small weekly stipend, we recruited a team of 18 homeless researchers.³ Starting out with an intensive training in research methodology, the team met every week for three hours from the fall of 2011 to the fall of 2012. Data collection took place between meetings, while the dissemination of results continued well into 2013.

Using a deductive process,⁴ the research team came to agree on the following research question: “Do roofless people in Budapest experience discrimination by representatives of the state and if yes, in what forms and to what extent?”⁵ To answer this, we drew upon four main sources of data. First, the personal experiences of homeless researchers regarding discrimination were documented and discussed throughout the project. Second, the team developed a questionnaire that included questions about stereotypes and personal experiences of direct and indirect discrimination as well as individual advocacy.⁶ Close to 400 homeless people responded to the questionnaire at various locations including drop-in centres, public spaces and food lines.⁷ Third, in order to support our statistics with qualitative data, we completed 18 interviews with professionals who work with homeless people or have an impact on their lives (including social workers, police officers, public-space supervisors, ticket inspectors on public transportation, health-care professionals, administrators in the social services and elected representatives).⁸ Finally, secondary data included official statistics about encounters between police officers and homeless people and about complaints filed against police officers and public-space supervisors.

² The author is one of the co-founders of the group and has been working there as a volunteer since 2009. The PAR project was also a part of her dissertation research for the City University of New York.

³ By the end of the project, we had 11 homeless researchers, most of them from the original team. The original team members were János Balácsi, Anna Bende Géza Bene, Tamás Filder, Károly Gadányi, Krisztina Gyureskó, Mária Gadányiné Simon, János Jáger, Jenő Keresztes, Linda Kőházi Andrásné, Gergely Lőrincz, Gabriella Némedi Lászlóné, Csaba Oszvald István Petrák, Ferenc Sándor, Ferenc Sziráki, Zsuzsa Szűcs and Gábor Takács.

⁴ We started out with a very broad question: “Are street homeless people able to exercise their rights?” and listed all the possible aspects of this question. In the end, we tried to find common threads and mould all of our questions into a single one. Then we moved on to formulating the sub-questions based on what we previously listed.

⁵ We defined “roofless” as those who live in one-night shelters, on the street, in self-built shacks or other places not meant for human habitation such as empty buildings and caves. We included those who slept in one-night shelters because they are only allowed to enter in the evening and have to spend most of their day in public spaces or drop-in centres. In addition, as one-night shelters only offer a nightly contract, people are always at risk of not getting in because of limited capacities. Overall, our target group consisted of at least 5,000 people in Budapest, 2,000 of whom sleep in one-night shelters and 3,000 in other places. For the purposes of our study, we defined the “representatives of the state” as those who perform a public duty or get their salary from the central or local government, including uniformed officers, administrators and health-care professionals.

⁶ The questionnaire, which we developed collectively over a couple of months, included 40 questions grouped into the following categories: general descriptive questions; the social perception of homeless people; general opinions about discrimination; first-hand experiences of discrimination; the behaviour of uniformed authorities; and personal experiences and opinions regarding advocacy and civil rights.

⁷ The sample was established as being quasi-representative of the homeless population of Budapest if compared to the results of the February 2012 “homeless survey”. Respondents in our survey had been homeless for an average of seven years; half of them were homeless for less than five years, while 24% had lived on the street for more than 10 years at the time of the survey. Over half of the respondents slept in one-night shelters and one fifth of them on the street; 29% slept in abandoned building, shacks, tents and other places. In terms of income, 30% of respondents gained an income from some kind of recycling activity (e.g. paper, plastic, cans etc.); 18% from occasional or regular work; and 15% of the research subjects claimed to have no income.

⁸ We picked the interviewees using our personal and professional contacts as well as snowball sampling. We analysed the completed interviews using a collective technique of iterative content analysis. First, we selected those parts of the interviews that were relevant for the topic of discrimination and then organized them according to various themes such as “mistakes in the system,” “systemic discrimination,” “individual discrimination” and “solutions.” After all the parts were categorized in this way, we discussed each one, established trends and drew general conclusions.

Figure 1: The development of the research process in *Justice on the Streets*⁹

Preparation

Advocacy work by The City is for All → Selection of research topic (2009–2011)

Forming the research team

Development of recruitment plan → Recruitment of homeless researchers (August–October, 2011)

Information forum for interested homeless people → Training of homeless researchers (October–November, 2011)

Research question

Development of main research question → Development of sub-questions (November–December, 2011)

Research methodology

Selection of target groups → Selection of research methods for each target group (January, 2012)

Development of questionnaire → Practice of survey administration (February–March, 2012)

Administration of surveys → Statistical analysis of surveys (April–June, 2012)

Development of interview guide → Selection of interviewees (May–June, 2012)

Completion of interviews → Content analysis of interviews (June–August, 2012)

Final report

Group discussion of structure of final report → Write-up of final report (August–September, 2012)

Collective reading and feedback on final report → Finalization of final report (September–October, 2012)

Write-up of short research summary (October, 2012)

Dissemination (actions)

Development of dissemination plan → Dissemination of research results

(e.g. press conference, roundtable discussion, training sessions) (October, 2012 – ongoing)

The research produced important data about prejudices and stereotypes regarding homeless people, the formal and informal manifestations of discrimination, as well as civic consciousness, and individual advocacy among homeless people.¹⁰

⁹ In the summer of 2012, Barbara Erős, an anthropologist from the University of Miskolc, proposed conducting some interviews with homeless co-researchers about their experiences of participation in *Justice on the Streets*. This had not been originally planned as part of the research, but the group decided to integrate it to some extent because it seemed like a good opportunity for self-reflection and external evaluation. Barbara came to present her findings to the entire research team in the fall of 2012. Some excerpts from her interviews are also included in this article.

Regarding direct discrimination, the vast majority (83%) of survey respondents thought that homeless people experienced discrimination, and a similarly high proportion (75%) of respondents had first-hand experiences of direct discrimination. Non-homeless civilians such as passers-by, youth and passengers on mass transportation, as well as public-space supervisors and police officers were mentioned as being groups that discriminate against homeless people the most often. At the same time, in response to a more concrete question, a shocking 57% of respondents reported to have been treated in a humiliating manner, most often by public-space supervisors, police officers and non-homeless civilians.

Homeless respondents identified public transportation as the arena where they experienced the most discrimination. Forty-three percent of respondents said that they had been forced to get off some form of public transport because they did not have a valid ticket, had broken the rules of conduct (e.g. travelling in dirty clothes or taking a larger bag), or simply for being homeless. The issue of public transportation highlights the relationship between the first-hand experience of discrimination and structural exclusion. Informal conversations with respondents and homeless people in other venues revealed that many homeless people regard the fact of being forced out of public transportation as a form of discrimination in itself. While they are aware that travelling without a valid ticket or a pass is in breach of official rules, from their point of view, the fact that they do not have a ticket is rooted in the same condition as their homelessness: extreme poverty. In this way, the moment that they are expelled from the bus or the tram for not having a valid ticket, their structural exclusion is translated into concrete terms. In this way, it is not only exclusion from public transportation in the absence of a valid ticket that qualifies as discrimination, but also the fact that homeless people cannot afford to use public transportation to satisfy their most basic needs.

After public transportation, discrimination from uniformed officers was reported to be the most frequent. Almost half of homeless respondents experienced discrimination from uniformed authorities and 50% of them had been spoken to in a demeaning way. This finding was also confirmed by an interview with public-space supervisors, who talked about “using a stronger tone” when a homeless person refuses to leave a place after repeated requests. Altogether, only 26% of homeless respondents felt that uniformed authorities treated them as equal citizens. As many as 13% of respondents reported having been physically abused by the authorities.

At the same time, many respondents also identified uniformed authorities as sources of help. Almost one quarter of the respondents had received support from public-space supervisors or police officers in the form of food, money or information, which was also confirmed by the official statistics provided by the Budapest police headquarters about the interaction between police officers and homeless people.¹¹ Interestingly, respondents identified leniency on the part of authorities as a specific form of help. For example, public-space supervisors often give homeless people a verbal warning instead of a formal punishment for an infraction, such as rummaging through garbage. This practice was also confirmed in an interview with a public-space supervisor: “How would I fine a homeless individual? Where would they get the money from? This makes no sense.”

¹⁰ Given the nature of participatory action research as a possible tool for advocacy, some of these findings may be biased due to the inadvertent selection of respondents by homeless researchers who are keen on voicing complaints or who are more ready to answer questions posed by someone associated with a well-known advocacy group. Throughout the research process, we placed great emphasis on reducing this bias by assigning researchers to various venues of data collection, and moving beyond personal acquaintances. In the training of homeless co-researchers, we also discussed different strategies to avoid the danger of obtaining guided or suggested responses. The nature of the questionnaire may have also played a role, as it focused on instances of discrimination and other negative experiences rather than inserting such a question in the middle of a variety of other topics. In this way, the attention of the respondents may have been called to instances that they would otherwise not have remembered or pointed out.

¹¹ These charts were provided to *The City is for All* under a freedom of information request in 2010.

Because of their dependence on specific social services, which are often spatially concentrated, as well as their heavy use of public spaces, homeless people are especially exposed to police harassment. In fact, being stopped for an ID check is the main source of tension between police officers and homeless people. While ethnic profiling in Hungary is relatively well-documented (see Kádár et al., 2008; Ivány & Pap, 2012), the targeting of homeless people has not previously been explored. In this way, the findings of *Justice on the Streets* provide a significant contribution to our understanding of profiling based on social status. Fifty-nine percent of homeless respondents were checked by the police over a one-month period, and more than one third had been stopped more than four times. These findings support the long-held perception of homeless researchers and activists, that despite formal equality before the law, the lack of housing leads to increased control, supervision and harassment for pursuing life-sustaining activities (e.g. standing in line for food, eating on a bench, urinating in public, etc.).

Universal health care is a very ambivalent area from the point of view of homeless people. Of all homeless respondents in the survey, 25% said they had experienced discrimination within social and health-care facilities. Fourteen percent of the respondents were not attended to in a hospital, and 10% were not taken by an ambulance when necessary. At the same time, homeless people also mentioned several positive experiences, especially when doctors and nurses made extra efforts to provide them with appropriate care. According to the head of a homeless health-care facility: “Some people are really sweet patients and nurses love them. When they find out that they are homeless, they give them all the left-over food and they find them nice pyjamas.”

While the *Justice on the Streets* questionnaire measured direct discrimination, the interviews conducted with professionals also revealed indirect discrimination and systemic issues. First of all, many interviewees identified homelessness as a state of social exclusion itself, a stigmatized condition that is almost impossible to leave behind. In addition to this general sense of exclusion, the interviews revealed four concrete areas where the social-services system discriminates against homeless people, including labour support, welfare, health care and social housing.

The segregation of homeless people in public services is the most concrete manifestation of indirect discrimination. There are two public agencies in Budapest that treat homeless people in a segregated manner, and these are often described as discriminatory by both professionals and homeless people: the unemployment centre for those “without an address” and the municipality’s homeless welfare office. In certain cases, the existence of an institution dealing with only one particular segment of the population could be justified by the special needs of its clients (see the need for special offices for veterans in the US). However, as noted by our interviewees, administrators working in the two homeless-specific offices in Budapest neither receive any special training, nor do they offer any extra services.

In addition, there also exists a parallel (and in many ways inferior) system of health care exclusively for homeless patients. The so-called homeless health-care centres have three main functions: first, to prepare homeless people for the regular health-care system through parasite removal, cleanup and nutrition; second, to take them in after a hospital discharges them and sends them “home”; and third, to provide basic medical services and referrals for those who do not have a proper address. While these institutions save lives by providing safe havens for homeless people, they also point out the inability and often reluctance of generally accessible health-care services to serve everyone’s needs equally.

The existence of segregated facilities for the homeless is a good example of the politics of marginal space (see Larsen, 2004). On the one hand, the separate hospitals and segregated labour and welfare offices have all been developed to ensure that homeless people are able to minimally access services. However, while they ensure the survival of homeless people as physical bodies, these institutions also reproduce their status as second-class citizens. The fact that many homeless people choose to go to a “homeless doctor” instead of a general practitioner (even if they are eligible for regular health care) because they are afraid of discrimination illustrates the extent to which marginality has been internalized. In this way, these spaces do not undermine social inequality but, instead, reinforce it.

Finally, professionals interviewed in *Justice on the Streets* have also identified social housing as an area of discrimination. This is particularly paradoxical, as subsidized housing could be one of the few permanent exits out of homelessness. However, because of their extremely limited availability, applications for social housing units often set criteria of eligibility that are difficult or impossible for poor people to meet (e.g. a certain number of years of official residence in the district, the obligation to renovate the apartment or a large deposit). In this way, instead of addressing the structural inequalities of the housing market, the current system of social housing also tends to reinforce social inequalities.¹²

4. THE PRODUCTION OF RADICAL KNOWLEDGE IN *JUSTICE ON THE STREETS*

The concept of “deep participation” describes the collective process of reflection and knowledge production in PAR. For different authors, the concept means slightly different things. For Billies (2010), deep participation refers to the fact that all researchers are involved in all aspects of the research from conception through data collection to analysis and action, while critical consciousness is raised. For Francisco (2010), it is used to describe a situation where it is not only those who suffer directly from oppression who share their knowledge and experiences but everyone, including academically trained researchers. For Torre et al. (2008), the depth of participation refers to interactions and transformations across social status. In the following, I analyse the unfolding of deep participation in *Justice on the Streets* from the perspective of: (a) critical consciousness; (b) the dynamics of participation; and (c) the deconstruction of power and inequality.

a. Raising critical consciousness

PAR creates a space where participants can explore their personal experiences, connect them with those of others and uncover the roots of their oppressions. In this way, while valorising the personal experiences of co-researchers, PAR aims to connect these with the broader context of structural inequalities. Fine and Ruglis (2009) discuss the ways in which circuits of dispossession become embodied experiences of shame and failure in high school students of colour in the US. In fact, the same is true for homeless people who suffer from the consequences of neoliberal policies that slash social housing and welfare, but are expected to see themselves as the primary sources of failure and dysfunction.

Developing a critical understanding of social experiences in a structural context allows people to see themselves and their difficulties in a way that empowers rather than oppresses them. With the help of systematic inquiry at different scales (see Fine, 2006), disenfranchised groups are able to produce (self-)representations that go against dominant discourses, which not only

¹² For a more detailed description of results, see *A Város Mindenkié* (2013).

stigmatize, but often also paralyze them.¹³ By building strategic knowledge and politicizing participants, critical consciousness helps to build power to confront injustice at both the individual and collective levels.

As is clear from the findings of our research, homeless people's acute awareness of negative social attitudes towards them determines not only their relationship with mainstream society, but also their self-esteem and their relationships with each other. As one homeless respondent stated: "There is negative discrimination against homeless people by homeless people themselves." According to a longitudinal study from 1998 to 2000, homeless people disproportionately suffer from the insults of their homeless peers (Dávid et al., 2005: 99). The internalization of prejudices leads to a lot of suspicion, which is also one of the biggest obstacles in the way of organizing active solidarity.

Unhoused people often cope with these prejudices by distancing themselves as individuals from the socially constructed image of "the homeless." In fact, despite the lack of adequate housing, many "homeless researchers" did not identify as such. As Jenő Keresztes put it: "Homelessness does not mean sleeping on a bench in a park; it is a state of mind."¹⁴ By rejecting the label "homeless," many unhoused people reject exactly this state of mind and the lack of social perspectives it implies. While the rejection of homelessness as an identity is helpful to maintain self-esteem, this attitude tends to overlook the structural roots of poverty and focuses on its psychological aspects.

For people experiencing homelessness, the development of a critical consciousness has to start with gaining a positive identity that is not articulated against the deficiencies of others. On the one hand, the research project created an opportunity for homeless researchers to develop a positive sense of being in the world. Zsuzsa Kovács¹⁵ echoed these feelings when she said that:

I have always had self-confidence, but in certain cases the feedback I got diminished it. Being beaten at home destroys your self-confidence and you need time to get out of it. This research process was very useful for that: the group, the training, the fact that I was with people, I had things to do and I had a goal. I wasn't on the street to find out what I was going to do in the next five minutes but I was there with a goal. This was good.¹⁶

On the other hand, homeless co-researchers engaged in conversations with people in similar situations, which indicated that they are not alone in their predicament and that there is something systemic about their experiences. In this way, the research helped them recognize the humanity of both their own self and of other homeless people. As Jenő Keresztes reported about changes in his own attitudes:

I realized that when people open up, they have a lot of values. The research piqued my interest in people who I would never have talked to otherwise. I have always been a snob. I haven't stopped being one, but I realized that every person has something valuable in them.¹⁷

¹³ It is important to note that institutional forces and social stigma are not the only factors that determine the self-perception of homeless people. For an in-depth discussion of how unprocessed traumatic experiences shape homeless people's life and identity, see Fehér (2011).

¹⁴ Excerpt from a series of unpublished interviews completed by Barbara Erős in July and August 2012.

¹⁵ This is a pseudonym, as the researcher did not give permission to use her real name.

¹⁶ Excerpt from a series of unpublished interviews completed by Barbara Erős in July and August 2012.

¹⁷ Excerpt from a series of unpublished interviews completed by Barbara Erős in July and August 2012.

Finally, the development of critical consciousness is not limited to a mental state but should also lead to a greater ability to act on one's own behalf – both individually and as a collective. By learning about their rights as equal citizens and gaining more experience to interact effectively as a team, co-researchers often became more assertive in their everyday communication. As János Jáger put it: "I have learned that I have a right to different things. ... I learned that through struggle and lobbying, you can achieve things."¹⁸ For several co-researchers, this renewed confidence had very practical consequences, as they were able to assert their rights and needs vis-à-vis people in positions of authority such as social workers, administrators and public-space supervisors.

b. Participation

Creating a truly collaborative process was one of the main challenges in *Justice on the Streets*. The team worked hard on creating procedures that allowed as much participation as possible, did not marginalize anyone, and also helped us to proceed effectively with our work. To ensure procedural justice (see Deutsch, 2000), we followed many of the principles developed earlier in *The City is for All*. This included, among others, the broad distribution of information, the active facilitation of discussions and consensual decision-making. The research team also worked out ethical principles¹⁹ that would guide us throughout the research process, which provided a framework for our interactions. Such processes were especially crucial given the initial differences in knowledge and experience regarding both activism and research among homeless and housed researchers, as well as older members of AVM and newly recruited researchers.

In the vast majority of cases, this strategy of collaboration seemed to work well. While not everyone was able to participate in all aspects of the research, everyone participated in some aspects of it. One example is that of Krisztina Horváth,²⁰ the youngest of the group, who was very quiet during our group discussions, but turned out to be a superb survey administrator: she not only became very confident in approaching people with the questionnaire, but people were also much more willing to answer her than many other members of the group. She was also one of the most active researchers when it came to the content analysis of interviews – Krisztina had a very sensitive and acute eye for finding the quotes that were most relevant to us, and then analyse them according to our own pre-determined categories. By contrast, Gábor Tóth,²¹ one of the oldest members, was very good at brainstorming research questions and providing conceptual input, often posing challenging questions as we put together the questionnaire and the interview guides. On several occasions, he was also selected by the group to present our work in public. At the same time, he was not very successful at completing the questionnaires, as he was unsure about how to approach people on the street. Overall, the overwhelming feeling in the group was that the project has been a truly collective process. As Zsuzsa Kovács put it: "Everyone contributed in their own ways. It wasn't two or three people who said one thing and then we said yes, but everyone contributed."²²

¹⁸ Excerpt from a series of unpublished interviews completed by Barbara Erős in July and August 2012.

¹⁹ This included, among others, the imperative to participate in the research process to everyone's best ability, to learn from our mistakes, to respect each other's opinions and to motivate each other.

²⁰ This is a pseudonym, as the researcher did not give permission to use her real name in publications.

²¹ This is a pseudonym, as the researcher did not give permission to use his real name in publications.

²² Excerpt from a series of unpublished interviews completed by Barbara Erős in July and August 2012.

In addition to the overall collaborative nature of the project, three instances stand out in which homeless co-researchers made an intervention that greatly impacted the course of the research, thus highlighting the significance of participation in defining both research goals and the research process itself. The first of these was the exact topic of the research. While AVM originally recruited co-researchers to study the harassment of street homeless people by uniformed authorities, newly recruited co-researchers insisted on expanding the question to include all forms of discrimination. In addition to a division between older and newer members, there was a clear class-based pattern in the focus of interest: homeless researchers were more interested in how they are treated in general, while housed researchers were interested specifically in the behaviour of uniformed officers as the agents of criminalization and oppression. It became clear that for many homeless people, harassment and criminalization are only two aspects of a more general condition of exclusion. As a result, the priority for homeless co-researchers was to challenge this dehumanization and re-establish their full personhood instead of challenging a few symptoms of their exclusion. In the end, as the findings above illustrate, it was this approach that prevailed, and the team addressed criminalization in the broader context of discrimination.

Second, while the original team of activists wanted the research to focus almost exclusively on abuses of power by the authorities, and highlight homeless people's negative experiences regarding the state, positive experiences came up very early on in the process. As homeless participants of the first recruitment session recounted positive impressions about the authorities along with negative ones, they challenged us to expand our combative activist stance and to include a much broader range of experiences. In fact, this is the reason why we included the question about the ways in which the authorities were of help to respondents in the final questionnaire (which, in the end, turned out to provide us with very valuable information).

The third example is when Ferenc Sándor suggested that we get involved in the annual Homeless Survey conducted by sociologists and homeless service providers. He proposed that we volunteer to administer their questionnaires and in order to help out and also use it as a training ground. In the end, we did get involved, received training about how to administer and analyse questionnaires, and gained important hands-on experience of completing a survey. These experiences were very useful for the development and completion of our own questionnaires. In addition to gaining some valuable experiences, Ferenc also suggested that we integrate our questions in the Homeless Survey, which would have a much broader scope than our own. After some lobbying, one of our questions regarding harassment was included, which was only the second time that the survey addressed this issue over a long period of time.²³

The active engagement of homeless researchers was not confined to *Justice on the Streets*, but provided a segue into broader democratic participation. While the intensity of their involvement varied, all co-researchers participated in some of the demonstrations and actions of *The City is for All*, most often as participants but at times also as organizers. Some of them also engaged in the broader public sphere by publishing articles on AVM's blog²⁴ and writing an open letter to the European Union about social rights, for example. The dissemination of research results (the "action" component of PAR) was also an important form of engagement with the broader public sphere: homeless researchers not only educated fellow activists in AVM about our

²³ The question included in the February 3 survey was the following: "Have you ever experienced negative discrimination by the authorities (officials, police officers, public-space supervisors) because you were homeless?"

²⁴ The address of the blog is: www.avarosmindentkie.blog.hu

findings, but also held a press conference, appeared on the media several times, and presented our findings to various audiences including homeless people, social scientists, law students and law-enforcement officials.²⁵

Following in the footsteps of Guishard (2009), I find it important to point out moments of failure and messiness in the research process. In *Justice on the Streets*, one incident in particular pointed out the ways in which social inequality may limit the depth of participation. Through a grant, homeless co-researchers got a small weekly stipend (the equivalent of 10 dollars/week). In this way, homeless members of the research team were the only members of AVM who received any financial compensation for their work.²⁶ It had not been an easy decision for AVM to introduce the stipend, but it seemed necessary to ensure a steady level of participation in the research. Throughout the process, the research team handled money issues with relative ease, and most disagreements were quickly resolved. However, at the end of the project, the team had to decide what to do with the money that was left over. It took quite a lot of bickering and frustration to make the decision as we took up the issue at three consecutive meetings. The basic tension revolved around the question of whether co-researchers should split the money among themselves or let AVM as a whole spend it on its other activities. In the end, some co-researchers implied that the presence of non-homeless members prevented an honest discussion from taking place, so the two ally researchers left the room and let the homeless co-researchers decide about the money on their own. In the end, they voted on the issue and decided to have *The City is for All* as a whole decide about the fate of the money.

Overall, the escalation of this conflict had as much to do with money as with the underlying dynamics of authority and social status. This instance made it clear that homeless co-researchers were sometimes reluctant to openly contradict the position of allies, even though they had a clear opinion on a particular issue. While in general, AVM does not always consider voting a fair way of making collective decisions, the fact that homeless researchers decided to break this rule and use it to settle such a crucial issue was an important sign of autonomy. Even if the decision was the same as before, the fact that homeless researchers were completely on their own with an important decision was a difficult but significant moment of empowerment. Unfortunately, this incident was not processed thoroughly by the group and left some scars on most people involved. At the same time, it was an important reminder of the ways in which inequality and oppression are reproduced through the terms of a discussion, language use and social roles, among others.

c. Bridging inequality

Participatory action research represents a contact zone where people consciously work together across and against power inequalities (Torre et al., 2008). While such contact zones are infused with implicit tensions and make inequalities both visible and tangible, they are also an opportunity to recognize, deconstruct and transform hierarchies. However, the question inevitably arises as to whether it is possible to co-construct the entire research process when there are such extreme differences in knowledge, access to resources and experience. One of the most important features of critical PAR is to address these dilemmas by actively engaging with them. Acknowledging and interrogating differences in power, knowledge and experience is

²⁵ As a more far-reaching action, the findings of this research will be the basis of a joint project by the Hungarian Helsinki Committee and *The City is for All*, where the discriminatory practices of the police regarding identity checks will be tested and brought to the Equal Treatment Authority (*Egyenlő Bánásmód Hatóság*), if the evidence confirms the discriminatory treatment suggested by *Justice on the Streets*.

²⁶ Other members of *The City is for All* – both homeless and non-homeless – do their work on a purely voluntary basis without any remuneration.

part of the process of developing critical consciousness. *Justice on the Streets* has revealed many forms and dimensions of inequality at both the micro and macro levels, which we attempted to challenge in a number of ways with varying degrees of success.

At the macro level, *Justice on the Streets* is a response to the silence in academic and public discourses of those most affected by homelessness. In academic or professional publications, homeless people almost always appear as the object of help or scrutiny, but rarely, if ever, as active citizens and intellectual subjects. This project created a space for a group of homeless people to develop a public voice and challenge systematic exclusion and marginalization at the discursive level by asking their own questions, collecting data and producing and disseminating their own interpretation of it. At the beginning, most co-researchers were not sure about their own role in research. As Gábor Tóth said, “At the beginning, there were a lot of doubts about whether this was feasible. It was hard to believe that we would have results that could be used as a reference, and that it could be done in a professional way.”²⁷ However, towards the end of the project, homeless researchers became more confident in their research skills, as well as in the relevance of what they had to say. When they presented our findings to various audiences, they managed to turn the research gaze around and held up a mirror to those who play an important role in shaping the lives of homeless people, either directly or indirectly.

In addition to challenging dominant discourses and representations, macro-level empowerment involved three interrelated processes of political emancipation (see Gaventa & Cornwall, 2001). First, regarding the systematic examination of state discrimination against homeless people, the project produced knowledge with the intention of informing public decisions and measures in law enforcement, health care and housing policy. In this sense, it was a source of empowerment for homeless people in Hungary in general. Second, by embedding the research in the work of *The City is for All*, a group with a strategic agenda to fight against criminalization and for the right to housing, the research enabled individual and collective action against injustice, and brought significant resources to a grassroots movement. Third, the project set out to change the consciousness of those on the margins of society – homeless researchers – about themselves, as well as about the social, political and economic world. The research process contributed to the construction of a different kind of subjectivity (that of the researcher and of the activist) and to the empowerment of homeless researchers to advocate for themselves more effectively, both individually and collectively.²⁸

At the micro level, the existential gap between housed and homeless researchers seemed almost impossible to bridge. A good illustration of this was provided by the simulated map of Budapest, which the research team created at the beginning of the training. On the imagined map of the city, everyone had to stand in the place where they lived and explain their circumstances. For homeless researchers, home included a bench, an ATM machine, an entrance hall and a squat, among others. Engaging in research from these material circumstances cannot be compared with the stable homes equipped with a bathroom, heating and internet where the two housed researchers live.

²⁷ Excerpt from a series of unpublished interviews completed by Barbara Erős in July and August 2012.

²⁸ For some researchers, this empowerment was more temporary than for others. While some felt they became more assertive vis-à-vis figures of official authority, others became very active in *The City is for All* and – not independently from this fact – also managed to improve on their own life situations, especially in terms of finding more stable sources of income and overcoming substance abuse issues.

However, it would be a simplification to reduce inequality among research team members to a dichotomy between being “housed” or “homeless.” Some divisions were created along more general lines of education and socialization. Ally researchers were not only better off materially, but also tended to be more educated, have better social connections and greater self-confidence. Jenő Keresztes made some poignant (and painful) observations about the limits of consensus-based democracy and collaboration in this context.

Those who are more cultured and more intelligent can articulate their opinions better, raise more questions. They present their arguments to the others, who reflect on them, but the intellect of those 4–5 people has the most influence.²⁹

In fact, despite all the efforts to the contrary, homeless activists who possess good verbal skills and present more conventional intellectual rigour tend to command more respect in AVM as a whole. While this is an important resource, it can also create hierarchies. As Jenő Keresztes, a homeless researcher with a law degree, suggested:

I know many people who sleep on Gellért hill, and if I went there and told them let’s carry out research together, they would say yes, let’s do it! I would give them ideas, then they would give me their opinions. But in this process, knowledge and intellect will come out sooner or later.³⁰

In a research project, the significance of these skills is even more pronounced than organizing skills and access to material resources.

Undoubtedly, the structural reasons behind such extreme inequalities cannot be alleviated through a single project. However, once we decide to conduct research together, efforts have to be made to level the playing field as much as possible. Some of the ways we tried to reduce this asymmetry have included the provision of a weekly stipend and public transport tickets to homeless researchers for research-related trips, as well as snacks and drinks during meetings. Printed copies of all the notes, minutes and readings were widely distributed, and we projected texts on the wall in large letters to facilitate collective analysis and help those who did not have strong enough glasses.

To bridge differences in access to information and communication skills, we organized a short IT training session, where each researcher created an email address and learned the basics of using a computer. In order to ensure everyone’s participation, many different tasks were identified, which were more or less equally distributed among team members. We also did a lot of preparation and analysis in small groups. While the two housed researchers were part of the discussions in the big group, they did not participate in the small-group discussions. As such, small groups served as the arena for more quiet people to speak up and not have to cope with the dominating and, at times, intimidating presence of others.

In terms of analysis, the research was developed in an iterative way: we always summarized what had been said before and revisited the same issues on several occasions. We devoted a lot of time to planning and preparing for various tasks, such as learning to use a digital recorder, taking notes, conducting an interview, etc. While some of these are rather technical adjustments, they were important in equalizing relations and creating the conditions for serious individual and collective

²⁹ Excerpt from a series of unpublished interviews completed by Barbara Erős in July and August 2012.

³⁰ Excerpt from a series of unpublished interviews completed by Barbara Erős in July and August 2012.

engagement. In fact, the success of this approach was attested to by János Jáger when he made a modest, but far-reaching statement: “When I came here, I didn’t know this language. Now, I can even contribute to the discussions.”

4. CONCLUSION

With a few notable exceptions (see Intézet a Demokratikus Alternatíváért, 2011; Missetics, 2010), critical research about homelessness has been virtually absent in Hungary. As the majority of contemporary homelessness-related research is produced by professionals who are involved in the social-services system, they do not engage in a radical critique of existing systems and practices, but aim to improve them as they are. While these studies offer important insights, they continue to operate within the dominant paradigm that manages, rather than prevents, homelessness and treats homeless people as clients rather than citizens.

Because of the lack of radical discourses and systemic critique, social movements have started to engage in their own research and theorizing to provide a conceptual basis for their work. The work of *Justice on the Streets* is best understood in this light. Besides responding to the lack of critical inquiry and political disempowerment, this intervention illustrates how people outside of social services and mainstream academic institutions can produce valid knowledge that contributes to a better understanding of homelessness and the development of more effective social responses to it.

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WORKSHOP CONFERENCE ON SCIENCE AND TECHNOLOGY STUDIES IN HUNGARY

(Gólya Community Centre, Budapest, 3–4 January, 2013)

GÁBOR SZEGEDI¹

The two-day conference, organized by **András Novoszáth** and **Márton Fabók**, was sponsored by the European Association for the Study of Science and Technology. The conference was launched with a keynote lecture by Zsuzsa Gille, followed by five “tone-setting” lectures on broader topics (politics, nature, space, the body, the economy) and their possible links to STS. Two panels followed in the afternoon, and the next day there were three panel sessions, most panels hosting four presentations each, which added up to 45 presentations altogether. There was a colorful range of panels, from information technologies to body and spirit, from gender in science to assistive technologies and disabilities. Day one finished with a discussion on STS in Hungary and abroad, and the conference had a closing summary panel and a meeting of the organizers of the STS network.

The keynote lecture by **Zsuzsa Gille** (University of Illinois) was thought-provoking and highly entertaining. She spoke about the contemporary materialization of the exercise of power; that is, how unequal power structures can be maintained throughout the material world even if there is an equality of opportunity on an abstract political level. She presented two case studies on Hungary after the EU accession: the Hungarian paprika scandal in 2004 and the Hungarian goose liver scandal in 2008. These were two products of Hungarian agriculture that increased their market share after the EU accession; rare occurrences, as the otherwise unprepared sector received less from the CAP than expected, had to face quotas conserving low production and could not fill the many expectations of Western European food chains. Goose liver and paprika had been doing well for a few years but their reputation was seriously harmed by these scandals, and Gille argued that they were in line with the materialization of power. The EU, if taking Latour’s concept of global assemblage, based on these examples, differentiates between member states via selective regulation. The particular, socio-material networks of weaker member states within these assemblages is not taken into account – in the case of Hungary, aflatoxin control was not taken over by the EU after accession and Hungary did not have the financial means to work with these controls on its own. Thus the question arises: the socio-material networks of which countries are taken into account or are preferred in the regulations adopted by the global assemblage?

As for goose liver, Hungarian goose liver export was partially blocked – and thereby its reputation was seriously damaged – through an animal rights campaign by a German non-profit organisation. Gille cited Rancière’s theory of the ethical community replacing the political community, where the political community supposes dissent (everybody should count) while

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the ethical does not, as everybody is automatically part of the community. Those who are marginal are either designated by accident or by those who are destructive – a second group which is not “material” for debate, they are excluded from public discourse as they are seen as threat to society. The example for this is “Infinite justice” where the victim's viewpoint is used by the “ethical community” and even the violation of the (human) rights of others can be justified when representing the victim. As a result, the representation of nature and material goods in parliament or elsewhere is not innocent: “Who should represent the geese?” (the animal rights activists, the geese owners, the veterinarians) becomes an important question.

Gille used the concept of “post-socialism”, which she sees as being sustained by changing the structures of difference on the one hand (inequalities reduced to differences) and by the materialization of differences. As a solution, one needs to politicize materiality. It has to be acknowledged – going beyond Latour – that material can be used beyond the micro level and this idea of logistical power on a macro level (as used by Mukerji) needs to be uncovered.

The five tone-setters followed. Gábor Király spoke about nature, differentiating between three ways of constructing risks and explaining the following three constructs through the example of disasters.

- The antropocene view holds that humans have become the largest nature-influencing force, and here scientists represent an objective reality that politicians need to implement so that humans adapt to the laws of nature.
- The political ecology view says there is no nature, as societies create their own networks, which construct different kinds of “natures”. Technological changes induce natural change: the hole in the ozone layer is an example of this. The scientist is a representative, a speaker, but natural facts don't speak for themselves and so politics have to represent nature in the parliament of “things”. Natural elements, therefore, become subjects of politics: animals, and future generations.
- Relativisation of nature: e.g. Zizek's idea of nature as ideology. Nature is the representation of social order. Which societies think of what as important? The example being when the Global North tries to force its concepts onto the Global South. The question of “natural” here can only be understood in a power space. The scientist plays a political role, even if unconsciously (Zizek: “there has been no mother nature”). It is hectic, ruthless, not predictable. Disaster is natural and constant, it will always happen, technology needs to be used for preventing it.

As a closing question, Király asked: which perspective is best when we try to lay the foundations of sustainability?

Gábor Dányi gave a speech on *politics and STS*, and he presented his research on the Hungarian parliament, 2006–2010, from an STS point of view, taking into account the history of the building (a “disproportionate beast”), the old practices and concepts (like the Holy Crown) and how these methods worked in the 21st century. He checked the house rules as a manual for the political mechanism/machinery and scrutinized the way that the parliament's representation function worked.

Márton Czirfusz discussed *space and STS*, referring to complex action networks and asking questions related to these (e.g. what *distance*, *translation* or *performativity* means in such networks), or how one can interpret power relations with the help of these (is power *a priori* existent, or created by action networks?).

Emese Lafferton talked about *the body and STS*, using the case of ethnology and physical anthropology in *fin-de-siècle* Hungary. She claimed that in these projects, one can detect increasing nationalism but this was still relatively moderate in the international context and in Hungary there was a lack of “vulgar racism” that one can detect in Western anthropological

traditions. The biological definition of race was almost completely missing because the strategies that were employed at an external colonization could not be of use for the internal colonization that the Hungarians were carrying out.

Zsuzsanna Vargha's talk on *the economy and STS* was based on her work which analysed the operations of a bank before the financial crisis. She checked what software was used, how staff spoke with clients, what explanations they gave in everyday operations. She used ethnomethodology as a concept and introduced CRM, a software for customer relationship management, which custom-tailored and personalized the banks offers based on aggregate data. A hybrid client was thus constructed – technology-made flesh.

As for the various panel sessions, two samples will be mentioned here, both from Saturday.

GENDER IN SCIENCE

In the Gender in Science panel, **Eszter Nádasi** spoke about the perspectives of gender in science and provided answers to three questions: increasing the ratio of women in science, including gender within other fields of research, and the status of gender as a stand-alone interdisciplinary field of science. **Ágnes Kovács** applied Georg Lukács's Ontology of Social Being for arguing that a gender perspective could be introduced in the natural sciences as well. She used the kinetic gas theory to show how the general worldview of society at the time appeared in scientific theory, and called for a feminist metaphysics that would introduce anti-essentialism, relationalism and a criticism of dualistic thinking in the field. **Beáta Nagy** discussed the reasons for the low ratio of women in technical sciences, focusing on the masculine organization of knowledge transfer, which limit women's options in five ways: in the family; by teachers of high schools and universities; through social expectations (there is in all three a “hidden curriculum” that expects women not to enter these fields); male students of technical sciences; and workplaces that are custom-tailored for males. **Veronika Paksi's** presentation invoked the metaphor of the “leaky pipeline” to explain why women disappear easily from natural sciences. The “pipeline” refers to a rigid, institutionalized career model, which is custom-tailored for white, middle-class men of the 1950s and 1960s and hasn't changed much ever since. For more women to succeed in such careers, she believed that the following are needed: gender neutrality, professional support, flexible careers and a good work-life balance.

EXAMINATIONS AND SOCIAL CATEGORIES

In this panel, **Csaba Dupcsik** discussed a potential research project on doctor-patient communication, which would take into consideration the shifting power relations in health care, where the average difference between the schooling of doctors and patients is decreasing, the access of non-experts to professional (or seemingly professional) material has increased and the average life span has increased by 150% in the past century (therefore, non-experts have more and more experience of health care). **Vera Szabari** gave a talk on the possibility of examining sociological research (in particular: sociological elite research done after 1989) from a sociological perspective, referring to the innovation of this field: concentrating on the process of the production of knowledge and its social or community-based nature and the flexibility of the interpretation of the results. **Judit Gárdos** talked about a Roma-related research conducted by leading sociologists in Hungary in 2006, and argued that the rules that apply for professional articles (theoretical introduction, hypotheses, showing empirical data, conclusions, comparisons, interpretations, outlook) were disrespected and there were a great deal of *ad hoc* explanations. She maintained that the

research used knowledge elements besides the object of scrutiny, and she asked the question: why isn't there true scientific research on stereotypes in Hungary? **Barna Szamosi** discussed the identification of Roma in Hungarian medical genetics discourse. His research is based on interviews with human geneticists, who try to locate Roma as a separate group for research, as certain ethnicities/populations can have an increased incidence of certain illnesses (e.g. Tay-Sachs disease, which has a higher frequency among Ashkenazi Jews in the US). The possible problem with such research is identifying Roma: family-tree research, last-name analysis is not necessarily reliable. Those who argue for using race/ethnicity-based classifications in genetic research say that these can be used in a manner that is as objective and value-neutral as possible, and that the research outcomes (like in the case of Iceland or Cyprus) serve the interests of the population.



Márton Fabók's introductory words



The Gólya (small building to the right)



The building next to the workshop venue



Let's start the registration!

ÁGNES PAKOT¹

Geambaşu, Réka– Kardon, Béla– Megyesi, Boldizsár– Patakfalvi-Czirják, Ágnes (2013) Thirst for Science? Social conceptions of the research activity, the factors influencing career choices and the social impacts of the Researchers' Nights. Budapest: HÉTFA Research Institute – RCISD. Available: http://www.rcisd.eu/files/Thirst_for_Science.pdf [downloaded: 2014-01-01]

The above-titled study presents the social impact analysis of the Researchers' Night events organized in Hungary over three consecutive years between 2010–2012. The study not only describes the visitors to the events and the impact the presentations had on them, but also places this particular event in a broader theoretical and methodological context, that of the relation between *science* and *society*. Therefore, the following paper will concentrate mainly on the debates the abovementioned question raises and then describe the typical audience of the named events, with the possibility to draw conclusions on the impact-success of the Researchers' Night programs.

SCIENCE AND SOCIETY – ATTITUDES TOWARDS SCIENCE AND SCIENTISTS (IN THE 2010s)

Considering the relations between science and society, one of the first stereotypical associations is that science is not compatible with the general society (the lay people); therefore, science needs some popularizing or softening processes to be digestible for the public. Following this idea, the *public understanding of science*, the so called PUS model(s), is one possible way of approaching the world of science for the people, the laypersons, to society. Thus, the incompatibility of the world of science with the general public recalls some kind of a mystery in the former. The need to bring these worlds closer has increased since the 1950s. However, articles having as their focus the popularization of science started by affirming the unbreakable barriers between these two worlds (Thistle 1958), while today we are closer to theories which treat popularization processes more like communication models or debates. There has been a *smooth*² transition from PUS models to PEST (*public engagement with science*) models, the latter referring both to science communication (typical of museums, universities and science organizations) and policy-oriented approaches and decision-making (Davies 2013:688). Geambaşu et. al., in their presently reviewed study, also reach this conclusion, by noticing that *understanding* and *scientific literacy* today are being replaced by concepts which require a more collaborative approach, such as various forms of *participative democracy*. They also notice, citing Bensaude-Vincent (2001) that communicating knowledge and science has also undergone a democratic shift in the use of

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² Author's own italics.

vocabulary; formulating statements *in the name of science* has turned to new practices of interaction *in the name of democracy*.

Critiques of PUS models can be found from the early 1980s, but we have to be aware of the aims behind the several critiques. While the more recent critiques of the PUS models accentuate the deficiencies of the *deficit model*,³ such as treating the public as being incapable of fully understanding science (and therefore, the science communicated to the masses has to be simplified), the early critiques question the function of a public understanding of science. Authors like Trachtman say that in most the cases it is not useful or beneficial for the lay public to be aware of actual scientific findings, as these would not affect their everyday lives (Trachtman 1981). For a layperson to become *scientifically literate*, the author continues, is a laudable fact but needs governments to spend huge amounts of public funds on promoting this kind of literacy among the wider public; this is something that needs more thorough argumentation. A more or less moderate critique of the PUS model is the paradigm that considers it to be a rhetorical approach of the communication of science without judging it for its preconceptions (Locke, 2002).

Seen from another angle, probably the most important starting points in the early literature in the difficulties of popularizing science are the language barriers – lay people do not understand scientific terminology – and the problem of *what gets in*, as many analysts have assumed that science is not understandable by ordinary people and no matter how hard they try at least half of the information or the essence will be lost (Thistle, 1958). However, theories like the one mentioned have been supplanted by critiques focusing on the idea that we must reflect on the heterogeneity and many-sided aspects both of the interpretation and communication of science and the notion of the public, as there is no such thing as *the* communication of science to *the* public (Silverstone, 1991: 106), as science is never communicated in a vacuum (ibid: 108). There are huge differences in the levels of interest and knowledge of the audience due to all kinds of socio-cultural or economic stratifications, and similarly, the ways in which particular information is communicated through whatever channel to one group or another will differ, in the same way that the complexity of one piece of scientific information differs from the other.

Similarly, the first attempt to identify the image of scientists among high school students⁴ was conducted early in 1957 (Mead-Metraux, 1957 in Christidou, 2011:143), and the image the researchers found appeared to be quite consistent after several rounds of research, which we find similar to the findings of the present revised study. Thus, the relatively fixed portrait of the researcher/scientist is that of: *elderly or middle aged men, who have glasses and/or beards and work in laboratories surrounded by test tubes, Bunsen burners, flasks and bottles, taking notes and reading books. One day, the scientist may straighten up and shout: "I've found it!"* (Christidou 2011:143).

³PUS is also used as a deficit model.

⁴ Among students in US high schools.

In Bauer's analyses (2013), *modern science* can be interpreted through its three stages: (1) its beginnings from the 17th century to the early 19th century; (2) the second era from the mid-19th century to the middle of the 20th century; and (3) the third era from the mid-20th century to the present day. Each stage has its own view on research and scientists, the first being characterized as "*amateurs seeking authentic knowledge as a matter of sheer and often worshipful curiosity*"; in the second era, science became an *attractive career* but not necessarily the most profitable financially; and lastly, in the third era, science writ large gained a superior and bureaucratic character. But, the singular cases of scientists are not that evidently a success story, as the larger the scientific society, the more difficult it is to find good research positions, grants, salaries, etc. (Bauer 2013). However, "*the first era of modern science has left its mark on the contemporary view, according to which scientists are self-driven by curiosity with their only interest being to discover what the truth is. That certainly remains accurate for some individual scientists, but it isn't accurate overall. Most researchers nowadays are employees doing what they're paid to do, and influenced by a variety of conflicts of interest whose consequences can be decisive*", says Bauer; and probably this is why it is so difficult to draw conclusions about society's view of science and scientists without having to fear the prevalence of stereotypes.

AN OVERVIEW OF THE STUDY ON RESEARCHERS' NIGHT

The goal of the social impact analysis, the authors say, was twofold: first of all they intended to identify the popular and legitimate representations of science and scientists among the target group of the Researchers' Night program (mainly young people and students); secondly, they aimed to gather both the expectations and feedback and opinions concerning the event. However, the research design of the three years differed in some aspects; in each of the years there were conducted quantitative surveys with the help of online questionnaires, but quantitative methods were also used, like desk research and focus-group interviews.

According to the study, there can be identified three typical groups of Researchers' Night program visitors by their socio-demographic characteristics. The first significant group is constituted by young high school students with an average age of 16 years; the second group is composed of university students or young professionals (22 years old in average); and lastly, a group of young employed adults around 39 years old, often with small children. Most of the representatives of these groups live in Budapest or in its suburbs, and are relatively wealthy. The three abovementioned typical groups simultaneously have three typical and differing motivation sets. The high school students have as their main motivation to deepen and complete their knowledge in the preferred scientific areas, which could be their main subjects for their upcoming exams or potential directions in university-career choices; the university students, on the contrary, try to visit programs which are out of their scientific area to widen their knowledge and world-views. The young adults with small children most often look for quality family entertainment, through which they might cultivate an interest in science in their children.

Thus, concentrating on these three typical groups of visitors, the readers might observe that, although the Researchers' Night events have as their main goal the popularization of science and scientific careers and to

open access to science especially to younger generations (as all the programs are for free of access, only registration is required in some cases), they have an effect of forging and sustaining the already existing socio-economical differences in the accession of knowledge and science, and the available scientific career paths.

As concerning the visitors' attitudes towards researchers and/or scientists, a common view was, according to the authors, that being a researcher is not an ordinary occupation, researchers are not ordinary people. This finding recalls some early theoretical views mentioned few lines above. Similarly, as also predicted at the beginning, the gender stereotype that researchers are male still holds; however, through the deeper methods of focus-group interviews, these stereotypes could be softened, the researchers say. In contrast to the continuity of these stereotypical characteristics, the age-hypothesis loses its consistency, as researchers are considered to be highly active, therefore, (at least) not old. The further important and stereotypical topic in the portrayal of scientists is the issue of financial reward. As the scientific career is perceived from the second stage of modern science to be one which provides moderate wages, this view remains valid with an extended explanation: that in time, the financial benefits of being a researcher or scientist will grow – one just needs to be patient and consider the first years of research as an investment.

The career choices of the visitors – here the authors mostly refer to high school students, as this topic is most relevant for their situation – reflect high self-consciousness and determination; most of the students described their ideal job as being interesting, close to their field of interests, non-routine, highly paid and reputable. Despite the fact that being a scientist is appreciated among the young, even though it does not provide sufficient salaries and scientists turn out not to be well-known or famous, a scientific career is not yet one of the most popular among students in decision-making positions; in the rankings of professions, they only positioned it in ninth place. Thus, here again the text leaves the reader with the feeling that the answers provided are over-representative for the upper-middle class intellectual/managerial elite – more precisely, to their children.

Finally, we can deduce that visitors are interested in scientific knowledge. We can trace both PUS and PEST paradigms, as visitors are not always a passive public, but, as the interactive experiment-based or debate-oriented programs were also popular, it can be considered that people are willing to engage in scientific practices; they are interested in *real* science. Furthermore, the fact that non-scientific, mainly social events were not that popular, also underlines that visitors prefer at this kind of program to be introduced to an uncommon scientific *new* world. They also have the expectation that the *science* presented to them is understandable but not oversimplified, and also, as the potential new generation of scientists and researchers, they probably also expect to be treated as partners.

TOWARDS A CONCLUSION

Without repeating the main findings of the research, it has to be stated that the reviewed text is a theoretically and empirically well-grounded study which describes a very actual international question,

reflecting the position of science and their practitioners in society, at a particular scene: the case of a Central-European society, this time Hungary. As the popularization of science and scientific/research careers and opening the access to it is a large, European issue, the implementation of it in various small places will recall some specific characteristics. As for the present situation, in my opinion, it would be naïve to consider that open access to science and a scientific career, especially if it is one implemented from above, really means open access for the masses. The Researchers' Night program is a perfect example, as it is completely open; the majority who really benefit from it are already among the advantageous groups. Probably a more accurate question should be, instead of the one in the title: who could/might be thirsty for science in an East-Central European society?

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