Chapter 20
An Antidote to Stigma? *The People Living with HIV Stigma Index* in Malawi and the United Kingdom (UK)

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1 Introduction

> The thing is that the circumstances in which we were all infected are different, and yet vertically, at some point we get connected, by HIV and by experiences, and we sit at the same table we look at each other in the eye with some degree of understanding that we are headed in the same direction. Some of us have not yet experienced the level of stigma as others, but the path is the same, the issues we will face are the same, and resolving those issues will be different depending on circumstances. Through sharing and realizing that the problem exists, we will hopefully have some perspective. The project allowed people living with HIV to link and to reconnect with each other and initiated the process of finding a solution, not for now, but maybe later. (Researcher, UK, March 2011)

In 2004, in the shower of a sunny suburban flat in central London, the idea for *The People Living with HIV Stigma Index* (Stigma Index) began to take root.[1] Although the idea would grow and gain shape and definition over many years due to the insights of many different people around the world, in essence, the idea was for a community-based research initiative to fill a gap in our understanding about how people living with HIV experience stigma in everyday life and to what aspects of identity and/or settings it is attached. Unusual and ambitious, the idea had a twist— that it would not be traditionally researched, as something done by academics or

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people wearing white coats or even people necessarily with a university education. From the beginning, it was an initiative by and for people living with HIV—a research tool that could be just as meaningful in the process of its implementation as in the depth and robust nature of its analytical enquiry.

Many of the people whose lives would be touched by the Stigma Index in the years that followed had not the slightest inkling, in 2004, of the journey ahead. Alastair, the lead facilitator of the Stigma Index in the UK, was an actor and dancer in London's West End and facilitating professional development training during the day. David, a coinvestigator and driving force behind the roll-out of the initiative in Malawi, was the Controller of Programmes for Radio 1 with the Malawi Broadcasting Corporation (MBC). Pamela, the UK data entry manager, was studying and volunteering with an HIV organization in South London and was going through the initial entry process for the Royal Navy. And Faith, who was to become one of the core partners and life story interviewers with the initiative in Malawi, was working as a nurse and project officer with a local sexual health clinic. These four people—with their very different lives, backgrounds, beliefs and experiences—alongside many others in the peer-led research teams (between 20 and 35 in each country), would devote their energy, compassion and commitment to implementing the Stigma Index in the UK and Malawi more than 5 years later.

By "walking the talk", as an initiative by and for people living with HIV working in an inclusive and non-stigmatising way, the Stigma Index can be seen as part of an evolving research paradigm—performative social science—that essentially seeks to "perform" the desired outcomes of the research while also reporting on the process and results (Haseman 2006).

This chapter consolidates some insights about the process of the Stigma Index from two very different countries and contexts in terms of culture, wealth, religion, location as well as HIV profile—the United Kingdom (UK) and Malawi—and explores the notion of performative research through a discussion of power, participation and social change. The chapter does not review the detailed findings from the Stigma Index research nor does it explore the degrees and realities of stigma in these two very different contexts.[2] Rather, it focuses on the reflections shared by some of the research team in both countries and their experiences of being involved in a common initiative—one that has a framework similar enough to be comparable but flexible enough to be adapted to the local context. The quotations presented here come from the notes, diaries and reflections documented from the team members.[3] These inform a review of the process of implementing an action-oriented research initiative, by and for people living with HIV, as a model for both understanding and

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[2] National reports of the complete results from each country and future publications will present the details of the findings related to settings, degree and experiences of stigma. Although a composite index has been developed for the results from the Index, the national data should not be compared between countries (only within) given the different sampling approaches adopted in each country context.

[3] In the UK, from a reflection and evaluation workshop convened in December 2009 and written reflections collected in February 2011; in Malawi from a mid-process and end of collection reflection meeting held in November 2010 and March 2011, respectively.

addressing stigma. In conclusion, the potential of the initiative is explored as a transformative model for generating personal and social change in tackling HIV-related stigma.[4]

2 Power to Change

Recent shifts in three crucial areas—approaches to community development, to understanding human rights and to valuing the perspectives of people most affected in policy debates—have begun to recognize the agency and integral role that actors have in their own development and processes of change.

For development, this has been triggered by the evolution of participatory approaches, which draw on Freirean notions of self-critical awareness (conscientização) and a belief that "reflection—true reflection—leads to action" and that "oppressed" people themselves hold the key to their own development and sustainable social change (Freire 1972: 48; Freire 1974; Chambers 1997, 2008).[5]

For understanding human rights and indeed documenting human rights violations, this has been triggered by an increasing recognition of "actor-oriented" approaches.[6] Increasingly, the notion of human rights has been reframed as "shaped through actual struggles informed by people's own understandings of what they are justly entitled to" (Nyamu-Musembi 2002: 1; Wilson 1997; Uvin 2004). Such experiences have been recognized through international declarations and covenants, which necessarily implicitly decree that discrimination on the basis of HIV status (actual or presumed) is prohibited (United Nations General Assembly 1966a, b; United Nations 1949). Human rights are universal and are in principle guaranteed by international standards that legally protect individuals and groups (Kohi et al. 2006; Greeff et al. 2008; see also Chaps. 8 and 15 in this volume).

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[4]Further details about the research findings can be found on *The People Living with HIV Stigma Index* website (www.stigmaindex.org) or by contacting the country teams directly—IPPF in the UK or MANET+ in Malawi.

[5]Having been "induced from practice", theories of participation are deeply rooted in its practical applications and implementation (Chambers 1997: 104). Evolving from the origins of Rapid Rural Appraisal (RRA) in the early 1990s and Participatory Rural Appraisal (PRA), participation now represents a broader shift towards a "bottom-up" approach to development. The fundamental principles can be summarised into three main points: (1) Outsiders facilitate not dominate; (2) methods indicate a shift from closed to open, individual to group, verbal to visual and measuring to comparing; (3) partnerships and sharing of information—between insiders and outsiders and between organisations (Chambers 1997: 105–106).

[6]Traditional definitions of human rights have recently been challenged by the recognition of the role of agency and participation in the realization of human rights. Human rights traditionally have been defined as "norms and standards tend to be drafted by government representatives, negotiated in political fora, and incorporated in the body of international law in the form of international treaties which impose legal obligations on the governments that ratify them" (Gruskin 2004: 329). This would include, for example, the Universal Declaration of Human Rights (United Nations 1949), the International Covenant on Economic, Social and Cultural Rights (ICESCR) and the International Covenant on Civil and Political Rights (1966) and other key international declarations (Gruskin and Tarantola 2005).

For valuing the perspectives of people most affected in policy debates, programing and all areas relating to HIV, the GIPA Principle (The Greater Involvement of People Living with HIV) was formalized in the Paris AIDS Summit Declaration in 1994 and is now a core criteria for policy consultations, international grant applications and organizing committees relating to HIV (GNP+ 2009). The GIPA principle—based on principles of community organizing and community building—is central for effective interventions, and new models are emerging for advocacy and social change in response to HIV-related stigma (Mahajan et al. 2008: S75). More recently, responding to some experiences of tokenism, it has since become known as the MIPA principle—the Meaningful Involvement of People Living with HIV.

In all three areas, therefore, there has been a shift beyond dualisms (violator v violated, oppressor v oppressed, powerful v powerless) to recognize the benefit of proactively engaging people most affected by an issue (in this case HIV) in the process of defining the shape of the response.

In the context of addressing stigma and discrimination relating to HIV, it is rare that interventions have been designed with social transformation or community mobilisation in mind and have often been based instead on practises targeting behavior change (Parker and Aggleton 2003: 21):

> Only more rarely have interventions been designed with the goal of unleashing the power of resistance on the part of stigmatized populations and communities—in spite of the fact that empirical studies of empowerment and social mobilization in response to HIV and AIDS have clearly demonstrated that the most effective and powerful responses to the epidemic … have taken place precisely when affected communities have mobilized themselves to fight back against stigmatization and oppression in relation to their lives.

The process (of participation, of consultation and of understanding documenting human rights realities) can be just as important as the product or outcome.

Reflections from the Stigma Index offer an opportunity to hold a mirror up to nature. It challenges practitioners, policy makers and advocates—including people living with HIV—to recognize that people living with HIV are not a homogenous group and to critically question preconceived notions about the capacity needs and wants of people living with HIV. For example when, how and to what purpose is the GIPA principle applied? Whose voices are most often included and/or heard?

HIV, and the myriad of individuals whose lives are touched by it, extends beyond the virus to intersect with a bigger, more dynamic and complex reality—for individuals as well as for communities and countries. In 2011, 30 years into the epidemic, is the GIPA/MIPA model enough—is it fit for purpose to meet the needs of very different individual lives in diverse social contexts touched by HIV?

3   HIV-Related Stigma

Living with HIV today is a different experience for every individual. For some, taking treatment, seeking support, and accessing health services is routine and part of a wide selection of services and choices available. For others, information is

limited, support insufficient, or choices denied because of fear or marginalization. Stigma relating to HIV still remains a significant challenge because it has an impact on the accessibility and orientation of services (not only health, but also legal, care and support services) as well as on the self-worth, sense of belonging (e.g. in community or faith based settings) and general quality of life. Conversely, stigma can also trigger positive forces for change and networks of solidarity that rise to challenge the social norms and practises that marginalize, stigmatize and discriminate. See also other chapters in this volume.

Stigma can have a pervasive presence in the everyday lives of many people living with HIV as well as many people who care for, are married to or are friends with people living with HIV. Stigma can also affect people linked with HIV in other ways through their sexual practises (such as same-sex attraction) or professions (such as sex work) or behaviors (such as drug injection) that are associated with HIV transmission. Orphans and vulnerable children, carers, HIV-service providers, family members and friends can also experience stigma by association with people living with HIV. There is a need to focus on a structural understanding of HIV-related stigma that includes recognition of the dynamic interplay between an individual and the social determinants and power structures that influence people's lives, such as the intersection of race, gender, faith, ethnicity and/or livelihoods (Parker and Aggleton 2003; see also Chaps. 1, 2 and 3 in this volume).

3.1 What Is Stigma?

> Stigma only comes in because of [a] simple misunderstanding of people. (Participant, Malawi, December 2010)

> Stigma is a socially accepted excuse to justify a fear of intimate relations. (Researcher, UK, April 2011)

Stigma is imbued with power and is commonly understood as a process of devaluation or as a "mark" of discreditation (Goffman 1963; see Chaps. 1 and 2). Experiences of stigma are unique to individuals and to the context in which they live. Different types of stigma have been differentiated as enacted stigma (actions resulting from stigma, also known as discrimination), perceived stigma (fear that stigma will be experienced), stigma by association (stigma experienced because of perceived association with a stigmatized group or discredited behavior) and internalized stigma (the internalization of the negative or devaluing attitudes) (Link and Phelan 2001; Parker and Aggleton 2003). Stigma attaches itself not only to individuals but also to specific social contexts and can be layered or compounded for many different reasons (Goffman 1963; Manzo 2004). Often, stigma is something that is felt but can be difficult to articulate.

> I cannot describe stigma but I know what it means. There are people who are HIV-positive and they stigmatize themselves; they always isolate themselves from others. There is also the stigma which you can experience from other people because they are HIV-positive—they deny or refuse to accept what they are. (Participant, Malawi, October 2010)

And yet stigma is something that can be present and felt in different and seemingly mundane everyday experiences.

> I understand stigma because I do not talk about somebody; I talk about myself. Because I have gone through some difficult times and I have evidence. Stigma and discrimination exists [sic]. I do understand, and I am able to see it, because there comes time when they put a cross on your plate or your cup. When you ask for water you see that each time they bring you the same cup so that nobody else uses it. (Participant, Malawi, November 2010)

HIV—and the millions of lives it touches—triggers at times uncomfortable or unexpected conversations and is embedded within many personal, programmatic and policy priorities and agendas around the world. Stigma relating to HIV remains a significant challenge because it has an impact on the accessibility and orientation of services (not only health but also legal, education, care and support services—see Chaps. 6 and 8 in this volume) as well as on self-worth and general quality of life—which affects people living with HIV, their families, friends and carers, as well as broader social attitudes reflected in the media, in institutional policies, practises and in political debates.

HIV-related stigma can have an impact at three key levels.

1. Personal
   "Self-stigma" can be manifested in different ways, originating either from how one feels about oneself (a sense of self-worth) or how one internalizes the negative attitudes one may perceive from others. The distinction between the two is not always clear, and internalized stigma can negatively affect the quality of life and self-worth of people living with HIV and can create barriers to realizing other human rights (Simbayi et al. 2007; Li et al. 2009). Stigma has been shown to be associated with stress, depression and lower perceived quality of life among people living with HIV (Simbayi et al. 2007). People living with HIV can feel dirty, ashamed or guilty because of their HIV status, and it is uncontroversial and well evidenced that stigma exacerbates the already-heavy burden experienced by people living with HIV (Li et al 2009).

> Linked in with feelings of guilt was individuals' tendency to blame themselves for being infected—for example in Leeds, someone said 'My argument has always been you were there too… You are responsible for yourself. Surely you've got to take some of the blame as well.' Some blame others. One woman expressed anger towards God for being infected. Another individual stated that she held her husband responsible for infecting her because he was unfaithful. In my case, I knew my husband had a past so never blamed him. (Researcher, UK, February 2011)

2. Service
   Stigma creates barriers for accessing health services (Maman et al. 2009).[7] For example, research has indicated that stigma affects HIV prevention and treatment efforts, including the use of condoms, HIV testing uptake and uptake of prevention of mother-to-child transmission programs (Maman et al. 2009;

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[7] HIV-related stigma also creates barriers for people accessing other services (such as legal, employment, psychosocial care), but for the purpose of this chapter, we are focusing specifically on health services.

Genberg et al. 2009; Simbayi et al. 2007). Stigma has been identified as a factor contributing to the refusal to return for the results among people who have tested, to low HIV disclosure rates and to affect adherence to antiretroviral therapy (ART). Research has also found that experiences of stigma in a healthcare setting limit the uptake of these services by people living with HIV (Greeff et al. 2008; Kohi et al. 2006; see also Chap. 6).

3. Structural
   Stigma can reenforce power inequalities and processes of social marginalization (Parker and Aggleton 2003; Mahajan et al. 2008). It touches on intimate behaviors, decisions and moralities that are accompanied by a minefield of personal and societal attitudes, perceptions and principles (Dodds 2006). As such, stigma relating to HIV is often conflated with others such as racism, xenophobia, homophobia or sexism (Herek 1999; Nyblade 2006).

There is a need to focus on a structural understanding of HIV-related stigma that includes recognition of dynamic interplay between an individual and the social determinants and power structures that influence their lives.

3.2 What Is the People Living with HIV Stigma Index?

The People Living with HIV Stigma Index (Stigma Index) is a community research and advocacy initiative that has been developed by and for people living with HIV.[8] Championing a community research model, the power of the research process lies in the community of people living with HIV—those interviewing as well as those participating—in documenting experiences of stigma and discrimination relating to HIV in peer interviews. People living with HIV are at the centre of the process, driving each stage of the project implementation, and the interviews aspire to be empowering for both the interviewers and for the participants.[9] The questionnaire captures how people have experienced—and been able to challenge and overcome—stigma and discrimination relating to HIV over a 12-month time period.[10] The research is not looking for stigma per se but rather aims to monitor the nuances and document places (sites and settings) where stigma is experienced and assess the degree to which it is present during that preceding 12 months. The initiative is an example of a performative, actor-oriented and participative approach to researching health and human rights.

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[8]The roll-out of the international initiative is coordinated by the International Planned Parenthood Federation (IPPF), in partnership with the Global Network of People Living with HIV (GNP+), the International Community of Women living with HIV (ICW) and the Joint United Nations Programme for HIV and AIDS (UNAIDS) (www.stigmaindex.org).

[9]The core of the initiative can be summarised in 4 'P's, that is, the process was just as important as the product, that it was led by people living with HIV and that it guided by a partnership (IPPF 2009).

[10]The idea with the Index is that it can be repeated every 2–4 years, once the baseline has been established, so that trends can be compared overtime, and it can be useful for monitoring and evaluating the efficacy of policy changes and interventions.

Image 1 Members of the UK Stigma Index team reflecting on their experience (November 2009)

> You're all positive too? OK, Count me in. (Participant, UK, June 2009)

> It gave others confidence through me because when I was with somebody, be it … whoever I was relating with, because they knew that they are talking to a fellow person living with HIV, and I knew that I was talking to a fellow person living with HIV, so there was this companionship. There was this cross-fertilisation of confidence. (Researcher, Malawi, March 2011)

The Stigma Index has been implemented, to different extents and various degrees, in more than 40 countries around the world. As a direct result of working as part of the team implementing the Index, many lives have been touched and friendships formed that will (and already do) extend beyond the period of data collection and scope of the project.

> For many of us the process of engaging in a community research project was diving into uncharted waters for others like falling off a log… For all of us at some level the experience of being involved has been at some level empowering and for many of us transformational. (Researcher, UK, February 2011)

In the UK, the Stigma Index was rolled out in 2009 with follow-up qualitative interviews in 2010. Between May and September 2009, 867 people living with HIV were interviewed by their peers about experiences of living with HIV, accessing health and other services, experiences of stigma and discrimination, sources of support and living positively.[11] The interviews covered a vast area of the UK, including Aberdeen, Birmingham, Belfast, Cardiff, Edinburgh, Glasgow, Leeds, London, Manchester and Wolverhampton. The roll-out of the initiative was coordinated by IPPF, with more than 45 partner organization around the UK, providing guidance and technical assistance during the implementation (IPPF 2009; Sharp 2010).

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[11]The project was supported by the MAC AIDS Fund and the Scottish Government and the research guidance provided by Dr. Laura Sharp with the Centre for Psychosocial Research.

Image 2 Learning by doing—Members of the UK Stigma Index critically reflect on the research process and prioritize areas for advocacy based on the results (November 2009)

Image 3 Members of the UK Stigma Index team demonstrate their solution for overcoming stigma (November 2009)

Image 4 Side-by-side interviewing in Malawi—interviews designed to equalize the power relationship between interviewer and participant (October 2010)

In Malawi, a total of 2,272 people living with HIV were interviewed in the three regions of Malawi for the Stigma Index in 2010–2011. The results provide a baseline from which comparisons can be made, and the national response to HIV can be monitored over time.[12] The quantitative results from the Stigma Index were complemented by 15 in-depth interviews as well as a collection of 42 life story interviews.[13]

> It was unique that we had people who are positive collecting the data. Talking to people through the training helped them reflect on their experiences and helped them to have certain explanations about their feelings and experiences. For example, after seeing a question asked in the questionnaire, they would come and ask me about it and how it related to their story. (Researcher, Malawi, April 2011)

The results from the Stigma Index in both countries indicate that stigma is not only impacting the quality of health services available to people living with HIV, but also that it is impacting someone's quality of life and sense of self, within a dynamic and changing social context.

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[12]The study was commissioned by MANET + with financial support from IPPF and the United Nations Joint Programme on HIV and AIDS (UNAIDS) country office in Malawi. The research guidance provided by Dr. Maureen Chirwa and her team at Royal College of Medicine with the University of Malawi.

[13]The life story interviews were collected as part of an action research study coordinated by Lucy Stackpool-Moore, as doctoral research with the University of London (School of Oriental and African Studies and Birkbeck College) and the University of Malawi (Centre for Social Research).

Image 5 Collaborative writing of the draft report in Malawi (February 2011)

Image 6 The steering group for the life story component of the research in Malawi (October 2010)

4 Magic Listening and Empathy: A Kind of Antidote to Stigma

Being part of the team of one of the biggest HIV community research programs in UK has been truly inspirational and inspiring. We suggest that it was the fact that we had no idea how the research was going to turn out, and we were all eager to see the end result. Most of

us had experienced stigma at some point during our diagnosis, but the anticipation was trying to find out to what extent everyone was affected and what impact did it have on peoples' lives and in dealing with and managing their HIV.

I didn't want it to stop… I felt like I was possessing some magical powers, because in the end we had a tangible 'fact', we had policy and decision makers listening, we had MPs and politicians actually getting interested in HIV issues, we had national organisations requesting more data and coming up with strategies on how they can develop and work with the research…. (Researcher, UK, February 2011)

While the context and experiences of stigma in each country are diverse, some common reflections emerged from the teams implementing the initiative. Concepts emerging from the reflections of the research team can be loosely grouped under the themes of listening, empathy and trust. In many ways, these ingredients could also combine to provide a potion—a kind of antidote—to stigma.

From the quantitative (the Index questionnaire itself) and even more so from the qualitative interviews, the researchers appreciated the opportunity to listen to the stories of others. In many of the interviews, having an HIV-positive diagnosis was the only common ground linking the researcher and participant who might otherwise have very different lives. In both countries, this revealed to all members of the team the diversity of HIV and how it reaches different people within their community.

I guess the best part of this whole research was just listening. Listening to people living with HIV sharing and talking about the experiences of living with HIV and being stigmatized and discriminated against and in some cases not. On my part it was the humbling effect it had on me, realizing that some of the people do not talk about such issues in their households but they trusted me enough to indulge to share those experiences without any barriers and boundaries. I could relate to them and they could relate to me, and I was in no better place than anyone else. (Researcher, UK, March 2011)

There was also a sense of appreciation for the knowledge and opportunity that came from being part of the initiative. This was heightened when the absence of both became apparent in the response of some participants. This was particularly apparent in the context of knowledge of human rights in both countries.

I felt like I could be part of the audience to hear their story and also to be accorded that opportunity where they can share with you their story. It also helped me to have some insights on what is going on currently and the issues of HIV, both levels, depending on where I did the interviews. But, more so also to have a perspective because I think I had always thought that maybe when we were on ARVs [antiretroviral drugs] these are my rights. Like me I look at my rights and I safeguard them. But, then you go somewhere else where they don't even look at those things—to them they don't matter, you know? To them, it's just if I have to go to a clinic and get the drugs, that's all I need for now, and to me that's OK. So, you are also able to appreciate the other side of life where people don't ask for too many things, all they want is to make sure they get their ARVs and they're OK with it. So, we are able to appreciate the other side of life and see how people are managing in very underprivileged circumstances (Researcher, Malawi, March 2011).

There is a need to educate about people's rights. For one to identify that they have been discriminated against they need to know their rights. (Researcher, London, May 2009)

Many of the researchers found that in listening to the experiences of others, parts of their own story and their own experiences living with HIV were reflected.

> I have also found that voluntary testing is still a challenge. Joseph[14] came just like myself. I didn't go for testing voluntarily—I had to be sick, and very sick, that almost what you call near death sickness. So, when Joseph was talking about that I could relate with what I went through… From Joseph's and this other one I have discovered even when I look back to my own life I've discovered lifestyles contribute to [HIV] transmission. These are very things that are not discussed. Because when I look back, when these people were telling their stories, I was trying to look back at myself. (Researcher, Malawi, November 2010)

This included not only empathy with others directly involved in the national research initiative but also with others around the world—both part of the global initiative as well as more generally affected by HIV and involved in understanding and responding to HIV-related stigma.

> For me, it means a lot. But to mention a few [aspects] it gave me a wide range concerning [that] HIV is real. And that HIV is affecting or infecting people all over the world. Be it in town or villages. And it also gave me a wide range to realise that the world is concerned about HIV and AIDS. (Researcher, Malawi, March 2011)

The empathy and common ground made easier by the shared reality that both interviewer and participant were living with HIV not only facilitated empathy in the interview process but also helped enable a feeling of trust and openness. Particularly with the life stories in Malawi, this led to some surprising sharing even among people who knew each other quite well and a sense that the researchers were privileged to hear some of the more 'hidden' dimensions of the realities of HIV.

> Again for me, it was a learning experience. It gave me an opportunity to understand the life of the person living with HIV. A deeper understanding of the person living with HIV—the Malawian person living with HIV. That the person living with HIV is not the one my eyes see, it's not the one that my eyes see, but it's someone that is the inside self, the one that like he puts it, the hidden aspect of the epidemic. (Researcher, Malawi, March 2011)

> Everything I thought I knew about stigma in the UK and my own stigma I didn't really know. The deliciousness is in the discovery that you don't know the answers. It's been an amazing journey. (Researcher, UK, October 2009)

For some of the researchers, it was at times confronting to realize that stigma can start from within—that sometimes internalized stigma can be stronger than the experiences or perceptions received from others can be the sense of worth within.

> Participating in both the roll out of the research questionnaire, in a focus group and a follow up event reinforced to me how much stigma there is still around but also how, in my opinion, some of it is internalized. (Researcher, UK, 2011)

Each of the different journeys for the individual researchers in each country was unique. For each person, it yielded at times an unexpected moment of insight, a

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[14] Not his real name.

mirror to reflect back on themselves, or perhaps an opportunity for a shared story, soft drink or cup of coffee and at times even a tear or a smile.

> It was great to get together with so many people's different opinions; our differences are what made this process so interesting. (Researcher, UK, December 2009)

There were also difficult moments, where people argued or disagreed. For some of the researchers, at times the reflection in the mirror became too confrontational or too close to the bone and was upsetting. Often, but not always, when this occurred, support was at hand from others in the team and/or from the supervisor. On other occasions, the realities of daily life, for example, finding money for transport or refreshments to or from the interview, were a challenge.

Recognizing that people living with HIV are not a homogenous group, neither was the team, and a continuing challenge was engaging a cross-section of people living with HIV as researchers and participants in the initiative. This included a consideration of gender, age, geographical location, sexual orientation, race, time since HIV diagnosis, employment level, education level and economic status. In both countries, concerted effort was made to include the perspectives of men who have sex with men, sex workers, young people, people who could be seen as "elites" or professionals, prisoners or ex-prisoners, people with disabilities and the perspectives from other people living with HIV who can often be "harder to reach" or less visible. This was achieved to different degrees of success in both countries. One of the challenges in both the UK and Malawi was engaging professional people living with HIV to participate in the research. This could have been for many reasons, including the timing and location of the interviews, although every effort was made to schedule these at flexible times and diverse locations to be accessible to many.

In both countries, cross-sectional recruitment was challenge and some people were more open to participating than others. This could have been for many reasons. Some people may have chosen not to participate because they may not have disclosed to anyone in their workplace and feared that by participating in an interview their HIV-positive status would be revealed. Or perhaps, as some researchers in Malawi reflected, stigma can be experienced differently for people of differing social classes, and perhaps, it can be easier for poor people to disclose because there was a perception that they had "less to lose" and more to gain from disclosing. But, this was not necessarily the case because others in Malawi observed that poorer people may feel coerced to disclose (but still facing high levels of stigma) because of the promised benefits such as food supplements or additional salary benefits (for civil servants). This example highlights both the role of perception from the research team as well as the potentially conflicting motivations at work influencing why or why not someone living with HIV might engage with the Stigma Index. Another reason why some people did or did not participate may be perhaps because HIV is less present in their life or stigma seems to be no longer a big issue—they simply "get on with it" and have other more pressing concerns or motivations. There are as many reasons explaining why some people did

Image 7   Launch of the initial findings from *The People Living with HIV Stigma Index* UK at the Houses of Parliament, with Annie Lennox, for World AIDS Day 2009

Image 8   MANET+ Executive Director is interviewed by the national media to generate public debate about the results of *The People Living with HIV Stigma Index* results in Malawi (November 2010)

not get involved as explaining why some did and equally explaining their various degrees of participation, commitment and engagement. These reasons could relate to HIV-related stigma, or they could relate to other parts of life, such as opportunity costs or benefits of participating, availability, timing or location or even "belief" in the impact or value of research such as the Stigma Index.

It is clear that in the UK and Malawi, as in many places around the world, some people living with HIV are at the forefront, not only living through, confronting and overcoming devaluing attitudes and behaviors relating to HIV, but also speaking out against prejudice, supporting their peers and advocating for positive social change (see also Chap. 22). Yet, people living with HIV are very different. They face different life challenges and opportunities, have varying needs and desires and face different choices about how and to what extent they challenge stigma and are visible in the response to HIV. This was equally true in terms of the national response to HIV-related stigma in both countries as for the diversity of the individuals participating and researching as part of the Stigma Index team.

5   Conclusion

> HIV is not the whole story, it is just part of it. (Researcher, Malawi, February 2011)

For Alastair, Pamela, David and Faith and many people in the country teams in the UK and Malawi, the process of working with the Stigma Index was both challenging and rewarding, offering an opportunity to learn about the complexity of identity, identification (or lack of) with any one identity-based movement (e.g. based on gender, age, sexuality or nationality) and principles about modelling or "performing" the change envisaged for the world.

The teamwork dynamics, combined with the results and the process of implementing *The People Living with HIV Stigma Index* in the UK and Malawi, offer a model for further analysing the kind of individual and social transformation necessary to tackle the underlying causes of stigma and social inequalities that fuel ill-health (WHO 2008). The Stigma Index is unique in its ambition to engage individuals within the context of their own lives and different circumstances or realities, to shape the reflection, action and vision for change—an approach that straddles deeply personal feelings and wider social attitudes. Yet, for lasting change, the momentum and ideas generated through community action needs to be supported and reinforced by wider institutional, policy, social and legislative structures—either strengthening existing ones to be more supportive, or generating systemic change to create new ones where this is needed. Community-based action (of which the Stigma Index is one of many examples) is only one part of a multifaceted and complex picture needed for facilitating individual and social change.

It is clear from these two countries that the process of participating in the Stigma Index has had an impact. For the individual team members in the UK and Malawi, motivations for getting involved varied. Some became involved as an opportunity to

learn research skills and generate an income (structural level). Others became involved because they wanted better knowledge and access to treatment and health services relating to HIV (service level). Others were involved perhaps because they were recently diagnosed HIV-positive, or had only recently become open about their HIV status, and were looking to learn more from their peers about personal and social support relating to HIV (personal level). Some were motivated by all these reasons and more. For many, these motivations shifted and changed over time, and what they gained from participating was almost always different from what they expected.

There is great hope among the research teams in both the UK and Malawi that the evidence and analysis generated from the Stigma Index will influence positive change. In the UK, one of the main findings was a difference between knowledge of and actual engagement of services to address HIV-related stigma. The results and follow-up in-depth research have focused on understanding why that is and advocating for better or more targeted alternatives to meet the needs of people living with HIV. Other key issues emerging from the results that have formed the basis of advocacy work building on the Stigma Index relate to knowledge of human rights and the criminalization of HIV transmission, experiences of HIV-related stigma and accessing to services for migrants to the UK and issues concerning aging with HIV. In Malawi, the results provide new insight into the degree of HIV-related stigma experienced by people living with HIV. Initial results and analysis highlight significant differences between districts of the country as well as between men and women in terms of gossip, internalized stigma and access to health services. The results also indicate that although many of the participants know about human rights, few have sought redress to protect their rights when they have been violated. With a proposed draft HIV legislation in Malawi, the results from the Stigma Index can further inform community and policy consultations on the human rights and legal environment.

For the researchers and partners involved in the Stigma Index in the UK and Malawi, more than anything the experience left a taste of how addressing HIV-related stigma—in terms of both the personal and social responses it demands—is complex and all encompassing. To "perform" the kind of personal and social change necessary to overcome stigma, our efforts need to engage conscious attitudes as well as those less conscious. To effectively address a complex multilevel concern like HIV-related stigma, a complex multilevel solution is needed. In essence, the ingredients of an effective "anti-stigma" intervention include bringing different people together; bridging diversity; addressing the personal, service and structural levels of stigma; and enabling the total value of the process to be much more than the sum of its parts.

Understanding and addressing stigma related to HIV can—and must—look beyond HIV to engage wider issues of discrimination, marginalization, racism, homophobia and other social injustices. The meaning of HIV in someone's life varies immensely and changes during the course of someone's life. HIV is part of life, but it is not the whole story.

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