THE Innovia FOUNDATION

NEWSLETTER

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IN THIS ISSUE

FROM THE EDITORS

In March 2007, the very first issue of the Innovia Newsletter was sent out (to a considerably smaller mailing list than it goes out to today). In it, the editors and Innovia director Stuart Blume outlined the rationale for setting up the Innovia Foundation, its goals, and why Innovia should indeed have a Newsletter at all. The Newsletter is intended to be one of the primary focal points in Innovia's goal of establishing a 'virtual research institute' through which to foster the sense of an international community committed to exploring and exchanging ideas related to human health and health care provision.

We have now come to the 20th issue of the Newsletter. Looking through the past 19 issues, spanning 6 years, it is a delight to see the diversity of the contributions and the variety represented by those affiliated with and interested in the Innovia project. The topics covered and the contributors themselves represent over 40 countries across the globe, from Argentina to Austria, Cameroon to Cuba, Nepal to the Netherlands, and Bosnia and Herzegovina to Myanmar. We thought that we would take this opportunity of an 'anniversary' of sorts to reflect on what has been and to look forward to what is yet to come.

Since the past 19 issues cover such an interesting range of topics, we felt that it would be worthwhile to gather together some of the highlights. In the opening piece, we have gone back through the archive and done just that. Following this, Stuart Blume takes a moment to reflect on the motivations that drove the establishment of Innovia in the first place. He then poses some key questions related to Innovia's core purpose, and what its contribution can be in the future. Innovia is not – and should not be – a closed group with fixed ideas, immune to change. Rather, in order to keep it dynamic and relevant, it is important to keep moving forward, evolving, doing things better. Some members of the Innovia community were approached by Stuart with these questions; Godelieve van Heteren, Isabelle Baszanger, and Sylvia de Haan and Erika Silva offer some of their thoughts. We also heartily invite any and all critical reflections from other readers on how best to keep Innovia moving forward.

Following this, Monica Bustamante S offers her reflections on the participation of patients and civil society organisations in health care and research, examined through the case study of HIV/AIDS interventions in Ecuador.

As the main concluding piece, Siân Aggett and Stuart Blume focus their attention on one of Innovia's core principles, engagement, and examine the nature of this often used – and perhaps somewhat loosely defined – concept. What does engagement mean, what and who drives efforts for engagement, what are the obstacles and opportunities faced by such endeavours, and what indeed can be achieved through them?

As usual, we close the Newsletter with some announcements. These include the publication of an upcoming book, edited by Innovia collaborator Renu Addlakha, entitled *Disability Studies in India: Global Discourses, Local Realities*, announcements for upcoming conferences and calls for papers, as well as a brief introduction to the very young and emerging field of Global Mental Health.

The thoughts and reflections, articles and announcements, included in this our 20th Issue all lie at the heart of Innovia. This has turned out to be a rather self-reflective (and in some instances self-critical) issue, one that is longer than most. But hopefully it offers you, the readers, just as it has done us, some food for thought.

Zoe and Marianne

LOOKING BACK: HIGHLIGHTS FROM THE INNOVIA NEWSLETTER ARCHIVE

Marianne Bille & Zoe Goldstein

In July 2007, in the second issue of the Innovia Newsletter, Emm Barnes of the Centre for the History of Science, Technology and Medicine (CHSTM) at the University of Manchester, the UK, wrote:

> The inclusion of patients' stories and understandings of illness has enriched our historical narratives considerably, engaging a wider audience and so reducing the gap between outreach and academic historical work. The challenge is to capitalise on this move within academia and reach out more boldly to speak not just for or to but with those who have lived with the illnesses we study.

…and hit the nail on the head. Using her research on the history of cancer services in the UK, Emm reflected on the problems and opportunities that scholars at the CHSTM have faced in trying to combine academic scholarship with outreach activities. She also illustrated what is essentially Innovia's primary concern: fostering a wide range of collaborations between a variety of stakeholders – researchers and patients as well as global organisations and local community service organisations and NGOs. Innovia's vision is one of mutual involvement, multiple critical voices, and shared knowledge.

Sharing knowledge has never been so easy, and in facilitating a space for the exchange of ideas, the Newsletter strives to make the most of this and cultivate a lively virtual research community. Indeed, we have had the pleasure to publish a huge range of fascinating and critical research as well as biographies and reflections of academics and non-academics alike, too many to re-visit every single one. We have gotten to know local organisations as well as a range of national programs investing in better healthcare. We have learnt about mental health conditions, disabilities, and under-researched illnesses.

Many of the Newsletter's contributors have considered the meaning of scholarly research and why/how best to connect to other relevant (or non-relevant, for that matter) stakeholders. For example, Issue 13 saw Godelieve van Heteren, a medical historian and former member of the Dutch Parliament (who has also written something new for us in this current issue), reflecting on both her career so far, but also in particular on what it means to be progressive in an increasingly conservative climate, and how – and where – to make a difference when there are so many pressing issues requiring such urgent attention. In a similar vein, Stuart Blume addressed the question of how to shape governmental decision-making through local activism in Issue 14. There are also several illustrations of individuals and projects striving to forge connections between academic research (on healthcare provision, for example) with 'end users' (such as patients); for instance, in Issue 9, Zoe Goldstein provided an overview of user-led mental health research taking place at the Service User Research Enterprise (SURE), in London, the UK, based on an interview with Dr Diana Rose, SURE's Co-Director.

Indeed, many of our contributors have given us great insights into their very *(g)local* research. Deanna J. Trakas, in Issue 6, described her efforts to conduct medical anthropology in Greece in particular, and qualitative health research across Europe more generally, and the challenges she faced in having the work recognised by fellow academics and physicians alike. The same issue also offered a perspective on the development of medical anthropology in a very different part of the world, Nepal, provided by Kapil Babu Dahal. Goedele De Clerk, in Issue 12, an affiliate both of the University of Ghent and the University of Buea in Cameroon, introduced Innovia to her current research with the Deaf community in Cameroon. On a similar topic, and in an effort to foster greater inclusion and reflect the truly international character of the Newsletter's reader-/membership, in Issue 9 Carla Donoso offered the Newsletter's first inclusion of a non-English piece: a Spanish account of the Deaf communities and the initiation of cochlear implants in Latin America.

We were introduced in Issue 13 to the work of Nuria Rossell Curco, a psychologist in a paediatric oncology unit in El Salvador. Nuria has conducted qualitative research which queries the ways in which 'variables' such as poverty and religion are used in most (quantitative) studies into the abandonment of cancer treatment (which is free in El Salvador). Other research introduced to readers has included Selma Tanovic's history of the advocacy movement for autism in Sarajevo, Bosnia and Herzegovina (Issue 19), Jimena Mantilla's account of her PhD research on psychiatric diagnostic practices in Buenos Aires, Argentina (Issue 13), and medical anthropologist Aisha Oron (Issue 14) taking us through her Master's research on the experiences of Asthma and COPD sufferers of homeopathy in the Netherlands.

Issue 15 saw a fascinating contribution from Jacquelyne Luce, Senior Research Fellow in the Karl Manheim Chair for Cultural Studies at Zeppelin University in Germany. Jacquelyne introduced us to the 'Patient University', a pioneering initiative that aims to make health-related knowledge available to non-experts or lay persons, empowering citizens, patients, patient organisations, and caregivers, amongst others, to stimulate dialogue amongst all participants, as well as to create a critical awareness of the local social and economic factors shaping and being shaped by medical knowledge. In the same issue, Crispim Antonio Campo, Professor of Psychology at the Universidade Federal de Goiás-UFG-Campus Catalao-GO-Brasil, gave a historical account of disability activism in the vast and complex scenario of Brazil.

In Issue 16, Jill Shawe introduced us to the Margaret Pyke Centre Sexual & Reproductive Health Research and Innovation Forum at University College London, the UK, another illustration of a productive collaboration between research organisations and the public community. Moving across the Atlantic, Lorena

Teran, in her piece about the Community Engagement Unit (CEU) of the Institute for Clinical and Translational Science at the University of California-Irvine, USA (Issue 16), elaborated on another veritably concrete model of community-based research. By providing education, training, and funding directly to both researchers and community-based organisations, the CEU strives to facilitate working partnerships that will complement and improve research and with it the health of local communities.

Looking back to Issue 2, Wachara Riewpaiboon wrote about the Health Promotion Program of People with Disabilities in Thailand. Staying within the same region, in Issue 18, Thapin Phatcharanuruk described the difficult but ultimately rewarding process of developing a working relationship between the Faculty of Social Sciences of Chiang Mai University, Thailand, and the University of Traditional Medicine in Myanmar (Burma). In a similar vein, Francisco Suárez Sánchez and Alvaro Quintero Posada introduced us to the National Cancer Network in Colombia.

Innovia has community-based involvement at heart. In line with this, Tuula Vaskilampi provided an insight into the development and particularities of patient organisations in Finland (Issue 5). Indeed, throughout the Newsletter archive we have been introduced to numerous examples. Issue 1 introduced IDEA (the International Association for Integration, Dignity and Economic Advancement) – an international advocacy organisation for people whose lives have been challenged by leprosy. Issue 18 contained an article about the Coalition to Cure Calpain 3, a patient-founded organisation in the United States. Dr. Brigitte van Lierop, program manager for CrossOver in the Netherlands, an organisation which has conducted an international study looking at successful policies and practices for improving the employability and life prospects of young people with disabilities, wrote a piece for us in Issue 14. Maya Goldstein introduced us to the SNAKE project in Australia in Issue 17. This initiative was launched by Marie Stopes International, a not-for-profit NGO working in the field of sexual and reproductive health, and it is an inspiring example of how community-led, culturally sensitive programs can be achieved. Kapil Dahal's article in Issue 16 gave us an insight into Handicap International's project 'Empowerment and Social Change for Inclusion of People with Disabilities in Nepal'. This project, run through local partners, seeks to integrate people with disabilities into Nepalese society and facilitate access to a set of holistic rehabilitation services, which are particularly focused on enhancing quality of life through functional, social, and economic improvements. Ton Millenaar, Mama Josephine Bakhita and Zoe Goldstein wrote about the Amani Centre in Tanzania (Issue 7), a community-based rehabilitation and outreach centre for children with intellectual disabilities and their parents, set up by Mama Josephine Bakhita, the mother of a child with intellectual disabilities herself.

More local activism was covered when we got to know Nurse Rose Zgambo in Issue 11, an HIV positive nurse driven by her passion to end HIV-related stigma in a small sliver of northern Malawi. Issue 9 saw a more personal article by Vladimir Vladimirov, who shared his own experiences as a wheelchair user with muscular dystrophy in Bulgaria, which included his thoughts on the lengthy road Bulgaria still faces in terms of achieving patient empowerment and acknowledging the rights of people with disabilities.

Discourses surrounding health and healthcare always also involve politics of the body. What is possible? What is ethical? In issue 3, Professor Renée Fox commented on the bioethics she would like to see, comments she initially made upon receipt of a Lifetime Achievement Award from the American Society for Bioethics and Humanities. Issue 8 provided an insight into bioethical issues in Chile, provided by Carolina Valdebenito, wherein she described how both international developments and the country's political history have had an important influence on the institutionalisation of bioethics in Chile.

Another significant topic over the past 19 issues has been the connection between technology and scientific research in general. In Issue 2, anthropologist and political economist Guillermo Foladori presented his thoughts on his research on the impacts of technology on the working class and consumers in general, and the perils of profit motives driving health and technology developments. Similarly, in Issue 15, Ingrid Geesink, Senior Researcher at the Rathenau Institute's Technology Assessment Unit in the Netherlands, used the 25th anniversary of the institution as a moment to reflect on the evolution of Technology Assessment (TA). She talked about particular achievements, such as the acknowledgement of the significant role the general media plays in informing people about science and technology developments, and points out a 'soft spot' in TA, inviting us, the users, to present our perspectives of these new technologies that are becoming so intimately involved in our lives. Issue 8 closed with a conversation between Stuart Blume and Bram van der Ende about the Digital Experience Dossier in the Netherlands, which emerged over a decade ago within the Dutch patient movement as an effort to electronically collect and make available the illness-related experiences of patients. Additionally, Zoe Goldstein contributed a piece on the Luddites200 movement (Issue 18), which emphasised the need to remember and draw from history as we look for solutions to the problems we face now. In today's world, information is often exploited by powerful institutions and corporations, and technology and the 'machines of progress' are often developed and implemented without due democratic consultation. As much today as in the past, technology is never neutral and needs to be examined critically.

While the Newsletter has seen fantastic research contributions as well as a great array of reports on personal experiences and relevant groups, it has also served as a forum for documenting and sharing the upcoming news of, and outcomes deriving from, conferences and events. For example, Esther Thompson reported on the International Alliance of Patients' Organizations' (IAPO) 3rd Global Patients Congress in Budapest, Hungary, February 2008 (Issue 6). On behalf of Innovia, Selma Tanovic attended the symposium 'An Ideal Match?! Connecting NGOs and Academia in Research for Global Health', which took place in the Netherlands in September 2011 (Issue 17). Selma provided us with an insightful reflection on the need for local actors to participate in global health research agenda setting if successful and sustainable health research practices and projects are to be achieved. Similarly, Norma Morris reported on the Research Volunteers Forum, which was held at University College London, June 2011 (Issue 17). This workshop dealt with the involvement of patients/consumers in the design and planning of research projects.


Wellcome Images

Like us, we hope you have enjoyed – and perhaps even drawn some inspiration from – the immense variety of topics, countries, research locations, research questions, organisations, and people, which have all contributed to making the Innovia Newsletter as far-reaching and inclusive as possible, a 'virtual community' through which new ideas may be sparked and collaborations formed. After six years and many pages, we look forward to all that is still to come.

If you would like to peruse any of the past Newsletters, they can be found on the Innovia website: http://innoviafoundation.org/.

RETHINKING INNOVIA

Stuart Blume

The ideas that led us to establish Innovia a decade ago appeared simple enough. We were convinced that organizations of patients or health care consumers could be strengthened if they had better access to the findings of research. We were thinking not only of medical research (which treatments have been proven effective, and for whom, and where?), but also of the growing volume of social research on health policies, on patient and community involvement in research, on the effects of globalization (and the role of the pharmaceutical industry), on patient rights and satisfaction, and on the unintended (non-medical) effects of new medical practices. We felt that 'health social science' from a patient perspective, if it was to be seen as authoritative, should draw an important lesson from medical science. Clinical trials draw much of their authority from their 'multi-sitedness': their integration across different research sites, generally in various countries. To be sure, this is more complicated in the case of social research.

It was clear then, and has become clearer since, that the consequences of new medical practices and technologies (both positive and negative) depend on the way health services are organized, on resources and inequalities, and on cultural differences. They are not everywhere the same, so such a generalization becomes problematic. But we felt that an international group of scholars, committed to 'patient empowerment', coming from different disciplines, and collaborating in ways (that would have to be discovered), could help take us forward. Innovia could become a 'think tank' for the patient movement.

It has been more difficult than we expected. We underestimated the entrepreneurial skills and the resources of time and money that would be required. We need to rethink how Innovia is organized. But at the same time it is worth thinking again, and collectively, about the objectives and assumptions from which we started. Some of the questions that arise are these:

Can patient organizations (or health advocacy groups more generally) contribute significantly to improving the quality of health care?

If so, is access to research findings (potentially) of value to such organizations as they attempt to bring about improvement?

If so, to what research does this apply? In all probability, the greatest benefits are likely to follow from patient or community participation in national or local research; but might access to research carried out elsewhere (or to syntheses of such research) also be of value?

Related to this, is there scope for more mutual learning, both between countries and between what are generally regarded (and studied) as distinct and unrelated conditions; for example, disability, HIV/AIDS, cancer, reproductive health, etc.?

What need (if any) is there for 'broker' institutions, bridging the worlds of activism and research, which are thus neither principally research organizations nor advocacy organizations?

Is any such role necessarily a national one, or is there also scope for an international broker?

If an international broker role is potentially of value, what should its priorities be, and how should its priorities be established?

We would be interested in hearing from any readers who have thoughts on these or related questions, or on the future of Innovia. You are welcome to write to either of the editors, or to me.

ORGANISING GREAT AMBITIONS SUCCESSFULLY

Godelieve van Heteren

This issue of the Newsletter centres on ways to 'rethink' Innovia. I admire people who dare to 'rethink' even their original motivations and assumptions. But in the case of Innovia I am not sure whether it will provide you with many clues as to why the initiative did not fully meet all the original expectations.

In fact, I think there is little wrong with the original ambitions: to help strengthen organisations of patients and health care consumers by offering better access to the findings of research, both medical and social science; research on the effectiveness of treatments, but also on relevant health policies, on patient and community involvement in research, on the effects of globalisation (and the role of the pharmaceutical industry), on patient rights, satisfaction and experiences, and on the unintended effects of new medical practices. If anything, with the increasing complexity of things, there is ample scope for trustworthy 'intermediaries' of information, knowledge broker agencies who cannot be suspected of representing a particular commercial interest they wish to push, people who are trusted to work for the public good.

My sense is that the problem lies more in how to organise such great ambitions successfully in a world with many competing interests fighting for people's attention. This requires a solid strategy of where to focus, with whom to align oneself, and importantly, how to communicate oneself in a twittering world.

Key in that strategy would be that Innovia partners answer three questions:

a) How do you create a sense of ownership among the patients and consumer organisations who you are working with?

b) How do you create a sense of relevance, notably by using public moments and opportunities, to connect yourselves to ongoing concerns in the worlds of patients and health consumers?

c) How do you create a sense of urgency, which probably requires a sharper focus?

Regarding this last question, Innovia has seemed to want to mobilise on many fronts at once. And that at a time when more sustained mobilisation is tough enough in most settings. There is a curious paradox in communication generally: the faster its means the more people crave 'slow' messages: messages that recur, that stick and are around for a while. Innovia could benefit from this insight and not give up on its original aims, but apply a slightly more mono-manic, one issue at a time, focus. A well-selected issue may help to gather people around the founding ideas – more like in a campaign, perhaps. Work with people who react to the founding ideas, gradually build trust and expand. It is still doable, but it requires energy and endurance!

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A SCEPTICAL NOTE

Isabelle Baszanger

Innovia is based on the idea that research can be an important resource for patient/health care consumer organisations. It should help empower them. Innovia could act as a broker, helping develop better mutual understanding between researchers and patient organisations. I was asked to reflect on this in the light of my own quite long experience as a medical sociologist.

To be honest, I have never really thought my work could empower anyone. Of course, I have often *hoped* that it would help people to better understand how things work. But anything more than that? Looking back on the few experiences

I've had collaborating with physicians in clinical research projects and organizing a large palliative care conference, I now see them as interesting but also highly frustrating. I suspect working with patients groups would be quite similar. I was interested in collaboration because I was eager to learn more about physicians' ways of doing and thinking. Often I had found one or two people with whom prolonged work interactions made possible this collaboration, because we had already developed mutual understanding and respect. I wanted to help in a way, to participate in their everyday work, in conversations about what they were doing, or about their vision of the future of their work, its past… *But I doubt whether helping or participating is the same as empowering*. More often than not, the experiences were frustrating because it gradually became clear that most of them couldn't do much with what I had to offer (my research, thinking, knowledge, understanding…). Our goals were too far apart.

The fact that we were working on the same field but with different agendas made it particularly difficult. For one, I seek a sociological understanding of physicians and patients' work. Physicians and patients, on the other hand, must respond to the immediate problems and puzzles at hand. I suspect some physicians would have enjoyed listening to philosophers or historians more than working with me, for my research on the everyday lives of physicians, patients and families was too close to home, and I was examining things in a radically different way. At most, my research raises questions for them without framing answers.

Another source of difficulty, in my experience, derives from the very different tempos of our respective activities. We do not live in/with the same temporality. Both physicians and patients groups are first oriented towards action; they want to be able to act in the short-term. My work is not like that, and it doesn't lend itself to rapid application as it is primarily based on long term observation.

As for the idea of "brokering", well yes, that is important. The problem we have is an old one for the social sciences: that of translation. I can deal perfectly well on an individual basis with a physician or a patient, and sometimes even have the feeling that he or she can get something out of my work. But it's not at all the same when I have to deal with a group or a *collectif* (a patient association, for example).

In conclusion, all I can really say is that my experience has made me quite sceptical regarding the very idea of empowering anyone, let alone a group. I sometimes wonder whether, like physicians vis-à-vis hope for patients facing death, social scientists actually believe that they represent *the* source of empowerment for patients, as if patients themselves had no other source of hope or empowerment.

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THE IMPORTANCE OF CIVIL SOCIETY ORGANISATIONS IN HEALTH CARE ADVOCACY AND RESEARCH. THE PERSPECTIVE OF COHRED

Erika Silva & Sylvia de Haan

Since its founding in 1993, the international NGO 'Council on Health Research for Development' (COHRED) has been highlighting the importance of engaging civil society organisations (CSOs) in research for health [1, 2]. At COHRED, we believe that CSOs are an essential, but often neglected, partner in research for health and development, as they undertake important research and develop innovative modes through which to achieve better health, equity and development.

By CSOs we refer to organisations that are not-for-profit, and which operate between the state and the public and between the state and the market. These organisations represent or serve (often specific) groups of people, and are guided by a passion for contributing to social change, influencing health policies, and improving health outcomes through research, science and innovation. They can be of a charitable, research, social enterprise or educational nature, and are concerned with a wide range of health and health determinant issues. CSOs may act on an international, national or local level, and may contribute to research in different ways: some raise money to help fund or implement research projects, others implement health community projects or focus on improving health systems and health service delivery. Some CSOs have an educational focus or provide information to patients, while others campaign for more attention to particular diseases and major global issues, or lobby governments and international agencies to change public policy.

One of the most recognised roles of CSOs, especially of patient organisations, is that of advocacy, in particular for more research on certain diseases and for patients' rights to access new drugs, technologies or vaccines. Communicable diseases such as HIV, as well as non-communicable diseases such as cancer, are excellent examples of areas in which CSOs have helped to position issues on the international agenda. CSOs also empower patients to participate in and influence their own health care by providing information on new therapeutic agents, best practices, and new technologies, developments and drugs.

Currently, with the renewed spirit of Alma-Ata [3], much emphasis is being devoted to ensuring comprehensive primary health care and integrated delivery of health services, and to strengthening health systems towards providing universal access (instead of vertical or stand-alone disease programs), particularly in developing countries. In this context, are CSOs, including patient organisations in particular and health advocacy groups more generally, still needed? We believe that they are. Even in this new context, CSOs can contribute significantly to improving the quality of health care for all.

In spite of important progress, unresolved issues related to disease and health service delivery remain. Due to their holistic approach, CSOs are strategically well-positioned to work on these concerns. The key issues to be addressed are:

1) Quality of health care for minorities and vulnerable groups

Minority groups face specific barriers in terms of accessing health care services. Services, for example, may not be provided in the language of the minority, thus excluding those who cannot speak, read or write in the language of the majority. People living in rural areas, indigenous groups, the elderly, and the less educated are particularly excluded, even in high income countries. Language barriers affect quality of care, access to care, and leads to dissatisfaction among patients. More importantly, they may negatively affect health outcomes. CSOs can advocate for the cultural appropriateness of health services, for services to be rendered in the language of vulnerable groups, and for patients' rights to (appropriate) information and choices of treatment. They can also call for studies to understand who and where the vulnerable groups are and how their access to services can be improved. Furthermore, CSOs and communities can participate in deciding what services are needed, the best hours of operation, how the services should be organised, how treatment should be provided, and what food patients would prefer (to name just a few of the conditions that affect access to and use of services).

2) Social determinants of health

Patients, but especially community groups, can force health systems to address the social determinants of health and illness. Identifying the 'causes of the causes' of disease or health-related problems is a good starting point for finding a solution. Communities can bring different sectors together to address the social determinants of health and illness. For example, in order to address malnutrition at the community level and find lasting solutions, this should involve not only the health sector, but also the education, water and sanitation, and agricultural sectors.

3) Integrated delivery of health services
In spite of being well positioned in the international agenda, integrated services still need the participation of CSOs, especially in terms of advocating for and providing evidence of the benefits of integrated services and continuity of care. This is particularly so for sexual and reproductive health and maternal and child health. Many developing countries face the problem of vertical health programming, where one disease such as HIV/AIDS gets funding but endemic or complex issues like maternal care are neglected.

4) Essential package of interventions
Where true universal access to health care is not yet possible and resources are limited, CSOs can play a significant role in promoting and assuring the essential services that need to be offered in health insurance plans.

Access to research findings is crucial and particularly valuable for CSOs, as relevant findings can offer important evidence for advocacy and for bringing about change. It will also be much more difficult for health services and health authorities to disregard community demands as unnecessary or unfeasible, if these demands are based on evidence. Evidence is needed from clinical and technological research, but also from research on the organisation of health care services and their cultural appropriateness, as well as on the quality of these services. Access to both locally conducted research, as well as research carried out elsewhere, is valuable. Research and knowledge gained in one context, for instance, can be used in another, and individual communities can learn from other communities about their contribution to improving the quality and management of health services.

Intermediary organisations such as COHRED and Innovia are trying to play a role in all of this. Such organisations can facilitate access to research and research findings for communities or for CSOs. They can synthesise research results and translate them into a language that is accessible to all, improving access to research results and facilitating sharing and networking among CSOs and community groups. COHRED, through its Health Research Web [2], is facilitating the sharing of best practices and experiences among CSOs. In addition, COHRED brings out the voice of CSOs in the regional and global meetings it organises – making sure that the international community for health research hears what CSOs can do and how they can use research at the community level.

The 1978 Alma-Ata Declaration [4] recognised people’s participation in health systems as central for effective health care and prevention, and as an integral part of the health system. However, routine and structured participation rarely occurs, either in health care or in research, despite the obvious advantages it brings. Broker organisations or intermediaries can make a contribution in this regard, but they are only one piece in the much larger puzzle of organisations, people, interests, policies and structures.

[1] http://www.cohred.org/downloads/CallForCSOEngagementFinal.pdf
[2] www.cso.healthresearchweb.org
[3] WHO (2008). *The World Health Report 2008: Primary health care – now more than ever.* Geneva: World Health Organisation.
[4] The Alma-Ata Declaration was adopted at the International Conference on Primary Health Care (Alma-Ata, former USSR, 6-12th September 1978), and expressed the need for urgent action by all governments, all health and development workers, and the world community to protect and promote the health of all people of the world. It was the first international declaration underlining the importance of primary health care (see: http://www.who.int/hpr2/backgroundhp/almaata.htm).

The opinions and ideas expressed in this article are based on the experiences of Erika Silva, who worked for many *years on community-based health care projects for PROCOSI – a Bolivian network of 36 national and international health NGOs – and in primary health care programs in Bolivia, and she has personal knowledge of many community-based programs in other low and middle income countries. Currently she is part of a research team in Canada analysing the health status of linguistic minorities. In 2012, Erika Silva worked with COHRED as the CSO research officer. She can be contacted at: silva@cohred.org.*

Sylvia de Haan is Programme Director at COHRED and contributed the COHRED perspective to this article. She can be contacted at: dehaan@cohred.org.

THE ROLE OF PATIENT ORGANIZATIONS IN HIV/AIDS INTERVENTIONS IN ECUADOR

Monica Bustamante S

Participation of the community – including patients and those affected by specific illnesses – in research in Ecuador is very limited. Nevertheless, patient organizations play a very important role as both health advocates and project executers (in particular, in the distribution of financial resources and in monitoring and evaluation projects). They give patients the possibility to organize in order to fulfill their own needs and establish their own priorities within health care provision. But these organizations only have such possibilities because they work in conjunction with international organizations, which empower them economically and socially to intervene in the national health system.

In addition to the economic resources that patient organizations gain from their connections with international organizations, they also obtain valuable knowledge. However, the brokers of both financial support and international research information can directly affect intervention practices in Ecuador, especially through the training they deliver and the specific national and international academic publications which they make available.

In the field of HIV/AIDS, the project proposals that patient organizations set up are required by international organizations to include specific components. The knowledge required to implement these components is consolidated through the provision of training. In this way, various notions of health and health care that drive the international agenda are appropriated by locally focused patient organizations, and in some ways such notions also serve as guidelines for national interventions.

The interventions of patient organizations are, however, not always completely positive. Sometimes personal and institutional ambitions get in the way of the common good, and even though these organizations have the mechanisms to make changes, they may not intervene appropriately.

In this paper I provide a brief overview of the activities and impact of patient organizations in Ecuador, using the field of HIV/AIDS as a case study. This paper therefore presents some of the key events that have taken place regarding the history of HIV/AIDS in the international community and in Ecuador in particular, focusing specifically on the timeline 2000 to 2009.

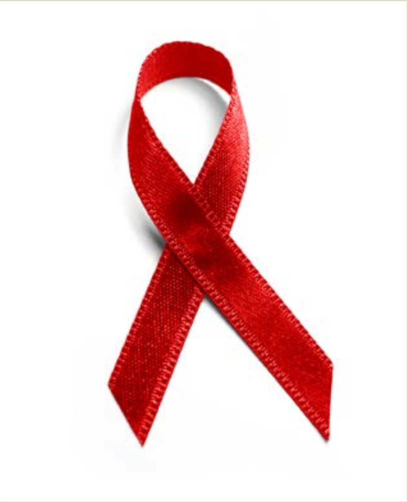
International perspective

Between 2000 and 2001, the international perspective towards HIV/AIDS changed, and the need for countries to work together on a global scale in order to reduce its spread and impact was recognized. This attitude shift included recognition of the need for greater devotion of financial resources to the issue.

The United Nations Development Program (UNDP) began to consider the relationship between poverty, development, and HIV/AIDS. They also recognized the need to tackle the lack of access to antiretroviral medicines (ARVs). In 2001, a Declaration of Commitment on HIV/AIDS was established by eighty-nine members of the United Nations.

This shift in thinking regarding HIV/AIDS in part contributed to the formation in 2002 of the Global Fund to Fight AIDS, Tuberculosis and Malaria. The Global Fund was also influenced by other international agreements, including the Millennium Development Goals (MDGs), established by the WHO in 2000.

Once HIV/AIDS was officially recognized as a global pandemic, new national initiatives emerged in Ecuador. For example, in 2001 the first National Strategic Plan on HIV/AIDS 2001-2005 was presented. This plan focused on strengthening health care services and infrastructure, in particular laboratories and blood banks. However, the budget allocated for the period was insufficient (Barragán & Laufer 2006), and the efforts did not bring about any significant changes.



HIV/AIDS and NGOs in Ecuador

In Ecuador in 2002, 765 cases of HIV were reported to the National Program for Prevention and Control of STDs/HIV/AIDS (PNS), of which 403 (52.7%) were in the stage of AIDS (MSP 2002-2008). Around this time, primarily driven by the continued shortages of ARVs, people living with HIV in Ecuador began several processes of training and empowerment, and as a result patients began to demand respect for their rights.

With the creation of the Global Fund in 2002, the first round of economic grants was offered to thirty-six countries. Through the Global Fund grant, the initial efforts in Ecuador to tackle HIV/AIDS were managed through two patient organizations, 'Mirik' and 'Equilibrium'. Mirik, an organization of Dutch origin founded in 1999, runs programs to support people living with HIV, and it became the primary organization promoting the Code of Good Practices for Organizations working on HIV/AIDS. Mirik has developed guided interventions to reduce the impact of HIV/AIDS on people's lives. It also joined the International HIV/AIDS Alliance, and set itself the objective of becoming a national and international reference in terms of strategies and actions regarding HIV/AIDS. In 2003, Mirik positioned itself to help manage the international resources available for national level HIV/AIDS interventions (Acosta & Orozco 2003).

The other main organization managing HIV/AIDS interventions in Ecuador, and that became a mediator between HIV positive people and civil society, was the Ecuadorian foundation Equilibrium. This NGO was founded in August 1999 with the mission of promoting policies for the defense and protection of human rights and for comprehensive health care for the LGBT community, including HIV/AIDS and STD care.

As the efforts to tackle HIV/AIDS gained momentum in Ecuador, patient organizations became increasingly relevant, especially in terms of acquiring financial resources for the different projects. Above all, they were dedicated to the monitoring and evaluation of the investments and their impacts.

Some organizations also played a fundamental role in critiquing the early interventions in Ecuador. This led to a mutual learning process, whereby patient organizations actually brought about change in national interventions. For instance, early reports of the national interventions in 2003 posed questions about how they were being developed, in particular the notion of focusing prevention activities on 'at risk' populations (until then, interventions were primarily centered around the gay population). This critique, led by Equilibrium and Mirik, established the existence of an 'epidemiological bridge' (or bridge population) – such as men who consider themselves heterosexual, many of whom are married, but who also have sex with men, or men who have sex with sex workers in addition to their regular partners – who should be integrated into the national interventions (Acosta & Orozco 2003).

In 2003, 'the Association' emerged. In addition to mediating interventions within Global Fund projects, the Association sought to promote the participation of people living with HIV in the interventions, and to improve their access to health care, especially ART. Among its tasks was helping in a project of the International Treatment Preparedness Coalition (ITPC), which aimed to promote the participation of people living with HIV in fighting for their rights. This included providing legal assistance to HIV positive people, sensitizing health personnel, and establishing support care committees.

In 2009, the Ecuadorian branch of the ITPC, which included twenty-three groups of people living with HIV, had trained 500 people on HIV/AIDS issues with the support of the international NGO CARE Ecuador. They have implemented several interventions. First, they ensure that at least one volunteer is always present when people are diagnosed for the first time; this person explains HIV/AIDS from the patient perspective. Secondly, they continually monitor the release and delivery of ARVs in all hospitals, and monitor health care practices with HIV/AIDS patients. Finally, they have been able to pressure the Ecuadorian Ministry of Public Health in order to demand ARVs, as well as to decide on their quality (they were able to choose among several generic varieties) and their adequate release.

Structure of the interventions

In 2004, the Declaration of Nuevo León was signed by thirty-four countries during the Special Summit of the Americas, which outlined a commitment to ensuring the treatment of at least six hundred thousand people living with HIV in all countries of the hemisphere, including Canada and the United States of America.

In seeking to manage resources for the development of these agreements, countries received support for the development and maintenance of a comprehensive national system for the monitoring and evaluation of HIV/AIDS interventions. They also benefitted from a growing variety of other sources of technical assistance, for example the Global System of Monitoring and Evaluation of AIDS (derived from the World Bank and PEPFAR). UNICEF and WHO (ONUSIDA [UNAIDS], UNICEF, and OMS [WHO] 2008) also intensified their technical assistance in terms of monitoring and evaluation.

The Global Fund has played a key role in developing national programs for monitoring and evaluation of HIV/AIDS and interventions through the provision of funding. In order to receive these funds, they require certain commitments from the recipient country; for instance, each country has to have had a social and economic partner for project management for at least two years. In Ecuador, this partner was the Coordinating Mechanism Committee (CMC), which was directed until 2005 by the General Health Director of the Ministry of Public Health, and from 2005 until 2009 by a member of civil society, Dr. Lilly Marquez. The CMC project under the Global Fund was for several years the agency in charge of the interactions between the government, people living with HIV, the private sector, and civil society.

For its implementation, the Global Fund project in Ecuador required two principal recipients, to be determined by the CMC, and nine sub-recipients, which would be able to participate after signing agreements with the beneficiary country. The main recipient in Ecuador was the Ministry of Public Health, and it was responsible for the supervision, management and financial execution of public policies according to the project. The second main recipient was CARE International, responsible for the technical administration of the project and the interaction with patient NGOs.

Comprehensive care for people living with HIV became one of the primary thrusts of further development in the country between 2005 and 2008. This included the importing of generic drugs and prophylactics for HIV, such as ARVs and condoms. With Global Fund resources, twenty-six clinics nationwide were created to provide ART, and teams of health professionals were trained in the comprehensive management of HIV. Furthermore, free CD4 tests (which measure the strength of the body's immune system) were introduced thanks to these funds, as well as condoms.

Problems with the organizations

Even though patient organizations have helped national organizations to achieve a better health system for HIV patients in Ecuador, they also face several problems. A member of one of these organizations stated in an interview in 2009 that "through the mechanism of intervention, we created different practices and different subjects, some of them with problematic ambitions". Some NGOs have resorted to some questionable practices, for instance the forging of signatures for attendees at their events in order to fulfill the requirements for monitoring and evaluation purposes, as demanded by international organizations.

Until 2008, Mirik, with support from the Global Fund and CARE Ecuador, ranked as the most important organization in the country in terms of their work with HIV/AIDS. However, funding problems, clashes with management staff, and controversy over cases of internal misconduct reduced the number of volunteers and weakened its position and reputation.

From focus groups with HIV positive patients conducted in 2009, I found that some people living with HIV were distancing themselves from Mirik because they felt that they were being used. Patients also considered that the NGOs in general only received and spent the available resources, and that there were no long-term sustainable projects. Furthermore, patients complained that only 2% of the income of the NGOs was actually being received by beneficiaries.

Despite Mirik's troubles, in 2009 it was nevertheless positioned as the main civil society recipient within the proposal submitted by Ecuador to the Global Fund, wherein it was established that it would be responsible for managing the funds for 2010. This was a political decision that the Ministry of Public Health placed on the global agenda.

Discussion

International brokers have a very important role to play regarding HIV/AIDS interventions. They can dictate the framework of the interventions, especially in terms of recognizing research and establishing parameters for projects. In general, patient organizations act as the national arm of the international brokers. However, in terms of the relationship between the two, this case study reveals conflicts and problems as well as benefits. In order to understand the relationship between international brokers and patient organizations, more research is required on the interactions between different organizations, as well as their practices.

Patient organizations and international brokers appropriate and change much of the established information and frameworks, based on local practices and contextual knowledge. The limitations of patient organizations, as well as their strengths, are related to the interaction mechanisms of these organizations with other international organizations and brokers. In order to achieve mutual learning, it is important that patient organizations are considered as equals, and they should be supported by international organizations in the co-creation of their intervention strategies. Contextual design of projects and structures may simplify and improve patient organizations, and this could lead to lessons learnt from both past mistakes and successes.

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ENGAGING WITH RESEARCH

Siân Aggett & Stuart Blume

Engagement with science is much talked about these days, and it is possible to read quite a bit about ‘citizens’ juries’ or ‘citizen scientists’ that are trying to work closely with local farmers or local communities [1]. There's a *Fondation Sciences Citoyennes* (Foundation for Citizen Science) based in Paris (see http://sciencescitoyennes.org), and the *World Forum on Science and Democracy* will soon be holding a conference in Tunis.

What is this all about? What lies behind these initiatives? In the UK, the idea of ‘public engagement with science’ evolved a few years ago out of what was then called 'public understanding of science'. The older term implied something along the lines of improving people's understanding of science and the benefits it yields, and was essentially one-way. The newer term implies dialogue. The change was triggered by specific incidents that eroded public confidence in health research in Britain. One was the controversy over the Measles, Mumps and Rubella (MMR) childhood vaccine. Another was the extensively reported BSE (or 'mad cow') 'crisis'. In both stories, there was perceived to be potential risk to the public, which was initially denied by both the government and mainstream science. The conclusion was drawn that there needed to be more dialogue between the research community, the public, and policy makers. This is a shift from the idea that the public only needs to be 'educated' in order to appreciate research, to one where public perspectives and opinions are regarded as an important aspect of the context in which research is conducted and used.

So the intention is to establish dialogue, which should in turn lead to greater mutual understanding between researchers, those who are likely to be principally affected by the research, and the wider society to whom researchers should be accountable. Researchers may want to ensure that their research design respects participants' sensitivities, and that participants, and (perhaps) their communities, have given their (informed) consent. Engagement, as an ideal, represents the attempt to democratize research and make it accountable to those whom ultimately it is supposed to help.

All of this is certainly relevant in the case of health-related research. In one way or another, better health and well-being is the goal at which all kinds of research are aimed: fundamental laboratory research; clinical trials of new drugs; epidemiological research exploring, for example, the correlates of population differences in disease prevalence; and social research addressing questions like the functioning of health systems, patient experiences, and cultural differences in ideas regarding health and illness. Old notions of there being a single scientific method notwithstanding, the scientific disciplines involved are diverse and the questions they strive to answer vary in complexity. Disciplines differ significantly in terms of the ways in which they gather data, their conventions regarding what constitutes convincing evidence or proof, and the specificity or precision with which the questions addressed by individual projects are formulated. Scientific approaches also differ in what they seem to promise, the expectations they arouse, and the kinds of consequences they are likely to have.

The quest for a magic bullet readily inspires enthusiasm. So, for example, a study of experiences of living with chronic fatigue syndrome or Alzheimer's disease is unlikely to attract the publicity or the excitement that one identifying a responsible gene might do – let alone one promising a cure. When a new drug looks promising in laboratory studies, research and development continues, propelled along well-established channels as long as the promise is sustained. Contrast that with a study of asylum seekers' problems in accessing health care, for example, or of a community's struggle for acknowledgement of the effects of industrial effluents on its children's health. For studies like these to have any practical consequences, much more, and quite different, kinds of work will be needed; and because they potentially threaten established routines and interests, their findings may be ignored or challenged.

Many stakeholders have an interest in research that points towards better health. Researchers have a reputational interest. In the competitive world of modern science, their careers and reputations depend upon publishing results that offer new theoretical insights or solutions to intractable problems. Medical professionals have an interest in being able to do more for their patients, as well as in the status and career rewards that providing innovative treatments may offer. Industrial corporations have an interest in research leading to new, potentially more effective and ultimately profitable, drugs or devices. Governments have an interest in research that shows how health care can be provided more effectively, efficiently, or equitably.

What of the civil society organizations (CSOs) – associations of patients (or health care consumers), local communities – that are supposed to become 'engaged'? Sociologists and anthropologists have shown how patient organizations, in some countries at least, are increasingly involved with research. Sometimes inducements are offered. Patient organizations or communities may be mobilized in order to facilitate the recruitment of research participants, or to add legitimacy to the research. For example, industry may provide financial support to under-funded patient organizations. Organizations carrying out clinical trials in poor communities may offer health care that is otherwise unavailable. (Which inducements are ethically acceptable and which not is a question that we cannot go into here.) Or a purely token presence in a steering committee may be offered. On the other hand, there are also examples of patient organizations gaining real influence over research.

But why should CSOs care about research? Why should they want to become involved? Patient organizations have a clear interest in attempts to develop tools that promise reduced risk or improved quality of life for their members or their members' children. Such a tool might be a genetic marker, or a more certain diagnostic test, or a treatment with fewer side effects. Here it is not difficult for them to work together with (medical) scientists and the (pharmaceutical) industry. They also want to know what works, and for whom; to know how far hopes of an 'imminent breakthrough' or a 'miracle cure' are justified. So they may also have an interest in clinical/epidemiological research, and potentially also in qualitative research that synthesizes patients' experiences of a particular treatment (another way of looking at 'what works').

Research of this kind can be used both in advising members and in lobbying for a new test or treatment. Interest may extend beyond having access to the results of research. Some organizations have managed to establish a leading role, influencing which lines of investigation are prioritized, or the eligibility for admission to clinical trials, or what end-points are to be used in trials. In the case of social science research, they may have views about which research methods are acceptable and which are not. What this signifies goes beyond an instrumental interest in gaining access to the best available care (and indeed patient organizations do not necessarily agree about what they mean by good care). Nor is it only about gaining acknowledgement of the 'experiential knowledge' that comes from living with a life threatening or chronic illness or disability. There is also a demand for what we might roughly call 'respect', 'dignity' or 'agency': the desire to be seen not only as the passive object of research but also to be respected as a knowing subject.

Patient organizations are a particular sort of CSO. In Western Europe, North America, Australasia, there are many of them, often well organized (though in much of the world this is not the case). They represent people who share broadly comparable illness experiences, and often they have well-established contacts with relevant professional and research specialities. For example, in Europe associations of people suffering from arthritis have long-established links with rheumatologists and immunologists.

Local communities are rather different. What do local communities want from health research, or what might they want? How does their engagement come about and what does it entail? The ideal – dialogue based on mutual respect – is the same, but community engagement and patient organization engagement are likely to differ.

What local communities share is geographical proximity rather than an illness experience. To be sure, both have an interest in the quality of the services they receive. But whilst for many patient organizations their focus is on a particular kind of service (obstetric care, for example, or cancer treatment), in the case of communities their concerns are potentially broad (health services, education, water quality, etc.). Only rarely will there be a long-term goal corresponding to the search for a magic bullet, or well-established links with a particular medical or scientific speciality.

So far as health is concerned, the discipline with which links have most to offer local communities is probably epidemiology. Although epidemiology has traditionally worked with a highly individual notion of risk, in recent years the need for a focus on collective, community risks has been discussed. Related to this, some epidemiologists now emphasize the need to work *with* communities in collecting data "that reflect the ecological reality of life...as people experience it" [2]. Strong arguments have been put forward for what has become known as 'community based participatory research' (CBPR), one of which is a greater likelihood that epidemiological research will be translated into action [3].

Some researchers are nevertheless now suggesting that even allowing community panels and focus groups real influence in designing and conducting research (as in CBPR) does not go far enough. Based on their experience in working with a "resource-poor but experience-rich Spanish-speaking community in the United States", Montoya and Kent have introduced what they call a 'dialogical action' framework [4]. Their approach, however, makes major demands on the locally-based researchers who participate, and enabling the community to determine the research agenda may not easily yield the kinds of publications that university researchers are under pressure to produce [5].

Public engagement is best thought of as an ideal: an ideal of partnership between science and society based on dialogue and mutual respect. But 'society' in any practical realization of this ideal is not a unity: it involves a variety of (potentially interlocking and overlapping) entities, of which patient organizations and local communities are two. Research can be of great value to each, and 'engagement' should facilitate both the accountability of the researchers to society and the relevance of the research. But there is no single answer to what precisely 'engagement' entails (or might entail) in practice, or to how it can be brought about, or (not to be forgotten) to the pitfalls and risks of co-optation that may well be lurking round the corner.

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[5] The Suriname Indigenous Health Fund (SIHF) has been working along similar lines. See http://www.sihfund.org/publications.htm.

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ANNOUNCEMENTS

Call for contributions to a peer-reviewed edited volume: *'A Right that Isn't? Abortion Governance and Associated Protest Logics in Postwar Europe'*

Editors: Lorena Anton, Ph.D. (University of Bordeaux, University of Bucharest), Silvia De Zordo, Ph.D. (University of Goldsmiths-London, University of Barcelona), & Joanna Z. Mishtal, Ph.D. (University of Central Florida).

This book will examine abortion governance and associated protest logics developed in Europe since the 1950s around abortion legislation and access. In particular, it will explore the strategies and discourses produced and deployed by social movements, political groups, as well as individuals, to enhance or, on the contrary, limit women's reproductive rights in different historical periods, political transitions, and geo-political contexts. Broadly speaking, two historical periods of distinct politico-economic changes relevant to the struggle for abortion rights can be identified: the post-war period between 1950s and 1980s, and the advent of New Europe since the 1990s.

The deadline is 31st May 2013. More information and abstracts (not more than 500 words) including a 5-page CV should go to: Lorena Anton (lorena.anton@g.unibuc.ro) or Joanna Z. Mishtal (joanna.mishtal@ucf.edu).

1st EUPATI Conference: '*EUPATI: A Vision for 2020*', 19th April 2013, Rome, Italy

The goal of this conference is to look to the future: 2020. How could EUPATI make a difference to patients, advocates, patient organisations and the public? The conference programme has been structured around three key topics: patient involvement in medicines research and development; patients' voice in access to new medicines; increasing public awareness of the benefits and risks of new treatment development. As EUPATI is an IMI funded project, participation in this conference is free. For further details and registration, please see: http://www.patientsacademy.eu/index.php/en/events/event/1-eupati-2013-conference-a-vision-for-2020.

Call for Papers: Special Issue *Dissident Feminisms*, July–December 2014, Journal *Universitas Humanística* No. 78, Pontificia Universidad Javeriana – Faculty of Social Sciences

Guest Editors: Marta Cabrera Ardila and Liliana Vargas Monroy.

Under the name of 'Dissident Feminisms', number 78 of *Universitas Humanística* seeks to gather reflections and inquiries in the emerging tensions of feminist theories and practices that look forward to question the proposals developed by the so-called white, western, heterosexual and hegemonic feminism. Here, they are interested in convening thinkers from queer, postcolonial, Chicano, lesbian, anarchist, anti-systemic and black feminism, among many others; especially those that are investigating in a reflective, situated and performative way, and that are doing so using alternative languages and forms of doing research, to understand contemporary social issues. One of the central aims of this special issue is to present a comprehensive panorama of the role that a variety of dissident feminists have played in the reconfiguration of contemporary social theory and research. In this sense, they will give priority to contributions that are framed in researches that give account for specific research trajectories.

The deadline for abstracts – not exceeding 500 words – is 8th April 2013. For more information, please see: http://alturl.com/q84e6.

New Publication:
Disability Studies in India: Global Discourses, Local Realities, edited by Renu Addlakha

(Routledge Taylor & Francis Group India, ISBN: 9780415812122)

Since the 1970s, the international disability rights movement, the United Nations and national governments across the world have attempted to ameliorate the status of the disabled population through a range of legislative and policy measures primarily in the areas of health, education, employment, accessible environments and social security. While the discourse in the disability sector in India has shifted from charity and welfare to human rights and entitlements, disability studies — as an interdisciplinary academic terrain that focuses on the contributions, experiences, history and culture of persons with disabilities — has not yet taken root.

This volume collates some of the most recent pioneering work on disability studies from across the country. The essays presented here engage with the concept of disability from a variety of disciplinary positions, sociocultural contexts and subjective experiences within the overarching framework of the Indian reality. The contributors — including some with disabilities themselves — provide a well-rounded perspective, in shifting focus from disability as a medical condition only needing clinical intervention to giving it due social and academic legitimacy.

This book outlines key issues that would be germane to any disability studies endeavour in India and South Asia, and will appeal to academics, activists, institutions, laypersons and professionals involved in social welfare, sociology, disability studies, women's studies, psychiatry, rehabilitation, and social and preventive medicine.

Renu Addlakha is Associate Professor at the Centre for Women's Development Studies, New Delhi.

The movement for global mental health: A brief overview

(Summary adapted from Jagannath Lamichhane)

The movement for global mental health, which began in October 2008, is a new health field devoted to strengthening mental health all over the world by providing information about the mental health situation in all countries, and identifying mental health care needs in order to develop cost-effective interventions to meet those specific needs. It was the first platform of its kind where people from diverse backgrounds can join and work together irrespective of their educational, cultural, and geographical roots. Taking into account cultural differences and country-specific conditions, it deals with the population distribution of mental disorders in different countries, their treatment options, mental health education, political and financial aspects, the structure of mental health care systems, human resources in mental health and human rights issues, among others. For more on this new interdiscplinary field, see the writings of Jagannath Lamichhane, President of the Nepal Mental Health Foundation, at: http://ekantipur.com/2013/03/15/opinion/evolution-or-devolution/368469.html.