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## FROM THE EDITORS

Let us start by wishing all readers of the Innovia Foundation Newsletter a belated happy new year. Issue 8, our first of 2009, is arriving to you somewhat later than planned. Yet in spite of a few minor hitches, heavy work loads, and 'flu-like illnesses, we are delighted to bring you this latest instalment. Better late than never, naturally.

We open this issue with news from Stuart Blume, Innovia's Director, regarding the activities of some Innovia Fellows. This includes the recent publication of two books covering topics within Innovia's spectrum, which are outlined, and their relevancies highlighted. With the first related to the development and evolution of the field of bioethics, and the second discussing patient movements in Europe, they hold much potential interest for Newsletter readers.

Following this is a continuation on the theme of bioethics, with an analysis by Carolina Valdebenito of the role it plays in scientific research in Chile – not only biomedical research but all scientific research, including qualitative social science. While bioethical standards of practice are being promoted across the globe, they are subject to differential local implementation; how they are figured out at national levels – in different socio-political contexts – is of great interest.

We are then pleased to introduce another member of the Innovia community, Charles B. Rwabukwali, Associate Professor of Sociology at Makerere University, Uganda. Dr Rwabukwali is actively involved in research and community service projects, in particular focusing on issues related to HIV/AIDS in Uganda. One of his current research studies looks at people's experiences of services, and their perceived and encountered barriers to access. This work is of great importance if the march of HIV/AIDS is to be halted.

Finally, Stuart Blume concludes Issue 8 with a conversation with Bram van der Ende, one of the developers of the Dutch Digital Experience Dossier (DED), a project which in 1998 aimed at digitally archiving patient experiences. Though the project failed to achieve its intended aims (for reasons outlined in the piece), its ambitions – to empower

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individuals and patient organisations, and assemble a valuable database of patient experiences – and its potential – to provide leverage for patient organisations to participate in setting research agendas and generate potential revenue – remain fundamental. With the development of simpler, user-friendly technology, such an endeavour may prove more successful a second time round, if given the chance...

From the Innovia newsletter team, we hope you find something thought-provoking in these (digital) pages. And if you would like to respond to anything in this or other issues, or let the Innovia community know about projects related to our common goals, we would love to hear from you!

Zoe and Dale

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## NEWS FROM INNOVIA

### Stuart Blume

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Two books that have appeared in the last few months, co-authored by Innovia Fellows, will be of interest to all readers of this newsletter. Renée Fox and Judith Swazey's *Observing Bioethics* (Oxford University Press, ISBN 978-0-19-536555-9) has been widely reviewed and some readers will certainly know it already. Both authors have been involved in one way or another with bioethics since its very beginnings, though when and how bioethics began is a matter of continuing discussion (and is addressed in the book). Many social scientists studying health, illness, and medicine have been exceedingly critical of bioethics. They have been critical of the assumption that there can be any 'principles' providing medicine with a universally valid ethical underpinning, irrespective of time or of culture. They have been critical of the 'imperialist' project that bioethics seems to have become. For some critics, the whole bioethical enterprise has been (and remains) a means of deflecting attention from the injustices and the inequalities of power inherent in doctor-patient relationships.

Using historical material, participant observation, and interviews with many of the first generations of bioethicists, this book is

rather different. It shows us how bioethics became what it has become. How, for example, did the complex philosophical issue of 'respect for persons' become narrowed down to little more than a standardized informed consent form? What happened to questions like 'How can biomedical advance best serve the common welfare'; the big questions that concerned the field's pioneers but somehow disappeared from its agenda? What becomes clear from this book is that there *are* bioethicists worrying about such matters: questions of injustice and inequity in health care; questions of the rights of communities (and not just 'persons') to respect and protection; the formulation of bioethical codes appropriate to cultures and societies in which social solidarity is highly valued; and so on. Renée Fox and Judith Swazey also show us a field that, having been drawn into the political mainstream, was then ruptured by the liberal-conservative divide over questions such as the status of an embryo, cloning, and stem-cell research, issues that marked Bush-era US politics.

The 'big questions' with which bioethics' pioneers were preoccupied are also central to Innovia's objectives, except, of course, that times have changed. People with chronic illnesses or disabilities now demand more than simply respect as individuals. They also demand a collective voice in determining how

medical advances can best serve their interests, and in establishing what those interests are. This fascinating book helps us understand the contribution that a renewed bioethics can make to their, and our, struggle.

The second book focuses directly on that 'struggle'. Edited by Madeleine Akrich, João Nunes, Florence Paterson, and Vololona Rabeharisoa, it is called *The Dynamics of Patient Organizations in Europe* (Presses de l'École des Mines, Paris, ISBN 978-2-35671-005-5). It includes papers and discussion from a two day conference held in Paris in the context of a European Commission-supported project, MEDUSE. All stakeholders were represented among the eighty or so conference participants: the patient movement, the social sciences, health policy makers, industry. The book addresses three themes that are as central to Innovia as they were to the MEDUSE project. How can and do patient associations work with industry? How can and do health organizations and research organizations collaborate with patient associations? What social and political issues arise in the formation and governance of patient associations? A presentation of Innovia is included in the book. There is also a discussion of the Digital Experience Dossier by Bram van der Ende, about which you can read more elsewhere in this newsletter.

The book ends with a number of recommendations, of which I can only refer to two here. "*Give patient organizations the means to*

*act*". For rhetoric to be turned into reality, patient organizations need to be provided with the necessary financial and material means, and they need to be guaranteed access to information. These conditions are all too frequently lacking in Europe. "*Make patient organizations actors in their own right in knowledge production*". This means that they need to be provided with the tools for extracting value from patients' experiences; tools which social scientists can do far more to help furnish than they in fact do. The book as a whole provides a useful overview of what, relevant for Innovia's work, is going on in (Western) Europe.

Last, but certainly not least, I'd like to say that Jo Weaver, who is a graduate student at Emory University in Atlanta, USA, has now finished work on the bibliography on 'Leprosy (or Hansen's disease) and Stigma' that we began in collaboration with IDEA ([www.idealeprosydignity.org](http://www.idealeprosydignity.org)). It contains approximately one hundred items, with detailed annotations, drawn from many sources. I would like to thank Jo – and everyone who provided her with material for inclusion – very much indeed. The Innovia website will soon include directions for accessing the bibliography. If we can find the (modest) resources needed, I hope we will be able to use this bibliography as the basis for further work. On that, more later.

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## BIOETHICS IN CHILE

### Carolina Valdebenito

#### *Background*

Despite economic growth, modernization, and left-of-centre presidents and governments, Chile has remained an ethically conservative nation, influenced by its colonial past and its

religious culture. Abortion is still forbidden and divorce has only been possible for a few years. Like other countries, Chile too has had to come to terms with the global debates regarding new science and technologies, and the new perspectives on developments such as the human genome project, cloning, and euthanasia. Over the past decade or so, a number of institutions have begun to work in

the field of bioethics, though their starting points differ.

One is the Pontifical Catholic University of Chile, which is heavily influenced by the Roman Catholic Church. An example of its conservatism was the public reaction of some of its professors to the new permissive euthanasia laws in Belgium and Holland. The professors accused both countries of devaluing human life. In contrast, the University of Chile has a more liberal and open-minded tradition. It offers degrees in bioethics within the Faculty of Medicine. Chile also has an office of the Pan-American Health Organization which includes a Bioethics Unit, in which I worked for six years. This unit supports the development of bioethics throughout Latin America. In association with the Interdisciplinary Centre for Studies on Bioethics at the University of Chile, it has developed a number of activities that include courses and workshops and other academic activities for disseminating the role and social importance of bioethical thought in scientific and clinical research. Finally, since 2006 there has been a National Bioethics Commission in Chile, established under the socialist government and leadership of President Michelle Bachelet. This organization has drawn its membership from a wide range of perspectives in order to develop a more inclusive and more integrated point of view with respect to bioethical questions. Its task is to provide universal guidelines for good practice in science in Chile, irrespective of discipline, location, or source of funding.

The Royal Spanish Academic Dictionary defines bioethics as *"A scientific discipline which studies the ethical aspect in medicine and biology in general terms, as well as the relationship between humans and other species"*. A second definition

developed by the Encyclopaedia of Bioethics defines *"Bioethics as the critical conscience of technological civilization"*. Today there are many types of bioethics. For example, Daniel Callahan has distinguished four variants: conceptual or theoretical bioethics; clinical

bioethics (focused on the decision making process during daily professional practice, and linked for example with clinical trials); bioethics oriented to public health decisions and to the justice debate (and so involving politics, social justice, and legal perspectives); and cultural bioethics (that seeks to relate the dilemmas of bioethics with the historical, ideological, cultural, and social context within which problems occur) [1]. There are also many approaches to bioethical practice, of which 'principalism' – emphasizing the well-known principles of (patient) autonomy, beneficence (to do good), no malice (to do no injury), and justice (recognizing the equal

right of all to healthcare) – is by far the most influential. According to Santos [2], in Chile the approaches employed are mostly 'principalism' and 'personalism' (the latter emphasizing the primacy of the human person and his or her wellbeing).

#### *Bioethics in Chile*

Whilst international developments have had an important influence on the institutionalization of bioethics in Chile, so too has the country's political history. Memories of the human rights abuses inflicted during the dictatorship period are strong. Since the emergence of bioethics in response to biomedical experimentation on human beings during the Second World War, the discipline has been extended to other scientific fields including the social sciences. Currently in Chile some of the more important social sciences' research foci relate to ethically



sensitive issues, including vulnerable populations, mental illness, covert research, research about sexuality, etc.

Much of the bioethical infrastructure in Chile is like that found in other countries. A key institution in terms of ethics regulation is the Ministry of Health. It plays the lead role in drug regulation, and has developed guidelines governing privacy and data protection, genetics research, and the conduct of clinical trials, among other things. The Ministry of Health has also established different kinds of local/institutional committees. For example, there are committees that review clinical research activities involving human beings, called CEICs (Committees for Scientific Evaluation), intended to protect human rights and human dignity in accordance with the Helsinki code. They should be made up of at least five persons, represent different areas of knowledge, include both genders, and be free of external pressures. Other committees include those involved in the ethical deliberations of hospitals. These committees are called CEHs (Hospital Ethics Committees), and are normally composed of professionals from the same healthcare institution who make recommendations regarding clinical decisions [3]. In 1997, the National Society of Bioethics was established, which currently has 129 members from various fields of research and practice.

An interesting feature of bioethics in Chile is the role of the recently-established National Bioethics Commission. After almost 10 years of debate in Congress, on September 22, 2006, law number 20.120 was approved. One component of this law was the creation of the National Bioethics Commission, which according to Beltrán [4] has “the legal duty of advising the Chilean State on ethical issues that emerge as a consequence of biomedical, scientific and technological development”. He adds that a further role is the promotion of related bioethical, social, and political debates. The commission is composed of nine members from different fields of science and research,

each of whom is appointed for four years with the possibility of renewal. Expertise as a bioethicist is not mandatory since it is not a recognized professional title in Chile, and is not required by law; more important for membership is previous experience in bioethics, and being free from external pressures.

The National Bioethics Commission works closely with the National Council for Scientific and Technological Research (CONICYT), to select research projects for funding by the Chilean government. In contrast with other countries, bioethics is a central issue for the National Research Council. According to Lira [5], *there is an agreement that all research, not just pharmaceutical research, implies ethical issues*. CONICYT, acting through the National Foundation for Scientific and Technological Research (FONDECYT), requires all projects applying for a national grant to conduct an ethical review from a human rights perspective. This applies to all research, no matter what field of science is involved. The goal is for any person who freely decides to participate in a study to be fully informed about the costs, benefits, and risks of the research, and this person must be able to quit at any time. A project will be “. . . well evaluated if all the team involved in a project, as well as the future participants, are completely and entirely informed about the project aims, methods, risks and possible uses of the results”. Paralleling the suggestions of Emmanuel [6], the Chilean government tries to ensure that research involves a real collaborative partnership, social benefit, and respect for participants and for communities involved in studies.

#### *Bioethics in social sciences*

Bioethics emerged in response to medical abuses under Nazism during World War II. Later it engaged with various aspects of science beyond strictly medical issues [7]. Its extension to the conduct of social science research poses particular problems, however. These may be all the greater in a society marked by memories of past human rights abuses, or by ethnic or

cultural divisions.

More than other disciplines, (qualitative) social science research depends on social interaction, which means that the principal research tool is the researcher him- or herself. All depends on the researcher's capacities for engaging in social contact and human interaction. The social science research process of 'social and cultural encounter' involves a lengthy process of social 'intromission'. It is a form of 'covert research' that implies many simple acts to gain acceptance and to attempt objectivity, such as avoiding personal opinion regarding the subject issues; in other words, to attempt 'neutrality and impartiality'. Overall, the purpose is to "get in there to conduct covert research" [8]. This can require a change of name, title, and even hiding the nature of the research. Thus the interview itself, and asking for a signature on an informed consent form, are just the tip of the iceberg after long, meticulous, and disruptive work.

Consequently, the ethical dilemma is no longer whether informants should or should not sign an informed consent form. It is more about the process of building rapport and of social insertion wherein the thoughts, beliefs, likes and dislikes of the researcher are necessarily and temporarily suspended in order to gain respondents' trust and obtain the needed research information. It does not mean that the social researcher cannot or may not feel any attachment to the informants, or that a real friendship cannot evolve, only that these are not the goals of the interaction. The challenge is not the informed consent but the process of 'enchantment' and, of course, the ultimate destination of the information. According to Kottow, *the main ethical principles for carrying out social science research should imply the free will of the participants, their informed consent, the proportionality of the costs and benefits, and the possibility of benefits for the participants* [9]. Carrying out 'covert' social science research involves risks and costs.

As mentioned by Gonzalez [10], in social sciences there are also problems related to

intellectual property. Similar problems have arisen in fields such as archaeology, where a frequent dilemma is deciding who owns the materials and theories. Is it ethical for native populations to manage their own archaeological patrimony and offer ethno-tourism, despite the consequences for the archaeological evidence? Is it ethical for international agencies to negotiate with native populations about offering 'archaeological experiences' to foreign tourists lacking any scientific background?

There are also a number of dilemmas which are situated between the natural and social sciences. Santos [2] gives an example of such a dilemma, relating to the genetic mapping project funded by IBM and the National Geographic Society. The purpose of this enormous project, comprised of around 100,000 samples of DNA, is to identify the origin of the human species. According to Santos, the issues involved in the genetic mapping of indigenous peoples require further legal clarification in Chile (as is also the case in other Latin American countries).

### *Conclusion*

I have tried to describe the meaning of bioethics and how it is developing within Chile as a multi-disciplinary and inter-disciplinary field of practice and reflection. This implies that ethical decision making should consider not only medical aspects but also philosophical, anthropological, social, and economic implications. I have focused on social science research in particular because it raises special problems, because the bioethics of social science seems to be receiving more attention in Chile than is the case in many countries, and because understanding the personal and community experience of ill health and of healthcare lies within the province of the social sciences.

Despite the difficulties and legacy of the past, a remarkable degree of 'bioethical security' has been achieved in Chile today, thanks to the enormous efforts of the Chilean government and other institutions to pursue

scientific advancement according to ethical standards. The fact that the social sciences are considered in the same way as the biomedical sciences may offer pause for thought to social scientists and bioethicists in other countries.

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### **Charles B. Kwabukwali, PhD**

Charles B. Rwabukwali is Associate Professor of Sociology, Faculty of Social Sciences, Makerere University, Kampala, Uganda. His research interests are in health resources utilization, social aspects of AIDS and other emerging infections such as Ebola, and patterns of fertility regulation. He obtained a bachelor's

degree in Social Work and Social Administration from Makerere University; a Master of Public Administration from the University of Arizona, Tucson, USA; a Master of Arts and PhD in Medical Anthropology from

Case Western Reserve University, Cleveland, Ohio, USA; and a postgraduate diploma in Population Research from Exeter University, UK.

In terms of research, Dr Rwabukwali and Dr Janet McGrath of the Department of Anthropology, Case Western Reserve University, won an NIH grant that enabled them to establish a Centre for Social Science Research on AIDS (CeSSRA) at Makerere University. The Centre has two complementary missions. First, it will develop and expand local capacity to undertake social science research on HIV/AIDS in Uganda through infrastructure development. Second, it will, through a small grants programme, promote, foster, and conduct social science research on HIV prevention and treatment. The Centre will meet these goals through a combination of in-country workshops, on-going consultation and mentoring, and participation in field research. In this regard, the overall research project is a longitudinal study of treatment access. The objectives of the study are to:

2. Examine treatment seeking practices and barriers to accessing care;
3. Identify factors that impact long-term adherence to care and treatment among patients on antiretroviral therapy (ARV);

1. Describe and compare the experiences of patients on ARV in Kampala (Uganda's Capital City), and Mbarara, a peri-urban area situated in amongst a primary pastoralist group in western Uganda.



In terms of community service, Dr Rwabukwali is a member of the board of trustees of the AIDS Information Centre (AIC). Since its inception in 1990, the AIDS Information Centre-Uganda was a pioneer in the provision of HIV Counselling and Testing (HCT) Services and information on HIV and AIDS in Uganda. It

targets the most-at-risk populations with HIV prevention, care, and support. The demand for HCT in Uganda remains high and recent studies indicate that 71% of women and 77% of men have never tested for HIV status, and hence are unaware of their status. AIC therefore has a critical role to play in ensuring that the percentage of people with no knowledge about their sero-status continues to decline.

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**“MEMBERS’ EXPERIENCE IS THE PATIENT MOVEMENT’S MOST VALUABLE RESOURCE”. THE DUTCH ‘DIGITAL EXPERIENCE DOSSIER’**

**Stuart Blume** in conversation with **Bram van der Ende**

The idea that became the Digital Experience Dossier (DED) emerged more than a decade ago within the Dutch patient movement. It was quite different from the Electronic Patient Record, about which health service administrators were so enthusiastic. Through the DED, patients would record their own illness-related experiences, on a regular basis, and over a long period of time. Bram van der Ende, at the time secretary of the Dutch association of people with rheumatoid arthritis, was invited to join a group that would work the idea out in detail. They decided to start with a pilot study focussing on the experiences of people who had been prescribed a particular new medicine just coming onto the market. Using a software tool by which experiences could be systematically recorded, reactions to this new medicine would be followed over a period of years. The work would be carried out by a new foundation, (*Patient in Zicht*), under the auspices of the umbrella organization of associations of people with chronic illnesses and disabilities, today called the *CG-Raad*.

This was in 1998. At that point the patient movement was becoming aware of the new possibilities that the Internet offered. Through the Internet they would be able to reach a much wider network of people. Moreover, the scope of their projects could be extended.

SB: *You mean a wider range of illnesses?*

BvdE: *Yes...or rather, a wider range of illness or handicap-related experiences.*

SB: *So not just medicine use, but all aspects of life?*

BvdE: *Exactly. All aspects of life. For example, what happens with people who become handicapped and who want to return to work? How do they manage to keep relationships going, or develop new ones? Or to participate in the community?*

So the objective became to develop a system in which this whole range of experiences from a large group of people could be collected. The plan was to start with a one year pilot, for which 1000 patients would be recruited. This would ultimately be extended, and in principle anyone would be able to apply to become a ‘dossier holder’.

SB: *Who were the intended users of this system?*

By the time the application for funding was ready, three distinctive levels of user had been identified. One was the individual patient. Having access to a systematic record of his or her experiences over time, for example with regard to medicine use, would give the patient a better basis for communicating with doctors, and would make for a more equal partnership in discussing treatments. The second level was that of the specific patient organization. The system was set up so that you could analyze the archived narratives of everyone belonging to a particular organization or with a particular condition. But it was also interactive. You could question that particular sub-group regarding, for example, how they’d been affected by a particular medicine no longer being reimbursed by health insurance. If the drug was being widely used, it would be important for a patient organization to know how their members had been affected by a policy change. Loyal members would reply fast and the resulting information would be a valuable resource in negotiating with the government, with service providers, insurance companies, the pharmaceutical industry, and so on. What’s more, all this accumulated experience,

analysable at the level of the patient organization, could become a source of revenue for them. It could be of great interest to industry or to researchers, who could be charged for access. Finally, the third level was the umbrella organization of patient associations. They could gain great benefit from knowing how very general measures, regarding for example the kind of expenditures that basic health insurance would cover, affected the whole patient group.

*BvdE: That was the ambition ... The patient organizations are always going around begging, producing proposals, applications, waiting ... begging for money, never knowing if they'd get it. How can you become strong if you're in that position? You can only become strong if you have a sure source of income over a period of a few years and can decide for yourself what your priorities are. That was the basis and the essence of the whole thing.*

*SB: What about accessing the system? How could you guarantee people's privacy?*

*BvdE: That's an interesting aspect. We'd worked that out together with TNO [the Dutch organization for applied research] and a start-up company that was looking for ways of adapting the work of the 'notary' to the digital age. They wanted to develop the software through which signing contracts, buying a house ... all of those kinds of things could be done via the Internet. So we worked it out together. You could only get into the system if you logged in via the 'digital notary'. That was true for the patient organizations as well. No one could access either the database or the dossier holders without submitting their request to the digital notary. Individual*

*patients could, however, access their own personal dossiers.*

The DED was an attempt to empower the patient movement in its negotiations with policy makers, and with organizations providing the goods and services people with disabilities or chronic illnesses need. It was also an attempt at constructing a radically new relationship between the patient movement and the world of research, reversing the usual dependencies. Instead of patient organizations depending on researchers for studies of their members' lives and needs, researchers would depend on patient organizations for access to the data they held.

Unfortunately, the project did not work out as intended, for two very different reasons. One was technical. Ensuring that data were of high quality and that privacy was sufficiently protected had resulted in a technically complex system: too complex for many patients. Instead of the intended 1000 users in the first year, only 270 patients were enrolled in the first half year. The second reason had to do with events wholly unrelated to the DED. The CG-Raad, responsible for the project, appeared to be encountering financial and managerial problems. Although it subsequently turned out that nothing had been amiss, the organization funding the project (that had the principal task of allocating government funds among eligible patient organizations) lost faith after the first half year. It announced there would be no funding beyond the one year pilot study. Half developed, the DED was brought to a premature end. Bram van der Ende recognizes that advances in digital technology mean that things could be done more simply today. The vision remains.