

EACME Newsletter

European Association of Centres of Medical Ethics

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CONTENTS

EDITORIAL <i>P. Schotsmans</i>	1
HUMAN RIGHTS AS A LINGUA FRANCA FOR INTERNATIONAL BIOETHICS <i>R. Ashcroft</i>	2
AN ETHICAL ANALYSIS OF TWO PROPOSED STRATEGIES TO SHORTEN THE WAITING TIME OF PEDIATRIC KIDNEY TRANSPLANT CANDIDATS <i>K. Thys</i>	4
(Ants) ANTHROPOTECH SEMINAR AND DISCUSSION LIST <i>S. Allouche</i>	5
PREVENTION DE L'HOMOPHOBIE EN SUISSE: LES CHOSES AVANCENT <i>J. Martin</i>	6
INTRODUCING THE BIPIC STUDY <i>G. Birchley</i>	7
PACT PROJECT	8
TELL ME PROJECT	8
BOOK REVIEW <i>J. Martin</i>	9
INTENSIVE COURSE ON FOUNDATIONAL APPROACHES, CONTEMPORARY AND EDUCATIONAL ISSUES IN THE FIELD OF NURSING ETHICS	11
ANNOUNCEMENTS	11
DEADLINE NEXT NEWSLETTER	12
EDITORIAL BOARD	12

EDITORIAL

Living bio-ethics on a gondola. Good memories to Father Francesc Abel s.j.



The last time I met Father Abel was during the EACME (European Association of Centers of Medical Ethics) conference in Venice (September 2009). We were hosted at one of the beautiful places which only can be found by someone like Renzo Pegoraro of the Fondazione Lanza (Padova). The attendance of

Father Abel was announced, but he was not yet there when I arrived. Suddenly, I saw him arriving from the Airport on a gondola...very "expensive" as he said, but the only way for him (with his difficulty for walking and moving) to arrive safely at our meeting place. To be honest: it felt like as my father in the real sense arrived. His presence made us all feel at ease: we could start to work. And working he did! He made a very strong intervention as a reaction on Eberhard Schockenhoff's lecture, a reaction welcomed by the great majority of participants.

I try to remember him, almost being with his hands on my shoulder during my whole lifetime in bioethics. Father Abel contributed to the spread of bioethics all over the world (e.g. also in Latin America), but he was certainly the key figure of bioethics in Europe. He may really be called "the father of European bioethics", and certainly the godfather of the European Association of Centers of Medical Ethics. In this context I am still impressed by his restless commitment to the construction of a European bioethics network; his crossing borders to the United States; and most

importantly of all: he was a deeply dialogical partner in exchanging ideas in a highly pluralistic bio-ethical environment.

I tell my story about him in a personal way. Our Center for Biomedical Ethics and Law in Leuven started in 1986, when the Barcelona Center in Sant Cugat existed already many years. I had to visit him in order to know how to construct and start such a Center. Therefore, my first encounter with Francesc was a personal visit in 1985 to Barcelona and to Sant Cugat des Vallès, together with Jean-François Malherbe (my colleague at that time of the Université Catholique de Louvain). He explained us how to create such a research center, how to build it up, how to integrate it in the network of local, national and international policy making. I was overwhelmed by his hospitality. He made profit of our visit to make with Jean-François concrete plans for the creation of a European Association, not of members, but of Centers of biomedical ethics. Edouard Boné and Jean-François Malherbe, Brussels, Maurice De Wachter, leading bioethicist in Holland, Patrick Verspieren, Paris, Richard Nicholson, London, and Nicole Léry, Lyon, joined efforts with him to build up the structure of such an Association. His conviction we should remain a network of “centers” (not “individual members”) was very strong. The magnificent conferences of this Association during all these years and the participation of so many young scholars in the last years proof he was right. We will celebrate in Bristol this year (with one year delay) our 25th anniversary and certainly pay tribute to him.

I was regularly surprised by his preparedness to invite people with totally different point of views and to enter into challenging dialogues with them. Dialogue should be understood in many ways. First of all, he was truly interdisciplinary and integrative. Being himself a medical doctor and trained in philosophy and theology, he knew how to bring the different disciplines together. Lawyers were also regularly invited...so that we could make the bridge to policy making. Secondly, he was never closed minded: he opened his heart and mind for the restrictive interpretations of Catholic teaching, but at the same time he was strongly supporting new ideas. He also brought radically anti-clerical viewpoints (and their representatives) in his meetings, which yet on itself created a really pluralistic dialogue. Finally, having worked together in Georgetown with André Hellegers (thé founder of the Kennedy Institute), he opened many doors to the United States of America. When I saw him arriving on a gondola in Venice, I did not know this would be my last meeting with him. But this event is still on my eyes and in my heart...a man travelling around the world to make us better understand that medicine is serving to accompany the finiteness of our life, and that human beings in their

ethical reflection have to make clear that wisdom, dialogue and integration are the pathways to work at a better future.

Dear Francesc: many thanks! And in the words of your faith: may you see now the Lord from face to face!

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HUMAN RIGHTS AS A LINGUA FRANCA FOR INTERNATIONAL BIOETHICS

Précis of a keynote address to the Annual Conference of the European Association of Centres of Medical Ethics, Istanbul, September 15th-17th 2011

Bioethics is a field of enormous interest worldwide. The problems and challenges of contemporary medicine and the life sciences from abortion and euthanasia, to stem cell research and preimplantation genetic diagnosis, from HIV/AIDS to synthetic biology, are recognised as important and difficult everywhere. One of the major achievements of the past 40 years has been the development of a field of academic inquiry and policy development, namely bioethics, which allows the ethical issues in medicine and the life sciences to be acknowledged, discussed, and addressed in ways which can be seen as reasonable and – we hope – wise applications of public reason.

It is the public character of bioethics which is particularly important here. On the one hand, participants in bioethical debates are normally expected to reason as members of a public, rather than as merely private deliberators about what they, on their own, believe, or as partisan representatives of a particular religious, political, or cultural affiliation. On the other hand, when we deliberate in the public sphere we are not simply practising abstract argument; we are participating in the development of values, practices and rules which need to be at least minimally acceptable and tolerable to all reasonable people. And reasonable people are not free of religious beliefs, cultural memberships, political views, social and economic status and so on. These are the things which make us up, as individuals, and as societies. They are not “mere accidents” which can be

ignored. We do not reason from behind the veil of ignorance, any more than we live behind it.

Substantive disagreement in bioethics is a fact, and were it not so, then much of the time we would have no need for bioethics. True, there would be situations where what we agree about is that we are uncertain or ignorant as to the right thing to do or the right policy to adopt. In those cases we would need a way of deliberating. But it is one thing to cooperate in finding a solution to a problem where we all share the same premises and values, and quite another to find a way to cooperate (or at least disagree with a degree of civility) where we do not share all the same values and premises.

One thing which is critical to the success of the cooperative venture of public reason is the availability of a common language. In the mediaeval and early modern period, navigators and merchants around the Mediterranean were able to use a common language, the *lingua franca*, which while not a literary or even everyday language, had a rich and necessary vocabulary for commercial and maritime discussion, which was known and used by merchants regardless of their nationality or home port. It is particularly poignant to be discussing this issue in Istanbul, situated as it is both geographically and historically at the great meeting point of cultures, trade routes, and empires which defined world history from ancient times. My proposal is that we need a *lingua franca* for bioethics.

Some would argue that we do have a *lingua franca* already: the vocabulary given to us by Thomas Beauchamp and James Childress in their seminal *Principles of Biomedical Ethics*. I think this is not quite right. First of all, the *Principles* has a rather different, universalist strategy. It seeks to identify the common core of morality itself, that which all reasonable moral agents substantially agree upon, notwithstanding the differences they may have at the level of theory at the fundamental level or specific concrete moral beliefs at the practical level. Secondly, at least in some quarters in bioethics, the *Principles* have been adopted as a kind of substantive morality in itself, and have been seriously criticised for that. For instance, we may consider the way in which “respect for autonomy” has proved both to be rather slippery in content, and nonetheless has tended (at least in Anglo-American bioethics) to acquire the status of master principle. The *Principles* have slipped from being an approach to thinking about moral problems in biomedicine to being a set of rules. Whatever the views of the authors of the *Principles*, this is all too frequently how the “Four Principles” are adopted and applied.

So my idea for a *lingua franca* for bioethics is that we need something which will enable us to agree on what

we are talking about when we disagree, whether such disagreements are philosophical, religious, cultural, political, or practical; and how we could talk about them in a way that our disagreements are intelligible to each other. We can think of a language as a medium, rather than as a view of the world.

My second proposal, if you are inclined to accept my argument that we need a *lingua franca* – especially in international bioethics – is that in a way we already have such a language, and it is the language of international human rights. This might be controversial. The history of the debates over the UNESCO Declaration on Bioethics and Human Rights has been messy and ill-tempered in many quarters. And it is also true that over its history the UN Human Rights system of instruments and institutions has been very controversial too. “Human Rights” is many things – a social movement, a career, a tool of diplomacy, a set of legal norms, an aspiration, a utopia. Taken modestly, however, it does provide a vocabulary which all nations have agreed to use for discussing certain kinds of problems; it provides a grammar for describing certain kinds of problems; and it provides an orientation to the human world which allows for the identification of certain kinds of problems. While it prescribes certain kinds of activity and proscribes others, for the most part it acts as a framework for thinking and arguing rather than readymade solutions.

It is not necessary for the *lingua franca* of human rights that we commit ourselves to any particular view of the metaphysics of rights, the role of rights in moral or legal theory, or even a concrete list of which rights should be acknowledged as fundamental or derived or redundant or “failed”. These are all substantive questions which can be discussed using the language of human rights. Philosophical questions about human rights can be posed within that language (just as jurisprudential questions can be posed within the language of the Law).

Can we say more? Is there some specific advantage which the language of human rights offers over and above the competing candidates for the common language of bioethics? There are three: first, it is in use, it is credible, and it is a language which works effectively in day-to-day practice in a wide variety of settings – government offices, courts, NGOs, the press and mass media, the street. Second, it is a language determinedly designed for public reason: it is in a modest way secular, neutral as to conceptions of the good life, flexible in interpretation but binding in the way those who use it must agree to its “grammar”. Its origins are not “Western” or “liberal” but draw equally on the major religious traditions, and the “developing” world as much as the “developed”. It does not come prepackaged with an ideology or set of political premises. Third, it is thoroughly focussed on the human dignity and welfare of all. Questions of social and economic justice, the

rights of women and children, cultural and ethnic equality are central to human rights in ways which they simply are not in much of mainstream contemporary bioethics, to the detriment of both bioethics and us all. While human rights language is not prescriptive of what we should say about global health inequality, for example, it is prescriptive that global health inequality is relevant and be taken into account in considering the human rights impact of novel technologies or controversial medical practices.

In conclusion: I don't claim that human rights is a panacea, or that we should simply replace our current teaching of our preferred philosophical theories with teaching of human rights. I do think that more serious attention to human rights substantively would benefit research and scholarship and most importantly policy-making in the field. But most of all, the use of human rights as a lingua franca will enable a more fruitful encounter and trade in ideas and understanding, whatever our origins, when we meet in the global public sphere.

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AN ETHICAL ANALYSIS OF TWO PROPOSED STRATEGIES TO SHORTEN THE WAITING TIME OF PEDIATRIC KIDNEY TRANSPLANT CANDIDATES

Background

Kidney transplantation is an effective and life-saving treatment option for patients suffering from kidney failure and generally offers a higher survival probability and a better quality of life than other kidney replacement therapies. However, as kidney transplantation has become an increasingly accepted treatment modality, the available supply of organs for transplantation is insufficient to meet the demand. At the end of 2010, ca. 10 300 candidates were registered on the Euro-transplant waiting list for kidney transplantation, while only 3 737 kidneys from deceased donors were accepted and used for transplantation. 551 patients died while waiting for a suitable donor organ (1).

Approximately one per cent of all waiting list registrants for kidney transplantation are pediatric patients (0-16

years) (1). For these patients, kidney transplantation is considered a more effective and comfortable alternative to long-term dialysis, which is a significant risk factor for future malignancies, cardiovascular disease, impairment of cognitive functioning, growth retardation and depression. Moreover, children and adolescents maintained on dialysis report lower levels of physical, emotional and school functioning compared to their peers with a functioning kidney allograft.

Kidney transplant outcomes in pediatric recipients have considerably improved in the last decades and graft survival rates at least equal those of adult transplantation (2). It has been shown that shortening or even avoiding pre-transplant dialysis duration has the potential to improve graft survival, to lower the incidence of acute rejection and, eventually, to increase life-expectancy of these pediatric patients. Pre-emptive kidney transplantation, i.e. kidney transplantation without preceding dialysis regimen, therefore is considered the optimal intervention for children in need for kidney replacement therapy (3). However, due to long waiting times for kidney transplantation, the advantage of reducing dialysis duration is often not obtained.

In this project, we will discuss two pathways that have been proposed to reduce pediatric patients' exposure to pre-transplant dialysis. The first pathway involves prioritization of pediatric patients on waiting lists for deceased kidney donors; the second involves the extension of the potential donor pool by allowing minors to become living solid-organ donors.

1. The use of pediatric allocation algorithms

A first strategy to reduce the waiting time of pediatric kidney transplant candidates is to prioritize them on the waiting list for a deceased donor organ. Transplant registries like UNOS and Eurotransplant give special consideration to pediatric patients by applying age-related algorithms. These algorithms include the attribution of pediatric bonuses, the awarding of zero-antigen mismatches and the mandatory coupling of pediatric donors to pediatric recipients. Such interventions to prioritize pediatric patients on transplant waiting lists raise ethical concerns however, as they may violate the principle of equal access to donor organs. They will prolong the waiting time of adults that are registered on the waiting list already for a longer time, with an inferior health status as a consequence of long-term kidney disease. Moreover, kidney transplantation in adolescents raises special concerns, as non-compliance to immunosuppressive medication is almost four times higher in this age group compared to that in adults, and leads to inferior long-term graft outcomes (4). Therefore, it has been suggested to delay transplantation until adulthood, in order to achieve better long-term outcomes (5).

2. Living kidney donation by minor donors

The second pathway that has been suggested to increase the available organ pool for pediatric transplant candidates is the possibility of minors to become living solid-organ donors (6). When no medically suitable adult donor candidate is available, living donation by minor siblings may be considered in order to avoid long waiting times for a suitable post mortem donor.

Until present, most clinical practice guidelines and normative documents have been reluctant to support living kidney donation by donors who have not reached legal age. A 2004 report of the Amsterdam Forum on the care of the Live Kidney Donor defends a total prohibition on organ harvesting from minors under 18 (7). However, an evaluation of this current consensus may be desirable, as transplantations with grafts from living donors yield superior results to those from deceased donors and post-nephrectomy morbidity and mortality risks for living kidney donors are considerably low.

Objectives and methodology

The aim of this project is to analyze and discuss the ethical issues that are associated with these proposed strategies to shorten the waiting time of pediatric kidney transplant candidates.

First, we aim to determine the moral desirability of waiting list algorithms that aim at prioritizing pediatric transplant candidates.

- We will describe current pediatric allocation rules and policies of national and international transplant registries;
- By conducting semi-structured interviews, we will assess expert physicians' attitudes and experiences with these allocation policies;
- After a fundamental reflection on the use of age as a criterion for organ allocation, we will provide normative orientations on the use of these algorithms.

Second, we aim to determine whether living kidney donation by minors is desirable and, if yes, under which conditions:

- We will systematically review clinical-ethical guidelines and position papers on living kidney donation;
- We will describe the legal framework on living organ donation by minors in several European countries;
- By conducting semi-structured interviews with expert physicians, we will describe their attitudes on and experiences with living kidney donation by minors;
- Based on the empirical research and the relevant literature, we will develop normative

orientations on living kidney donation by minors.

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(ANTS) ANTHROPOTECH SEMINAR AND DISCUSSION LIST

Dear colleagues

Heather Bradshaw, Alex McKeown and myself are currently creating a research seminar on human enhancement entitled "Anthropotech Seminar" (Ants). We plan to meet twice a month from March at the Center for Ethics in Medicine of the University of Bristol.

Beyond the Bristolian community, the Ants list aims to provide a discussion platform for any researcher interested in the topic. One of the main goals of the group is to promote exchanges between France and the UK in the European context, but if you are a researcher from another country, you are also warmly welcome as long as you are ready for friendly, robust and well-argued, in short philosophical, discussions.

If you wish to receive information about the theme or have the opportunity to discuss it with other researchers, you can read more about the ants-list on <http://tech.groups.yahoo.com/group/ants-list/> or subscribe to it by writing to ants-list-subscribe@yahoogroups.com

Kind regards,

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PRÉVENTION DE L'HOMOPHOBIE EN SUISSE: LES CHOSES AVANCENT

Début novembre 2011 ont eu lieu à Lausanne les Journées francophones sur la prévention du rejet basé sur l'orientation sexuelle et l'identité de genre chez les jeunes (PREOS), en particulier en milieu scolaire. Il convient de noter que la manifestation était soutenue par l'Office fédéral de la santé publique, par deux cantons et huit villes. Quatre Ministres cantonaux chargés de l'éducation s'y sont exprimés, s'engageant à ce que la prévention de l'homophobie soit partie intégrante de l'enseignement. Bill Ryan, de l'Université McGill de Montréal, a illustré la manière dont au Canada la lutte dans ce domaine était efficacement menée.

Il est intéressant de penser au chemin parcouru. Dans les années 1980, un de mes collègues médecins cantonaux (= conseiller du Ministre de la santé) était prêt à recommander l'exclusion du corps enseignant d'une personne homosexuelle (indépendamment de tout acte discutable de sa part). Dans les années 1990, Pierre-André Michaud, spécialiste internationale reconnu de la santé des adolescents, m'appelait en demandant si nous pouvions « prendre le risque » de proposer à un jeune homophile de contacter le Groupes Jeunes de VoGay, association récemment fondée chez nous de personnes homosexuelles, pour discuter de son mal-être. Nous avons assumé la démarche, tout en sachant qu'il faudrait répondre, cas échéant, à des parents qui accuseraient un service officiel de pousser leur garçon « vers la débauche ». Ici, il faut rappeler l'action forte de groupes homosexuels dans la prévention du VIH/sida, à une époque où la médecine restait relativement impuissante, et les collaborations constructives établies alors avec la santé publique.

Alors que vers 1990 des gays me demandaient l'appuyer leur demande de passages dans les classes pour parler d'homosexualité, j'avoue avoir dit que

c'était imaginable dans l'avenir mais que, en l'état, cela me semblait illusoire; aujourd'hui, il y a de telles interventions dans des cantons suisses alémaniques. A fin 2010, la qualité du changement m'a frappé en apprenant que les Départements de l'éducation de Genève et Vaud (Lausanne) avaient nommé une déléguée pour les questions d'homosexualité (qui a publié un ouvrage sur son expérience d'enseignante - 1) : en vingt ans, on est passé du silence gêné sur le sujet à l'engagement explicite des pouvoirs publics contre l'homophobie – souvent dans un cadre plus large de droits humains et de lutte contre toute discrimination, y compris raciste. Affichette placardée dans des établissements scolaires de Genève : « Ici, on peut parler de diversité sexuelle ».

Point majeur : la reconnaissance, par la médecine notamment, de ce que pour l'essentiel l'homosexualité n'est pas un choix (même si des facteurs de contexte peuvent jouer un rôle dans des situations d'ambivalence). D'où le besoin de se distancer clairement des voix qui continueraient à prétendre qu'il s'agit d'une maladie ou un péché ! Voir à cet égard que les Gay Prides ont été, pour les homosexuels et plus largement les LGBT (lesbiennes, gays, bisexuels et transgenres), la manière d'affirmer, de façon parfois provocante, leur droit à la différence. « I have the right to be on the outside what I am on the inside », cite Bill Ryan.

A plusieurs égards, notre société et son cadre juridique sont vivement sollicités. Si on entend prendre en compte les faits scientifiques et sociaux, le refus, confirmé récemment par le Tribunal fédéral suisse, de permettre à un membre d'un couple homosexuel d'adopter l'enfant de l'autre est discriminatoire. Même si pour des raisons de croyance ou d'opportunité politique on peut chercher à retarder les évolutions, la société ne saurait décider d'ignorer la réalité. « Les faits sont têtus ».

L'Eglise catholique affirme que « le masculin et le féminin se révèlent comme faisant ontologiquement partie de la création » (2). Oui, mais cela ne saurait légitimer une opposition à la reconnaissance de ce qu'un certain nombre de nos congénères ne se retrouvent pas dans une catégorisation rigide et objectivement simpliste. Il y a un problème civil et civique de fond si des convictions erronées sont maintenues, contre l'évidence, dans les lois qui s'appliquent à tous (3).

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INTRODUCING THE BIPIC STUDY

Judging Best Interests in Paediatric Intensive Care: The Location, Basis & Scope of Decision-Making (BIPIC)

BIPIC is an empirical ethics study being undertaken toward a PhD in medical ethics. The project intends to get to the heart of decision making on paediatric intensive care. By exploring how different stakeholders perceive the “best interests” of children in acute dilemmas and by asking them to reflect on their own experiences, the study aims to uncover and compare their values and beliefs. Knowledge of how best interests are perceived will allow the creation of ethical guidelines that will improve the process and outcome of decision making in paediatric intensive care practice.

The BIPIC study is based at the University of Bristol and funded by the Wellcome Trust, a charity which aims to advance human health and wellbeing, through a biomedical ethics research fellowship. This is an award open to health professionals to bridge the career gap between clinical practice and an academic career in bioethics. The chief goal of the project is to improve both the way we make decisions on behalf of children and the quality of those decisions. Such goals are in keeping with investigator's professional and personal ambitions gained from working as a nurse in paediatric intensive care for a decade, for such goals are acutely important in clinical practice.

The concept of best interests is central to the way decisions are made about children who, because of their age or disability cannot give any indication of their wishes. In the United Kingdom paediatric intensive care, such children's “best interests” are decided between their parents, doctors and nurses, and, in acute dilemmas, clinical ethics advisory committees. In cases where no agreement is possible, the law courts have the final say. Yet the term “best interests” is not self explanatory, and although the concept is sometimes used as though it represents a monolithic concept, it has been employed by the law courts in widely varying ways in similar cases. The few empirical

studies that have taken place imply that it may also be employed by clinicians in different ways depending on the circumstances. The existence of such variations undermines claims that “best interests” represent a fair or consistent standard, and it is unclear on what basis agreement takes place. Meanwhile there are also significant financial and time critical elements that may make approaching the courts undesirable and add urgency to the need for a decision. In the face of such pressures the process of making critical decisions about children may be subject to manipulation by intransigent parties, and children's interests may become peripheral to the final outcome.

Despite these problems, when making decisions about children who, because of their age or illness, have no antecedent wishes or desires to take into consideration, it seems likely that we need some framework. It is instructive that, despite a number of alternative approaches being proposed within the bioethics literature, they appear to be not so much new approaches as different shades of existing best interest approaches. For all their imperfections, it may be the case that the concept of best interests is the best we can practically formulate.

From such a practical point of view, it is important to know what the different groups involved in formulating a judgement of a child's best interests actually mean when they use the term. The BIPIC study will attempt to uncover this by performing around 50 semi-structured interviews with stakeholders in order to better understand these meanings. The interviews will follow a topic list informed by the ethics literature and use vignettes to ensure that similar cases are considered by all groups. Such interviews will create rich data, which will be subjected to thematic analysis in order to uncover the ideas that underlie conceptions of best interests. Finally a process of reflective equilibrium will be used to formulate a description of best interests that is coherent with wider ethical theory and useful when faced with the realities of practice. Through such an empirical ethics technique the study will reveal consensus or disagreement that would otherwise be hidden, and ultimately inform us if it is useful to talk in terms of best interests. BIPIC will make the grounds for agreement between families and clinical staff more clear, and will allow us to gauge the capacity for consensus between different groups and the appropriateness of consensual decision making as a strategy in this circumstance. It will also influence the direction of normative theory by illuminating how well it fits the realities of practice and by highlighting which claims are credible within the practice environment.

BIPIC is in its early stages. A preliminary review of the literature has now taken place and is informing a topic list. The project is currently undergoing institutional

ethical review, with plans to begin interviewing participants in autumn 2012, with analysis and writing up of a doctoral thesis continuing until early 2015.

I would be interested to hear from anyone doing research in a similar area.

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PACT PROJECT



A new EU funded project analyzes the relation between privacy and security

The European Commission – under the scope of the 7th Framework Programme - Security Theme, has funded a new research project that aims at analyzing the complex relation between privacy and security. PACT, PUBLIC PERCEPTION OF SECURITY AND PRIVACY: ASSESSING KNOWLEDGE, COLLECTING EVIDENCE, TRANSLATING RESEARCH INTO ACTION, is a 36 month collaborative project whose mission is:

1. to assess existing knowledge about the relation between security and privacy and the role played by trust and concern;
2. to collect empirical evidence through a pan-European survey on the public perception of the relation between privacy, fundamental rights, and security, and to analyze the main factors that affect public assessment of the privacy implications of security technology;
3. to develop and validate an evidence-based Privacy Reference Framework for Security Technology and Decision Support System that may assist end users and policy makers to consider privacy and fundamental rights when they evaluate pros and cons of specific security investments.

On the basis of such an investigation, the project will develop and validate i) a Privacy Reference Framework for Security Technology, which is a new,

evidence based, framework for incorporating privacy, ethical, and social considerations into security policies; and ii) a prototype Decision Support System, which may help end users to evaluate pros and cons of specific security investments also on the basis of the societal perception of privacy and liberty.

The project's Kick off Meeting was held in Rome on the 20th and 21st February 2012. PACT brings together the critical mass of relevant skills and expertise in specialist areas, say, social science, privacy, policy analysis, empirical research and survey, DSS technology. The project partnership includes academia, public and private research centres, medium and large enterprises, end-users. The partners come from eight diverse EU member states (Belgium, Spain, Ireland, Greece, Italy, Sweden, United Kingdom, France) and two associated countries (Norway, Israel).

Overall they represent at the highest level all research skills and disciplinary competencies necessary to successfully carry out the project, to effectively disseminate its outcomes among stakeholders, policy makers, and the public, and to inject results directly into the policy matrix.

PACT CONSORTIUM

The PACT Consortium includes 11 partners:

- Centre for Science, Society and Citizenship (Italy) - coordinator
- VITAMIB (France)
- Atos Origin (Spain)
- Centre for Irish and European Security (Ireland)
- IPSOS MORI (United Kingdom)
- KEMEA - Ministry of citizens protection (Greece)
- Ministry for Public Security (Israel)
- NCSR - Institute of Informatics and Telecommunications (Greece)
- Rand Europe (United Kingdom)
- The Peace Research Institute Oslo (Norway)
- Uppsala University, Department of Informatics and Media Studies (Sweden)

For further information, please visit PACT website at www.projectpact.eu

TELL ME PROJECT



Public health communication during epidemics outbreaks: a new EU funded project to develop innovative communication strategies

After the mixed results of public health campaigns aiming to prevent the spread of flu during 2009 pandemics (and some controversies raised by vaccination and anti-viral drug campaigns), there is a need to revise the current wisdom about people behavior in pandemics, communication policies, and the involvement of health professionals. In order to address these issues, the European Commission has recently funded a new research project, called TELL ME: Transparent communication in Epidemics: Learning Lessons from experience, delivering effective Messages, providing Evidence. TELL ME will provide evidence and will develop models for improved risk communication during infectious disease crises, notably flu epidemics and pandemics.

The TELL ME project is a 36 month Collaborative Project, co-funded by the European Commission under the Seventh Framework Programme for Research and Development (Grant Agreement n° 278723). It will develop innovative communication strategies encapsulated in an integrated Communication Kit for outbreak communication. The Communication Kit will then be tested through the use of innovative social simulation software, specifically designed by TELL ME to allow policy makers and decision takers to plan in advance communication policies and strategies during future flu outbreaks.

On March 1st and 2nd 2012 the project's kick off meeting was held in Rome. TELL ME gathers twelve institutions, including universities, national institute of health, media and communication companies, research centres, professional organizations, civil society organizations, representing eight countries (Belgium, France, Hungary, Israel, Italy, Latvia, United Kingdom, United States), and several different disciplines. As a whole the TELL ME team combines the highest expertise in different fields, creating a virtual centre of excellence on public health communication during epidemics.

During its 3 years of activity, TELL ME will answer three distinct research questions.

1. How can the general population be persuaded through public health communication to take effective preventative actions (e.g., vaccination, antiviral therapy, hygienic norms, etc.)?
2. What are the most appropriate communication methods to deal with complexity, uncertainty, ignorance, information asymmetries, overwhelming information, biased information, misinformation and malicious information?
3. What are the best communication strategies to support vaccine uptake, and to assist health professionals and agencies to engage with vaccine-resistant groups?

The TELL ME consortium aims to maximize opportunities and minimize risks, by creating conditions for exploiting the huge potential that the information society can offer in terms of participatory communication during epidemics and in epidemic preparedness. We aim at promoting transparent communication by delivering evidence-based messages and by involving both citizens and health professionals in decision-making processes.

TELL ME CONSORTIUM

Centre for Science, Society and Citizenship, CSSC (Italy) – Coordinator
Vitamib (France)
School of Public Health at the University of Haifa, SPHUH (Israel)
National Centre for Epidemiology, Surveillance and Health Promotion, CNESPS (Italy)
Bmj Publishing Group Ltd, BPM (United Kingdom)
CEDARthree Ltd, C3 (United Kingdom)
European Union of General Practitioners, UEMO (Belgium)
Latvian Centre for Human Rights, LCHR (Latvia)
Vrije Universiteit Brussels, VUB (Belgium)
National Disaster Life Support Foundation, NDLSF (US)
Zadig Ltd (Italy)

For further information on the TELL ME project please visit www.tellmeproject.eu

BOOK REVIEW

Catherine Myser (Ed.). Bioethics around the Globe

**New York: Oxford University Press, 2011
294 pages, ISBN 978-0-19-538609-7**

Discussed since around 1970 in the US, bioethics has been exported to developed and then developing countries, often within a paradigm of building "ethics capacity". This has occurred so rapidly that, the editor says, "there has been no adequate opportunity for self-study, self-critique and self-correction"

Catherine Myser, whose background is in philosophy/bioethics and anthropology, and who worked in medical schools and hospitals in six countries, has invited colleagues to analyze the cultural meanings and social functions of bioethics theories, practices and institutions around the globe. Recognizing that bioethics is contingent on culture, politics, economics, religion, history, the book aims to explore whether bioethics "genuinely serves the society in which it is discussed and practiced, rather than imposing unexamined values". This has to do with possible hidden agendas: governmental,

professional, religious, socio-cultural, you name them, linked to internal or external factors.

Bioethics around the globe presents studies on nine developing countries and five developed ones: in Asia, Africa, the Middle East, Latin America, North America, Australia and Europe. Fifteen authors out of 27 stem from Anglo-Saxon countries, seven from African and Latin America and five from Asia and Continental Europe. While these authors are involved in interdisciplinary endeavours, twelve of them are by training bioethicists/philosophers, ten social scientists and five physicians.

The book has four sections: the first one deals with the globalization of Western bioethics and what might be called "missionary bioethics" (I suppose that, adequate or not, this expression will be readily understood); with a chapter by DeVries and Rott presenting a general view (including possible unwitting harms of exporting the gospel) and two about India and Sri Lanka (the latter describing in particular efforts at capacity building). Section Two, under the heading of sociocultural interests and forces shaping bioethics, has chapters on the status and evolution of bioethics in France, the UK, Central Europe, Latin America (Chile and Costa Rica), South Africa, Malawi and China.

In France the factors shaping bioethics, with very little input from the lay public, are according to K. Orfali: a) its centralized State, trusted as the appropriate defender of the public good and in charge of implementing values such as human dignity and solidarity; b) the medical profession, remaining strongly paternalistic (even if things slowly change); the professionalization of bioethics (training bioethicists as such) is often still rejected. Orfali considers, contrary to a common idea, that the above factors are more influential than the Catholic Church. While the Catholic hierarchy wields major influence, often decisive, in several Latin American countries; as an example, according to Kottow and Russo, the "sanctity of life" claim is biasing there the discussion of several bioethical issues. In another respect, the current pushes (and "fashion") for private/for profit health care raise significant bioethical and social justice concerns in many countries.

Philosopher van Niekerk and physician Benatar describe how South African bioethics, after originating as "spillover" from British and European institutions, has along with the liberation struggle become linked to more indigenous concerns. In the next chapter, Mfutso-Bengo and Masiye, from Malawi, would like a reorientation towards indigenous traditions and morals, in the form of an African ubuntu (meaning being humane) bioethics; contrasting the communalistic Bantu values with the individualistic Western ethical

theory. The importance of decision-making in the family or social grouping is discussed in other chapters too, e.g. those about India and China; these authors deplore that Western thought and scholarship generally is not ready to give an adequate place to that societal fact. Qiu Renzong, from China, proposes a "reconciliation approach".

Section Three has two chapters, illustrating how bioethics might be a means for negotiating social, regional and/or national identity, and a tool for nation-building. This is done about Canada and Egypt - with, for the latter, special regard to the search for an Islamic bioethical identity, contesting the West as well as Saudi Arabia influences. Section Four shows how bioethics can become a battleground for religious and political "Culture Wars": with two chapters, on Australia and the United States, with particular consideration of the role of the conservative Christian Right and vs liberal views (it is said that the Christian Right perceives to be under siege in Australian society and politics, with the debate about embryonic stem cells described as an exemplary case). In the USA chapter, interesting discussion by Jennings and Moreno of "autonomy liberalism" vs "identity liberalism", which more highly values tolerance, mutual respect and social cooperation.

The author of this review (who happens to be a member of UNESCO's International Bioethics Committee) has been interested to read Prof. S. Chattopadhyay, from India (University of West Bengal), having measured consideration for the UNESCO Universal Declaration on Bioethics and Human Rights, adopted in 2005, marked in his view by moral imperialism : "Furthermore, from the perspective of billions of individuals who badly need public health measures, the idea that the interests and welfare of the individual should have priority over the interests of family and society is an absurd, if not dangerous, proposition " Well, strong words... the debate is certainly not about to be concluded regarding the substance and range of universal ethical values on the one hand and, on the other hand, what can legitimately be different from one culture to the other. It is a reminder that bioethics cannot be adequately elaborated and practiced without ongoing contacts and experience "in the field", in the practice of care in varied settings.

The purpose of Bioethics around the globe is not to present and discuss current bioethical issues, giving the argumentation of diverse stances on each subject ; it is looking at bioethics from sociological, anthropological and political science perspectives. It is a worthwhile contribution to self-reflection by all concerned, an apt introduction to the needed degree of relativism. I well know that, for a number of colleagues,

relativism is a bad word, if not anathema, meaning in their view that one is ready to dilute or put aside essential tenets of modern human rights. Yet, we in the North/West certainly haven't given the adequate weight to other frames of reference (the fact that documents by the United Nations and UN agencies have been approved by the community of governments notwithstanding). In their chapter, De Vries and Rott underline the need for "bioethics from below", suggesting that much of today's bioethics revolves around issues that, while fascinating, affect only a small minority of the world's population. Indeed, as compared with the pressing issues confronting developing regions, the themes of many heated debates in industrialized countries appear of modest importance.

The book is well written, agreeable to read and includes a detailed index. All in all, in several respects, a necessary book, which can be recommended to those concerned with bioethics everywhere, even if their involvement is limited to a country or region.

Dr Jean Martin
Member of the Swiss National Bioethics Commission
and of UNESCO International Bioethics Committee

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INTENSIVE COURSE ON FOUNDATIONAL APPROACHES, CONTEMPORARY AND EDUCATIONAL ISSUES IN THE FIELD OF NURSING ETHICS

Leuven, Belgium, 5-7 December 2012

The Centre for Biomedical Ethics and Law (of KU Leuven) is organising an intensive course on Nursing Ethics. The objective of the course is to foster exchanges on foundational and methodological approaches as well as on contemporary and educational issues in nursing ethics. This course works from an interdisciplinary (philosophical, theological, nursing, clinical-ethical) perspective.

During the course, national and international experts will give presentations on various topics in the domain of nursing ethics. There will be time for intensive discussions. The language of instruction will be English.

The course is of interest to participants from diverse professional backgrounds, such as nursing, medicine, philosophy and theology, health care administration,

and PhD students undertaking courses of study in these areas. The intensive course Nursing Ethics is part of the Erasmus Mundus Master of Bioethics programme organised by a consortium of three European universities, namely the KU Leuven (Belgium), Radboud Universiteit Nijmegen (The Netherlands) and the Università degli Studi di Padova (Italy). Because of this combination, participants of the intensive course Nursing Ethics, will join Master students from all over the world.

The course fee is € 650 if you register and pay as a participant before October 15th 2012, € 750 for registration and payment from October 15th 2012 onwards. This fee includes tuition and course materials, as well as refreshments, three lunches, a dinner and a concert in the Concert hall of Bruges. Detailed information on registration and payment can be found at our website www.masterbioethics.org under Intensive Courses.

Kind regards,

Professor Chris Gastmans (course coordinator)
Chantal De Keersmaecker (programme manager
Erasmus Mundus Master of Bioethics)

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ANNOUNCEMENTS

In 2012 the annual EACME conference will take place in Bristol (UK) 20-22 September 2012.

Celebrating 25 years of EACME!
The host will be the Centre for Ethics in Medicine.

The main topic for the conference will be: Other Voices, Other Rooms: Bioethics, then and now.

For more information: www.eacme2012.org

2012 registration is open and the early bird rate expires on Friday 1 June.

Call for papers - Collective Intentionality VIII – University of Manchester (UK) – August 28th-31st, 2012

Please send drafts (abstracts if preferred), for blind review to collintviii@manchester.ac.uk by 1st June 2012. Notification of acceptance by 1st July 2012.

Conference webpage:

<http://www.socialsciences.manchester.ac.uk/discipline/philosophy/events/ci/>

European Clinical Ethics Network Summer school on Clinical Ethics Support Services, 2-8 September 2012

The venue will be in the **Italian Dolomites**.

More information is also available at:

<http://www.vumc.com/afdelingen/Medical-Humanities/MoralCaseDeliberation>

DEADLINE NEXT NEWSLETTER

Deadline for the second edition of 2012:

AUGUST 15, 2012

If you wish to promote an event, or to inform your EACME-colleagues about the results of your work, descriptions of projects, book reviews etc. Any good ideas?

Don't hesitate to contact editor Rouven Porz: rouven.porz@insel.ch or Angelique Heijnen: a.heijnen@maastrichtuniversity.nl

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