

# EACME Newsletter

European Association of Centres of Medical Ethics

Executive Office: Angelique Heijnen  
Maastricht University, Dept. Health, Ethics and Society  
Faculty of Health Medicine and Life Sciences  
P.O. Box 616  
6200 MD MAASTRICHT, THE NETHERLANDS  
Tel: +31 43 3882145  
Fax: +31 43 3884171  
A.Heijnen@maastrichtuniversity.nl  
www.eacmeweb.com



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## EDITORIAL

### The power of images

The year 2011 is coming to an end. Some of you will celebrate Christmas, others won't, but none of us can withdraw from the enormous advertisement campaigns which roll over shops, stores and supermarkets. Incredibly colorful, overwhelming, 'buy this', 'you need that', 'this is a "must have" for this year's Christmas party', pictures of happy families and images of happy kids receiving their Christmas presents – well, we guess most of us are more than skeptical about the seductive images which pretend to tell us meaningful stories about the happiness of seemingly "good" families. Stories, narratives, pictures, meaning-making - we can offer you something more interesting inside this newsletter: Jan Sitvast investigated the role of photography to assist psychiatric patients in making sense of their illness experiences. He speaks of "hermeneutic photography". Participants were instructed to make photographs of what they value as important in their lives. These photographs were then used for further exploration of the photographer's subjective experiences. He reports that some patients then progressed in reconstructing their live stories, and that their research approach helped the patients to better re-conceptualize future life plans. This might be a new way to think about photos in a clinical setting and it proves that bioethicists can be innovative in combining common technologies within new settings and in relation to new applications. That brings us to another interesting point of this newsletter. New settings, new applications, the discipline of bioethics is steadily growing older, bioethics' identity is constantly changing and we will discuss these issues when we meet in Bristol next year for the 2012 EACME conference. It is not just another EACME conference, it is a celebration of the 25-years-history of EACME. We are very much looking forward to this and you find a



d'entre nous qui sont à l'interface entre les soins, la réflexion éthique et les milieux civils et politiques savent qu'il est difficile de convaincre ces derniers de donner une attention prioritaire à des problématiques bioéthiques.

A cet égard, il était bon qu'une session soit consacrée à la Convention européenne sur la biomédecine (Oviedo, avril 1997). Aysegul Elveris a rappelé que la Convention découle des grands principes que sont en particulier la dignité humaine, la protection de l'intégrité personnelle et le respect de la vie privée. On a parlé de son application en Turquie, y compris en ce qui concerne le droit du patient de refuser un traitement, qui reste controversé dans le pays. Richard Ashcroft a souhaité que les droits humains deviennent une « lingua franca » en bioéthique – comme ils devraient l'être en santé publique.

Quelques mots enfin sur les conférences de la dernière séance plénière : Yvonne Denier, jeune philosophe-éthicienne belge, s'est demandée ce que signifie « Justice » dans le domaine de la santé, en comparant les positions principales de la littérature ; Nikola Biller-Andorno (Zurich) a fait référence à la Déclaration d'Istanbul de 2008 sur le trafic d'organes et le tourisme de la transplantation, en expliquant les raisons pour lesquelles il importe d'appliquer, de maintenir et de surveiller la règle de la non-commercialisation des organes, rein notamment.

La prochaine conférence sera organisée par le Centre for Ethics in Medicine de l'Université de Bristol, Grande Bretagne, du 20 au 22 septembre 2012. Son directeur le Prof. Ruud ter Meulen a invité les participants à s'y retrouver.

Dr Jean Martin

Membre du Comité international de bioéthique de l'UNESCO  
La Ruelle 6  
CH-1026 Echandens, Suisse

[jean.martin@urbanet.ch](mailto:jean.martin@urbanet.ch)

**2012 ANNUAL CONFERENCE OF EACME IN  
BRISTOL 20 – 22 SEPTEMBER 2012**

Dear EACME members

It is a great pleasure and honour to invite you to the 2012 Annual Conference of EACME in Bristol. Bristol is a vibrant city located in the South-west of the United Kingdom, between Somerset in the South, Gloucestershire in the North, Wiltshire in the East and

the Welsh border in the West. Bristol has a history that goes back to the 11<sup>th</sup> century and there are still many old buildings and pubs to be seen. Bristol is well known because of its harbour (river Avon), the famous suspension bridge built by Brunel in the early 19<sup>th</sup> century, its University, and very recently because of its colourful and impressive street art (Banksy). Bristol has an international airport with many connections to the continent, is easy to reach by train or coach (for example from London Heathrow), and, for those who want to come by car, is conveniently located at the crossing of the M4 and M5 motorways.

The EACME conference will be organised by the Centre for Ethics in Medicine, founded in 1996 and located in the Faculty of Medicine and Dentistry. The Centre is one of the old members of EACME and has been contributing regularly to its annual conferences. The Centre has a strong reputation in national and particularly European research projects. It also boasts an extensive teaching portfolio, which includes significant input into the Medicine (MBChB) programme at Bristol, alongside programmes dedicated to the study of bioethics and health care ethics.

This 2012 conference will celebrate the first 25 years of the existence of EACME. This conference will celebrate and reflect on the many contributions made in and to European bioethics to date. The objective is to get a better understanding of the academic and social status of bioethics as it is being supported and practiced by various disciplines, applied to a wide range of areas and, after 25 years, still searching for its own identity. The conference theme, "Other voices, other rooms" is borrowed from Truman Capote's novel, which deals with issues of coming of age, including embracing one's identity, understanding others, caring and being cared for, searching for oneself and for those to whom one is relationally bound. The Conference speakers and participants will investigate how these issues reflect on the identity of European medical ethics, and the many places and people with whom it is intimately bound. "Other voices, other rooms" is therefore the theme for this conference, which wants to celebrate and investigate the many contributions which have made been to date, and speculate about the developments we might anticipate as European bioethics continues to evolve and expand.

I hope that many EACME members and non-members will come to Bristol to contribute to the conference by making a presentation, taking part in the discussions, to have dinner at Brunel's Steamship Great Britain, or to relax at the terrace of Wills Hall looking over the lawns of the Bristol Downs.

<http://www.eacme2012.org>

With very best wishes

Ruud ter Meulen



Chair/Director Centre for Ethics in Medicine

School of Social and Community Medicine  
University of Bristol  
Canyng Hall  
39 Watley Road

Bristol BS8 2PS  
United Kingdom

T: +44 117 3314512

[r.terMeulen@bristol.ac.uk](mailto:r.terMeulen@bristol.ac.uk)

**IntegratedEthics:  
AN INNOVATIVE AND COMPREHENSIVE MODEL  
FOR ETHICS IN HEALTH CARE**

“IntegratedEthics” is an innovative model for ethics in health care organizations that was developed by the National Center for Ethics in Health Care within the Department of Veterans Affairs (VA). VA’s health care system is a Federal government organization that provides health care to U.S. Military Veterans. Serving almost 8 million enrolled patients, VA’s health care system is the largest in the United States.

The IntegratedEthics model has been implemented in all of VA’s hospitals and regional networks throughout the U.S. The model is being continuously expanded and improved. A broad array of resources are available online including training materials, videos, evaluation tools, pocket reference guides, and tools to assist with program implementation ([www.ethics.va.gov/IntegratedEthics](http://www.ethics.va.gov/IntegratedEthics)).

As the most systematic and comprehensive program of its kind, IntegratedEthics has received substantial international attention. Elements of the program are being replicated and/or evaluated by organizations ranging from Kaiser Permanente of Southern California to Hamilton Health Sciences in Canada to the Health Ministry of Taiwan. IntegratedEthics was also selected as one of the "Top 25 Programs" in the 2011 Innovations in American Government Award competition conducted by the John F. Kennedy School of Government at Harvard University.

IntegratedEthics is based on management science, principles of continuous quality improvement, and strategies for organizational change that have been proven effective in other fields. The IntegratedEthics

model addresses the full range of health care ethics issues - including ethical practices in end-of-life care, resource allocation, and health care business and management - In a comprehensive, holistic fashion. IntegratedEthics, as implemented in VA, establishes clear standards, roles, competencies, methods, and performance metrics for ethics in health care. These and other tools enable health care leaders to manage ethics in much the same way as they manage other organizational imperatives.

The essential purpose of IntegratedEthics is to improve ethics quality in health care. When most people think of health care quality, they think of technical quality, such as clinical indicators, and service quality, such as patient satisfaction. But ethics quality is equally important. Ethics quality means that practices throughout an organization are consistent with widely accepted ethical standards, norms, or expectations for the organization and its staff. These practices are set forth in organizational mission and value statements, codes of ethics, professional guidelines, consensus statements and position papers, public and institutional policies.

**The IntegratedEthics Model**



The ethics quality of an organization can be illustrated by the image of an iceberg. At the surface of the ethics quality iceberg are easily observable *decisions and actions* in the everyday practices of an organization and

its staff.

Beneath that, organizational *systems and processes* drive decision making. But these factors are not readily visible – they become apparent only when one looks for them.

Deeper still lie the organization’s ethical *environment and culture*, which powerfully but nearly imperceptibly shape ethical practices. This deepest level consists of values, understandings, assumptions, habits, and unspoken messages – what people in the organization know but rarely make explicit. This level is critically important because it is the foundation for everything else.

Traditional ethics programs often make the mistake of spending too much time focusing on the most visible ethics concerns (i.e., the “tip of the iceberg”). However, to have a lasting impact on ethics quality, ethics programs must address the deeper organizational factors that influence observable practices. Only then will they be successful at improving ethics quality organization-wide.

The IntegratedEthics model is structured around three “core functions,” each of which targets a different level of ethics quality. The *ethics consultation* function addresses questions about ethical *decisions or actions*, providing assistance to patients, families, and staff. The *preventive ethics* function gives staff a step-by-step method for improving *systems and processes* that cause ethics quality gaps. And the *ethical leadership* function helps leaders to create an ethical *environment and culture* that inspires employees to “do the right thing.”

The remainder of this article will focus on the first core function of IntegratedEthics—ethics consultation.

### **ETHICS CONSULTATION: Responding to Ethics Question in Health Care**

In the IntegratedEthics model, ***ethics consultation in health care*** is defined as *a service provided by an individual ethics consultant, ethics consultation team, or ethics committee to help patients, staff, and others resolve ethical concerns in a health care setting*. The overall goal of ethics consultation is to *improve health care quality by facilitating the resolution of ethical concerns*. By providing a forum for discussion and methods for careful analysis, effective ethics consultation:

- promotes practices consistent with high ethical standards;
- helps to foster consensus and resolve conflict in an atmosphere of respect;

- honors participants’ authority and values in the decision-making process; and
- educates participants to handle current and future ethical concerns.

### **The CASES Approach**

In IntegratedEthics, ethics consultants use the CASES approach – a practical, systematic, step-by-step approach to consultation. The CASES steps were designed to guide ethics consultants through the complex process needed to effectively respond to ethical questions and concerns.

#### **The CASES Approach**

##### **CLARIFY** the Consultation Request

- Characterize the type of consultation request
- Obtain preliminary information from the requester
- Establish realistic expectations about the consultation process
- Formulate the ethics question

##### **ASSEMBLE** the Relevant Information

- Consider the types of information needed
- Identify the appropriate sources of information
- Gather information systematically from each source
- Summarize the case and the ethics question

##### **SYNTHESIZE** the Information

- Determine whether a formal meeting is needed
- Engage in ethical analysis
- Identify the ethically appropriate decision maker
- Facilitate moral deliberation about ethically justifiable options

##### **EXPLAIN** the Synthesis

- Communicate the synthesis to key participants
- Provide additional resources
- Document the consultation in the health record
- Document the consultation in consultation service records

##### **SUPPORT** the Consultation Process

- Follow up with participants
- Evaluate the consultation
- Adjust the consultation process
- Identify underlying systems issues

For details about the CASES approach, see: [www.ethics.va.gov/docs/integratedethics/Ethics\\_Consultation\\_Responding\\_to\\_Ethics\\_Questions\\_in\\_Health\\_Care\\_20070808.pdf](http://www.ethics.va.gov/docs/integratedethics/Ethics_Consultation_Responding_to_Ethics_Questions_in_Health_Care_20070808.pdf)

### Ethics Consultation Tools

IntegratedEthics includes tools to assist practitioners in using the CASES approach. These include a trifold pocket card for easy reference that outlines the details of each step in CASES

([www.ethics.va.gov/docs/integratedethics/Ethics\\_Consultation\\_CASES\\_Pocket\\_Card--20070228.pdf](http://www.ethics.va.gov/docs/integratedethics/Ethics_Consultation_CASES_Pocket_Card--20070228.pdf)).

IntegratedEthics also provides assessment tools and educational materials to help consultants enhance their proficiency and to improve the overall effectiveness of the consultation team.

In VA, ECWeb is a key tool for systematic analysis and understanding of ethics consultations. ECWeb is a secure intranet-hosted database software program. It is currently used by over 1700 ethics consultants throughout VA. Used locally to document ethics consultations, ECWeb reinforces the CASES approach, helps ethics consultants manage consultation records, and supports quality improvement efforts.

For example, it allows an ethics consultant to easily review content from prior cases for applicability to new cases. It tracks whether service requesters have provided post-consultation feedback on satisfaction with the quality of the service. And it allows the local service to review summative feedback from requesters to determine the effectiveness of efforts to improve service quality. At the national level, ECWeb allows for ethics consultation data compilation across the entire VA system. Since ECWeb went live in 2008, VA ethics consultants have recorded over 5000 consultations in ECWeb.

Feedback from consultation requesters is vital to improving ethics consultation quality. In VA, consultants are encouraged to seek feedback for all consults using a standardized feedback tool

([www.ethics.va.gov/docs/integratedethics/Ethics\\_Consultation\\_Feedback\\_Tool\\_20110822.doc](http://www.ethics.va.gov/docs/integratedethics/Ethics_Consultation_Feedback_Tool_20110822.doc)). Currently, 25% of ethics consultations in ECWeb have had evaluation feedback from at least one individual (e.g., patient, family member, or staff). That number has been steadily rising since 2008. As consultation services have begun to measure and review their feedback, quality improvement has followed. For example, in 2008, 79% of requesters rated the ethics consultation service as excellent or very good for being easy to get in touch with - rising to 91% by 2011. Likewise, very good or excellent ratings of whether the service was timely enough to meet the requester's needs rose from 74% to 87% over the same time period.

Another important way to improve ethics quality is to ensure that ethics consultants are competent. The Ethics Consultant Proficiency Assessment Tool, which was based on a 2011 report by the American Society for Bioethics and Humanities entitled *Core Competencies*

for Healthcare Ethics Consultation, is designed to help ethics consultants assess their own proficiency in the skills and knowledge that are needed to provide competent health care ethics consultation. In VA, each ethics consultant is required to complete the tool then work with ethics consultation service leaders to create an individualized professional development plan. ([www.ethics.va.gov/docs/integratedethics/Ethics\\_Consultant\\_Proficiency\\_Assessment\\_Tool\\_20110921.doc](http://www.ethics.va.gov/docs/integratedethics/Ethics_Consultant_Proficiency_Assessment_Tool_20110921.doc))

Through tools like ECWeb and the ethics consultation feedback tool, and programmatic standards set by VA policy

([www.va.gov/vhapublications/ViewPublication.asp?pub\\_ID=2035](http://www.va.gov/vhapublications/ViewPublication.asp?pub_ID=2035)), IntegratedEthics has brought a practical sensibility to the management of ethics in health care organizations. More information about IntegratedEthics can be found at: [www.ethics.va.gov/IntegratedEthics](http://www.ethics.va.gov/IntegratedEthics) or by contacting [vhaethics@va.gov](mailto:vhaethics@va.gov).

Authors: Melissa M Bottrell, MPH, PhD and Ellen Fox, MD

Melissa M. Bottrell, MPH, PHD

Chief, IntegratedEthics  
National Center for Ethics in Health Care  
Washington DC 20420 USA

Ph/Fax: 510-525-0979

[Melissa.Bottrell@va.gov](mailto:Melissa.Bottrell@va.gov)

### AUTORITARISME MORAL DANS LE DOMAINE MÉDICO-SOCIAL – EN SUISSE, UNE ATTAQUE REGRETTABLE EN RAPPORT AVEC L'INTERRUPTION DE GROSSESSE

La Suisse connaît le système de l'initiative populaire, par lequel le gouvernement est tenu de soumettre à votation populaire tout texte (proposant une modification constitutionnelle) qui a été soutenu par la signature de 100'000 citoyens. Dans ce cadre, on a appris en septembre 2011 qu'une initiative avait abouti qui entend retirer l'interruption de grossesse (IG) de la liste des prestations prises en charge par l'assurance-maladie sociale. Les initiants ne demandent pas à ce stade l'abolition du régime du délai qui est le nôtre suite à un vote populaire de 2002 (IG possible sur demande de la femme jusqu'à 12 semaines de grossesse). Toutefois, il est manifeste que les milieux (de type « droit à la vie ») qui ont lancé l'initiative actuelle sont ceux qui avait fait campagne contre le régime du délai, et dont les positions rigides en la matière, dans une sorte d'enfermement, sont de

notoriété publique. Bien intentionnées à première vue, leurs démarches tendent à réintroduire dans nos sociétés une sorte d'autoritarisme vertueux contrôlant les corps aussi bien que les consciences. Après des échecs antérieurs, les initiants ont choisi de porter le débat sur un terrain limité auquel l'électeur est sensible, à savoir la réduction des coûts ; affirmant que ce n'est pas aux bon(ne)s citoyen(ne)s de payer pour les hédonistes sans morale qui ont trop facilement recours à l'IG... NB : pas nécessaire de s'attacher à une évaluation quantitative fine pour apprécier que le coût global de l'IG ne pèse pas lourd dans la facture de la santé.

On ne peut que rester perplexe quand, en 2011, des dizaines de milliers de signataires d'initiative ignorent à tel point les difficultés suscitées, chez des femmes, dans les couples et les familles, par une grossesse lourde à porter ; la perplexité devient un vrai choc quand les signataires sont des femmes. Consciemment ou pas, on choisit de ne pas donner attention à quelques éléments : 1) aucune femme ne subit une IG par plaisir ; 2) personne n'aime l'IG, qui est toujours un échec mais qui, selon les circonstances et conditions de vie, est compréhensible ; 3) une carrière de santé publique m'a démontré comme à beaucoup d'autres que le régime du délai est la moins mauvaise solution légale. De loin, étant entendu qu'il n'y pas de solution idéale au fait social de la grossesse problématique. Les régimes punitifs que tant de pays ont connus ne font que multiplier les IG clandestines et leur cortège de complications et de morts.

Le grand William Osler parlait des « maladies sociales avec des aspects médicaux ». A propos de tuberculose et de maladies infectieuses liées au manque d'hygiène, de malnutrition et ses conséquences et d'autres pathologies où pauvreté et précarité jouent un rôle prédominant. D'un point de vue de santé publique, l'interruption de grossesse entre pour beaucoup dans un tel cadre, avec une importante dimension psycho-sociale.

En retirant de l'assurance de base la prise en charge financière de l'IG, on ferait de ces femmes des réprouvées. Il importe aussi de savoir que l'IG est plus fréquente dans les milieux défavorisés, parce que jeunes filles et femmes y sont moins informées et ont moins accès au planning familial. Le différentiel social (des risques de difficultés et de malheurs comme, à l'inverse, des chances de disposer aisément des moyens de se sortir d'un mauvais pas) est ici majeur. Et il est attristant de constater que des gens affirmant des convictions chrétiennes soutiennent une initiative insensible à la réalité et qui creuserait un peu plus les inégalités.

NB : Au cours des trente dernières années, le nombre d'interruptions de grossesse en Suisse a nettement baissé, d'un tiers ; ceci est dû en particulier aux bons services d'éducation sexuelle à l'école et de planning familial mis en place. On rappelle aussi qu'il est démontré que des jeunes qui ont bénéficié d'éducation sexuelle ont des relations sexuelles moins précoces, moins fréquentes et moins à risque que leurs congénères qui n'en ont pas eu. De plus, le nombre d'IG n'a pas augmenté depuis l'introduction du régime du délai et le taux d'interruptions en Suisse est un des plus bas d'Europe.

Dr Jean Martin

Membre du Comité international de bioéthique de l'UNESCO  
La Ruelle 6  
CH-1026 Echandens, Suisse

[jean.martin@urbanet.ch](mailto:jean.martin@urbanet.ch)

**DIGNITY IN CARE: ENHANCING ETHICAL PRACTICE AND CRITICAL REFLECTION THROUGH THE sTimul EXPERIENCE IN A CARE-ETHICS LAB**

INTERREG IV A "2 Mers Seas Zeeën" Project 7-029-BE\_Dignity in care

This project brings together six partners from four nationalities and three languages.

The project leader KAHO Sint-Lieven (Ghent, Flanders - B) has gathered together several European partners including the sTimul: care-ethics lab in Moorsele (Flanders - B), Lille Catholic University, France, via the Centre of Medical Ethics at the Ethics Department as well as its health institutions and health training facilities, Stichting Hogeschool Zeeland (Vlissingen) and ZorgSaam Zeeuws-Vlaanderen (Terneuzen) in the Netherlands, and East Dorset Council which houses Partners in Care (Bournemouth, UK).

The main objective of this project, which is taking place over 3 years, is to further ethical thought on 'care practices' of students and professional caregivers (doctors, nurses, nursing aides, physiotherapists, etc.) by building on the experiences gained in an care-ethics laboratory called "sTimul." This laboratory allows for the simulation of a primary care environment in which students in the medical and medical-social fields, who take on the role of health professionals, can have firsthand experience of the impact care practices have on patients "role-played or simulated" by health care professionals. The purpose of this project is to improve participants' ability to adopt good care practices which best respect the dignity of patients, especially that of people with chronic diseases, disabilities or addictions.

The focus is the manner in which care is provided. It is about attitude more than the necessary technical and clinical skills.

This project holds true to the priorities; these being improving quality of life and population-related services through developing good practices at the heart of institutions.

It will allow us to develop an understanding of ethics where care-ethics practices combine the importance of emotional involvement in ethics and an ethics code conscious of reflective thought on care practices. It will promote an approach to training built on experience and vocational based learning, training activities focused on knowledge of care giving and receiving, simulating a care practice environment in which (medical and medico-social) professionals and students can experience the impact of care practices in an direct way, and reflection and analysis of the simulation experience.

Such a project is underpinned by an understanding of care-ethics; it is both context-based and reflective and can be taken as reflective training.

Ethics of care ...

Care is concerned with looking after others through actions that meet to needs of their vulnerability. Here, we find the concept of assisting others. The "different voice" of ethics of care reminds us that vulnerability is a component of human life, which implies the need for a different ethics approach focusing on examining particular situations and putting an end to ethical principles in order to take a more question-based approach. In this way, according to Pascale Molinier, taking care of others implies "carrying out a certain type of task that is directly involved in looking after and preserving the life of another." It allows the other person to "concentrate on his or her proper interests." When dealing with issues of vulnerability and fragility, it provides the conditions necessary for encouraging patient autonomy. Care is therefore a work process and not simply a moral disposition.

...context-based and reflective at the same time...

This ethics of care approach is intended to be both context-based and reflective. Context-based because ethics is a critical reflection on human action taken in light of the complexity of its determining factors. Our belief is that ethical questions arise from the very heart of human activities and that those concerned provide or have already provided answers by drawing from their own resources. This approach can therefore be described as context-based. Reflective because and ethical approach must allow us to go back to the activity in order to understand, evaluate and transform it.

...taken as reflective training

A context-based and reflective approach such as this can therefore be called a reflective learning process, which consists of setting up:

- places where we can conduct necessary experiments in order to learn how to work together to draw up to most suitable shared ways of life.
- places for developing some form of collective understanding.

In this way, it promotes an ethical approach based on the ability of the people involved to build solutions through a continuous process of learning.

Leen Stevens, project leader (KAHO Sint-Lieven, Ghent) and Pierre Boitte, regional project leader (Centre of Medical Ethics, Lille Catholic University)

[www.dignity-in-care.eu](http://www.dignity-in-care.eu)

Pierre BOITTE  
Professeur d'éthique médicale  
Centre d'éthique médicale du Département d'éthique /  
Faculté Libre de Médecine  
Université Catholique de Lille  
41, rue du Port  
59046 Lille cedex  
France

[pierre.boitte@icl-lille.fr](mailto:pierre.boitte@icl-lille.fr)

## PHOTOGRAPHY AS A NURSING INSTRUMENT IN MENTAL HEALTH CARE

### How to use clients' photo stories for recovery.

The general aim of the thesis was to examine how nurses can use photography to assist psychiatric patients in making meaning of experiences of illness and to help them in the process of recovery. The study is based on a hermeneutic-phenomenological perspective, focusing on processes of experiencing and meaning making in the life world. Existential issues, e.g. the way how people give meaning to their suffering, play an important role in this process of being-in-the world. Caring can be seen as rooted in the nurses' response to the suffering of patients, which we conceptualized as a lack of agency (Ricoeur, 1992). 'Agency' concerns the extent of direction people feel in exercising influence on domains of their lives that matter to them. Patients' suffering compromises their agency to direct their own lives (being impeded by the impact of illness). By responding to their needs and constructing a shared understanding, nurses empower patients and strengthen their agency. Creating a shared understanding with patients about their

suffering and their needs is rooted in narrative through which processes of meaning making of suffering and recovery finds expression.. Narratives are relational. Relational narratives are developed through dialogical interaction. Relational narratives were realized through using hermeneutic photography.

More concretely we examined our application of hermeneutic photography: the photo-instrument. The intervention contains individual assignments to make photographs. The results are discussed in group meetings. At the start the participating patients receive a disposable camera. The first assignment instructs participants to make photographs of what they value as important in their lives here and now. These photographs are then used for further exploration of the photographer's subjective experiences. In a number of group sessions facilitated by two health workers (e.g. a nurse and an occupational therapist) participants select photographs and stories that belonged to them for an exhibition aiming at a wider public. Every participant presents his or her own photo-story. After the exhibition the cycle is repeated with a new assignment. The assignment now challenges participants to imagine who they want to be or what they would want to achieve in one or two years from now and what obstacles and chances they will meet on the route. This round of group sessions also ends with an exhibition of photographs and text that tells the story of every individual participant.

In our study we used a qualitative approach, combining various qualitative research methods. The overall approach of the study is that of 'focused ethnography' (Morse & Field, 1996), entailing a multiple case design in which each participant in the photo workshop represents a case. Cases were constructed from data found in participant observation, interviews with patients and nurses and hermeneutic analysis of photo-stories. In one of the substudies we combined this with a quantitative method, using a questionnaire to assess the perception of the impact of illness on daily functioning.

We found that the photo group provided a context in which participants started to reflect on their experiences and in the end formulated a new perspective and integrated this in their life story. The process of reconstructing their experiences in order to find new meanings was found to match Ricoeur's interpretation of the concept of mimesis. Mimesis is a creative process of interpreting a narrative in such a way that the listener or reader of the text integrates its meaning in his own frame of reference and appropriates it as a story that he recognizes as relevant for himself. We also found other ways of constructing meaning in which suffering was not confronted, but circumvented by the use of facades.

We described how these facades were functional in defending the integrity of one's self-esteem and how they facilitated transitional stages towards finding a more credible self beyond the identity of being a patient. This search for a credible self that can be recounted in visual narrative encompasses aspects of moral learning. The social context of the photo-instrument was found to foster moral learning. Moral learning involved taking up responsibilities by patients and new roles in social interaction. Through the opportunity of telling their story some patients progressed in terms of an increasing openness and understanding of their feelings and situation. Patients showed signs of hope and motivation to realize new future plans in line with their capacities. The communication with the nurses improved and more openness triggered a better tuning of care to patients' needs.

The intervention facilitates a patient to take a meta-position in relation to his suffering, thus creating room for reflection. The commitment of the intervention to real life experiences and its focus on values, wishes and ambitions are factors that lend this process of reflection a positive but realistic character.

Thesis Defence: December 6, 2011  
Auditorium Free University Amsterdam  
Supervisors: Prof.dr. T.A. Abma en prof.dr. G.A.M. Widdershoven

Jan Sitvast

GGNet Kenniscentrum  
Vordenseweg 12  
7230 GC Wamsveld

[J.Sitvast@ggnet.nl](mailto:J.Sitvast@ggnet.nl)

## PATIENT PARTICIPATION AND KNOWLEDGE

Patients are increasingly invited and willing to take a more leading role in managing their disease and life, not only in their treatment and individual contact with physicians, but also on other decision-making levels, such as guideline development, policymaking and the formulation of research agendas. Patients and consumers are increasingly empowered and less willing to adopt a passive role. The thesis of Karen Schipper is about the involvement of patients in research and the possible additional value of the perspective or knowledge that can be brought by patients. It explores how patients can participate in research and what patients bring from perspectives grounded in the illness experience.

The involvement of patients in research can happen in many ways. They can, for instance, participate as respondent of an interview or focus group or they may

participate as an equal team-member in a research team (research partners). This thesis shows that the collaboration with research partners in transdisciplinary research teams has several benefits for the research process itself, the researchers, the research partners and the respondents. Researchers gained, among others, a better understanding of what it means to live with a certain disease. Respondents felt more comfortable in the presence of the research partners. There was a mutual recognition between the respondents and research partners which created trust and an open atmosphere. Research partners themselves felt empowered by participating in the project and gained, among others, a better understanding and acceptance of their own situation. These benefits had an influence on the results of the research process itself: the collaboration has led to more profound and patient-relevant findings and the accentuation of certain themes that would not be stressed by researchers solely. The collaboration with research partners helps to get insight in the perspectives of patients and to gain a shared patient perspective.

This perspective of patients also emerges by having conversations (in-depth interviews or focus groups) with patients with several types of knowledge. Some scholars are however sceptical. They wonder whether the subjective individual stories of patients can be transformed into shared, valid and collective knowledge. They express worries: does patient involvement in research not only lead to subjective stories of individual patients and particularly the stories of the most assertive patients? Other doubts expressed are doubts about the potential overburdening of patients and possible exclusion of vulnerable patient groups who cannot participate. This thesis shows how this can be prevented. A unique objective, complementary patient perspective may arise by using the right tools and doing the right things. Investigating the perspectives of patients and using their knowledge leads to complementary insights, not earlier mentioned by professionals.

Please contact Karen Schipper for more information:  
[k.schipper@vumc.nl](mailto:k.schipper@vumc.nl)

VU medisch centrum  
Afdeling Metamedica  
Van der Boechorststraat 7  
1081 BT Amsterdam, The Netherlands

Thesis defence: January 18, 2012  
Auditorium Free University Amsterdam  
Supervisors: Prof.dr. T.A. Abma en prof.dr. G.A.M. Widdershoven

## EMBRYOS WITHOUT SECRETS. THE DILEMMA'S OF PREIMPLANTATION SCREENING

Towards the transparent embryo? Dynamics and ethics of comprehensive preimplantation genetic screening

The technical possibilities of genetic testing are booming and in the near future it will be possible to perform whole-genome sequencing at affordable cost. The role of genetic research in medical diagnostics increases as a consequence. Couples who carry a gene for a hereditary disease can choose for in vitro-fertilization (IVF) with genetic testing of the embryos. With this preimplantation diagnosis (PGD) only unaffected embryos will be transferred into the uterus.

Progressing technological development offers possibilities for a systematic offer of embryo testing to IVF-patients, the so-called preimplantation screening (PGS). In the future PGS can be used not only to select the best embryo to implant, but also to avoid the transfer of hereditary diseases and even to give parents the option to have the best possible child.

The ethical and societal discussion has focused mainly on PGD, but the possibilities of PGS raise new unanswered questions and dilemmas. The aim of this study is to identify the ethical aspects of various possible future scenarios.

The researcher will gain an overview of the technical possibilities and realistic applications of genetic testing of embryos and will talk to medical specialists and genetic counselors about their vision on the different applications of embryo testing and the possible dilemmas. Theoretically reflecting on this, the researcher strives to create a chart of moral challenges that will help clinicians and counselors to handle questions on genetic testing of embryos and new borns.

This project started on June 1, 2011

Researcher: Dr. Kristien Hens

FHML, Health, Ethics and Society  
P.O. Box 616  
6200 MD Maastricht, The Netherlands

[K.Hens@maastrichtuniversity.nl](mailto:K.Hens@maastrichtuniversity.nl)

## 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. Deadline for submission of abstracts: **March 1, 2012**. For more information: [www.eacme2012.org](http://www.eacme2012.org)

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### Call for Papers SOCIAL SCIENCE & MEDICINE Special Issue

Bioethics in the field: The social (re)production of bioethics in diverse cultural contexts  
Guest Editors  
Patricia Kingori, Kristina Orfali and Raymond de Vries  
**The deadline for submissions is 31st January 2012.**  
For more information: <http://ees.elsevier.com/ssm/>

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### Second Cambridge Consortium for Bioethics Education Paris, France, April 11, 12 & 13, 2012

Cambridge University Press invites your participation in establishing an international community of bioethics educators to address such questions as: Why are we doing this? What goals are we trying to achieve? Where is bioethics education taking place? How well are we doing? What next?

Key themes of the Consortium include:

Getting Serious About Goals  
International Program Development – what's happening around the world  
Bioethics Programs in Academic and Hospital Settings  
Undergraduate and Graduate Programs  
Innovative Methodologies  
E-learning  
Teaching Ethics Consultation  
Educating Ethics Committees  
The Social Context of Clinical Decision Making  
What Happens After the Classroom?  
Bioethics as Public Policy  
Preparing the Next Generation

For more information: [www.cambridgebioethics.com](http://www.cambridgebioethics.com)

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### 3rd INTERNATIONAL CONGRESS ON RESPONSIBLE STEM CELL RESEARCH - RSCR Vatican City, April 25-28, 2012

For more information:  
<http://www.stemcellsrome2012.org/>

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### 9 -11 May ESF Conference Towards a sustainable bio-based society: aligning scientific and societal agendas for bio-innovation. Venue: Amsterdam. Deadline for submission poster abstracts: 1 January 2012!

Confirmed Keynote Speakers: George Gaskell, Hub Zwart, Christine Hauskeller, Ruth Chadwick, Luuk van der Wielen, David Castle, Herbert Gottweis  
General information about submitting a poster abstract can be found in the pdf on this site: <http://bit.ly/rHjUSa>. The ESF Conference website, where you can register, will go online shortly. If you want to be informed about this, please contact Olga Crapels at [crapels@society-lifesciences.nl](mailto:crapels@society-lifesciences.nl)

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### Call for Abstracts

Eighth International Conference on Clinical Ethics and Consultation  
Holiday Inn Hotel-Anhembi  
São Paulo, Brazil  
May 16-19, 2012

For more information: is <http://www.ethics2012.org.br>

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### Minding Animals Conference 2012 4-6 July 2012 Utrecht University, the Netherlands

For more information:  
<http://www.uu.nl/hum/mindinganimals>

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### 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](mailto:collintviii@manchester.ac.uk) by 1st June 2012. Notification of acceptance by 1st July 2012. Conference webpage: <http://www.socialsciences.manchester.ac.uk/disciplines/philosophy/events/ci/>

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**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 first edition of 2012:

**APRIL 1st, 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](mailto:rouven.porz@insel.ch) or Angelique Heijnen: [a.heijnen@maastrichtuniversity.nl](mailto:a.heijnen@maastrichtuniversity.nl)

**EDITORIAL BOARD**

**Rouven Porz, Editor**

Ethics Unit  
Direktionspräsidium, Bern University Hospital  
"Inselspital"  
CH – 3010 BERN  
SWITZERLAND  
Tel: + 41 – 31 6321956  
[rouven.porz@insel.ch](mailto:rouven.porz@insel.ch)

**Alessandra Bernardi**

Fondazione Lanza  
Via Dante, 55  
35139 PADOVA  
ITALY  
Tel: + 39-334-600 9005  
[alessandra.bernardi@ioveneto.it](mailto:alessandra.bernardi@ioveneto.it)

**Jean-Philippe Cobbaut**

Université Catholique de Lille  
Centre d'Éthique Médicale  
56, rue du Port  
F-59046 LILLE Cedex  
France

Tel: + 33 3 20134046  
[jean-philippe.cobbaut@icl-lille.fr](mailto:jean-philippe.cobbaut@icl-lille.fr)

**Angelique Heijnen**

Maastricht University  
FHML, Health, Ethics and Society  
P.O. Box 616  
6200 MD MAASTRICHT  
THE NETHERLANDS  
Tel: + 31 43 3882145  
[a.heijnen@maastrichtuniversity.nl](mailto:a.heijnen@maastrichtuniversity.nl)

**Jeanette Hewitt**

Swansea University  
Department of Philosophy, History & Law  
School of Health Science  
Singleton Park SWANSEA  
South Wales SA2 8PP  
UNITED KINGDOM  
Tel: + 44 1792 518598  
[j.l.hewitt@swan.ac.uk](mailto:j.l.hewitt@swan.ac.uk)

**Elleke Landeweer**

Department of Medical Humanities, VUmc  
P.O. Box 7057  
1007 MB AMSTERDAM  
THE NETHERLANDS  
Tel: + 31 20 44 48394  
[e.landeweer@vumc.nl](mailto:e.landeweer@vumc.nl)

**Jean Martin**

La Ruelle 6  
CH- 1026 ECHANDENS  
SWITZERLAND  
[jean.martin@urbanet.ch](mailto:jean.martin@urbanet.ch)



**We wish you all a healthy, happy & prosperous New Year!**  
**We are looking forward to continue our fruitful working relationships in 2012.**