

Towards a European understanding of advance decision-making: a comparative, interdisciplinary approach



Seminar 1: Advance decision-making – the context, the promise and the pitfalls.

Programme



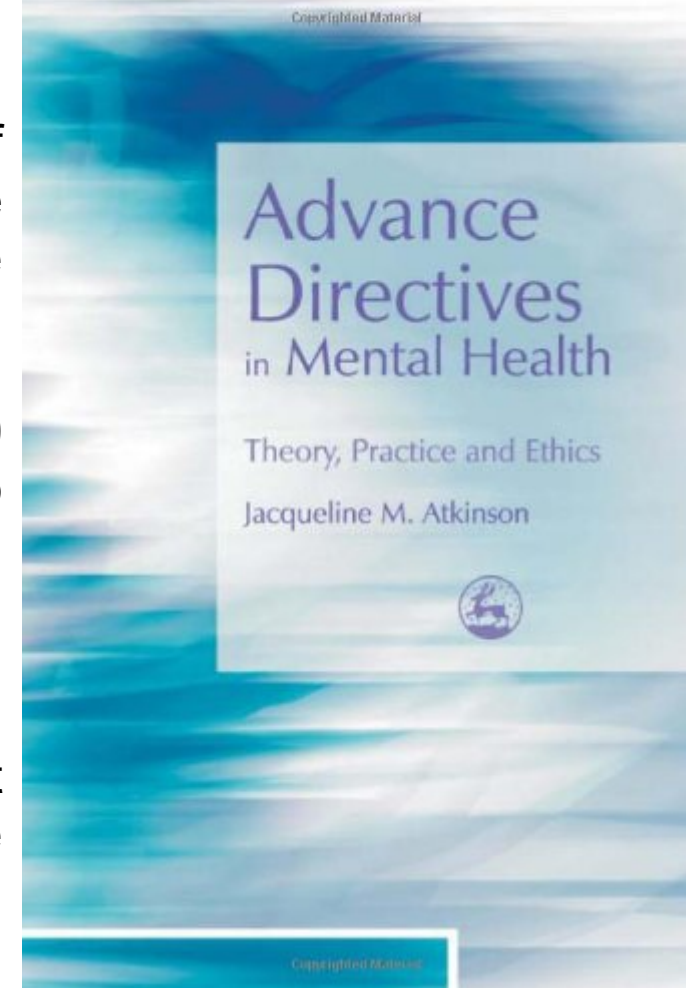
- Programme:-
- 09.30 Registration and coffee
- 10.00 Welcome, opening remarks and introductions
- 10.30 Jean McHale “Advance decisions and the MCA 2005: Just where did it all go wrong?”
- 11.30 Dianne Gove “Practical and ethical issues related to the use of advance directives by people with dementia”
- Followed by time for questions
- 12.10 Lunch
- 13.30 William Molloy “Let Me Decide: an update on recent research”
- 14.15 Coffee
- 14.45 Celia Kitzinger & Sue Wilkinson “Writing an Advance Decision: (How) Can We Facilitate the Process?”
- 15.45 Closing remarks
- 16.00 Close



Professor Jacqueline Atkinson



Formerly Professor of Mental Health Policy at the University of Glasgow she has carried out research in the area of mental health legislation for more than 20 years. She was advisor to the Scottish Parliament in respect of the Mental Health (Care and Treatment) (Scotland) Act. She published the first book on Advance Directives in Mental Health in 2007.



Professor Peter Bartlett

- In his own words:
- Peter Bartlett is Nottinghamshire Healthcare NHS Trust Professor of Mental Health Law in the School of Law and Institute of Mental Health at the University of Nottingham. He was specialist advisor to the House of Lords Post-Legislative Scrutiny Committee on the Mental Capacity Act 2005. With colleagues in Nottingham, he has recently completed a study of the use of advance planning and decision-making by people with bipolar disorder, the results of which will be published later this year in the *Journal of Social Welfare and Family Law*. Professor Bartlett is today sprinting towards a deadline imposed by a funder, and deeply regrets not being in Leeds at this seminar.

Dr. M.E. (Marike) de Boer



*Department of General Practice & Elderly Care
Medicine*

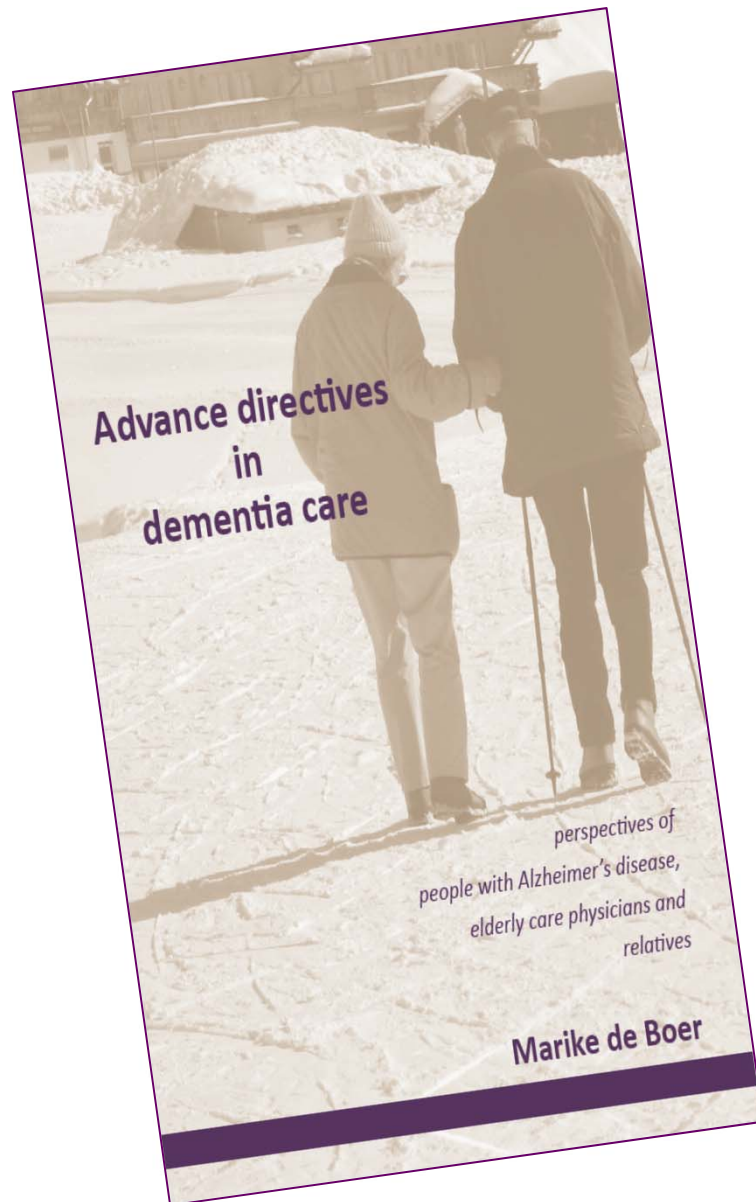
EMGO Institute for Health and Care Research

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Amsterdam, The Netherlands

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Journal of Alzheimer's Disease 40 (2014) 743–757 DOI 10.3233/JAD-131967
IOS Press 743

Factors Associated with Initiation of Advance Care Planning in Dementia: A Systematic Review

Jenny T. van der Steena,^a Mirjam C. van Soest-Poortvlieta, Meertje Hallie-Heiermana,¹
Bregje D. Onwuteaka-Philipsen^b, Luc Deliens^{b,c}, Marike E. de Boera, Lieve Van den Blockc,
Nicole van Uden^{c,2}, Cees M.P.M. Hertogha and Henrica C.W. de Vetd

^aDepartment of General Practice & Elderly Care Medicine, EMGO Institute for Health and Care
Research, VU

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^bDepartment of Public and Occupational Health, EMGO Institute for Health and Care Research, VU
University

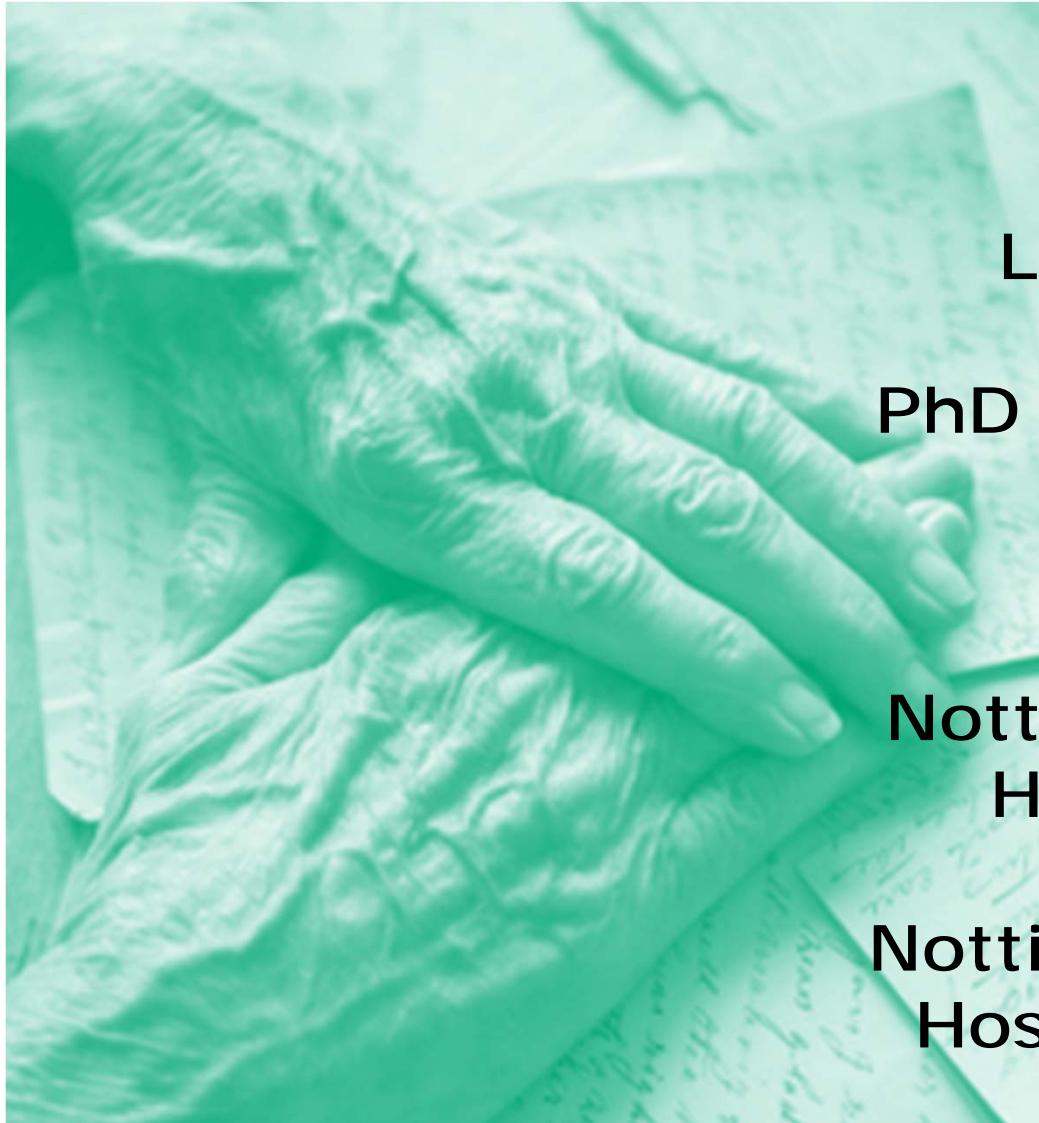
Medical Center, Amsterdam, The Netherlands

^cEnd-of-Life Care Research Group, Vrije Universiteit Brussel & Ghent University, Vrije Universiteit
Brussel (VUB),

Brussels, Belgium

^dDepartment of Epidemiology and Biostatistics, EMGO Institute for Health and Care Research, VU
University

Medical Center, Amsterdam, The Netherlands



Louise Bramley

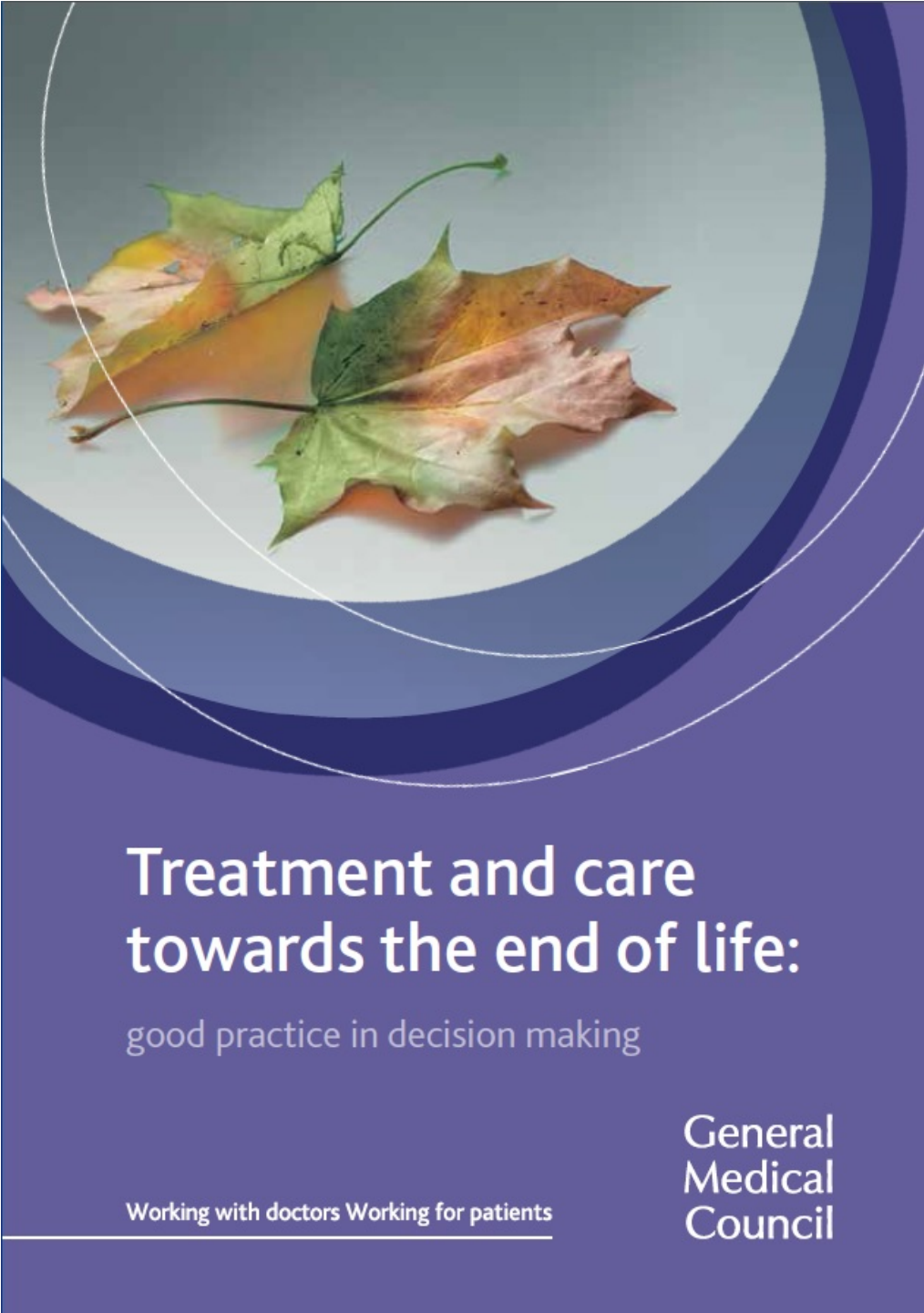
**PhD Student and Staff
Nurse**

**University of
Nottingham School of
Health Sciences**

**Nottingham University
Hospitals NHS Trust**

Sharon Burton

- General Medical Council (GMC)
- Head of Policy, Standards and Ethics



Treatment and care towards the end of life:


good practice in decision making

Working with doctors Working for patients

General
Medical
Council

Professor Martin Eisemann, PhD
Dept of Psychology, Faculty of Health Sciences
UiT The Arctic University of Norway in Tromsø

Related publications to "advance decision-making":

- Attitudes towards self-determination in health care -- a general population survey in northern Sweden.
- Relationships between various attitudes towards self-determination in health care with special reference to an advance directive
- Factors influencing Swedish doctors' decision-making in the care of incompetent elderly patients. 
- Decision making in the incompetent elderly: "The Daughter from California syndrome".
- Variability in physicians' decisions on caring for chronically ill elderly patients: an international study.
- Factors affecting physicians' decisions on caring for an incompetent elderly patient: an international study.
- Decisions and attitudes of nurses caring for severely ill elderly patients: a culture-comparing study
- Physicians' decision-making in incompetent elderly patients: a comparative study between Austria, Germany (East, West), and Sweden.
- Decisions and attitudes in treatment of incompetent, chronically ill, aged patients. A comparison between nurses and physicians: why does no one ask the nurse?.
- Decisions and attitudes of nurses in the care of chronically ill elderly patients
- Attitudinal patterns determining decision-making in the treatment of the elderly: a comparison between physicians and nurses in Germany and Sweden.
- Physicians' attitude in the treatment of incompetent patients. Comparison between East and West Germany
- The compliance of doctors and nurses with do-not-resuscitate orders in Germany and Sweden
- Doctors' authoritarianism in end-of-life treatment decisions. A comparison between Russia, Sweden and Germany
- Attitudinal patterns determining decision-making in severely ill elderly patients: a cross-cultural comparison between nurses from Sweden and Germany.
- Personality characteristics of physicians and end-of-life decisions in Russia.
- Decision-making in the treatment of elderly people: a cross-cultural comparison between Swedish and German physicians and nurses.
- Doctors' attitudes and end-of-life decisions in the elderly: a comparative study between Sweden, Germany and Russia.
- A new instrument to describe indicators of well-being in old-old patients with severe dementia--the Vienna List

Library of Ethics and Applied Philosophy 30

Yvonne Denier
Chris Gastmans
Antoon Vandeveld *Editors*

Justice, Luck & Responsibility in Health Care

Philosophical Background and Ethical
Implications for End-of-Life Care

 Springer

Prof Dr. Chris Gastmans

KU Leuven, Faculty of Medicine

Centre for Biomedical Ethics and Law
www.cbmer.be

Topics

- End-of-life care ethics
- Dementia care ethics
 - Care ethics

N°3/2007

Alzheimer Europe

Position Paper

Advance Directive (living will)





ADM?

~~Advance
Decision
Directive?~~

Tamara Hervey
(Tammy)

Jean Monnet
Professor of
EU Law

School of Law,
University of
Sheffield



Samantha Halliday, Associate Professor in Law, University of Leeds, UK

Research interests: comparative medical ethics & the law at the beginning and end of life.

Selected publications:

- S. Halliday *Reproductive ethics & the law: Autonomy and Pregnancy: A comparative analysis of compelled obstetric intervention*, monograph, in press, Routledge, 2015.
- S. Halliday “Comparative reflections upon the Assisted Dying Bill 2013: A plea for a more European approach” (2013) 13 *Medical Law International* 135.
- S. Halliday “Legislating to give effect to precedent autonomy: comparative reflections on legislative incompetence” (2011) 11 *Medical Law International* 127 – 172 (ISSN: 0968-5332.).
- S. Halliday “Advance decisions and the Mental Capacity Act” (2009) 18 (11) *British Journal of Nursing* 697-699 (ISSN: 0966-0461.)
- S. Halliday “Regulating active voluntary euthanasia: what can England & Wales learn from Belgium and the Netherlands?” in A. Garwood-Gowers et al (eds) *Contemporary Issues in Health Law and Ethics*. Chapter 14; pages 269 – 302. 2005 Elsevier / Butterworths. ISBN 0750688327.



S.Halliday@leeds.ac.uk

Gillian Lewando Hundt

Professor of Social Sciences in Health

THE UNIVERSITY OF
WARWICK

WARWICK MEDICAL
SCHOOL



Medical Anthropologist/Sociologist

Research Interests in the Area of Advanced Decision Making

- Views of People and Carers living with life limiting conditions on Assisted Dying – eg MND
- Models of compassionate communities
- Decision making of patients relating to end of life care
- Developing theatre from research



UNIVERSITY OF SALERNO - SCHOOL OF LAW



Prof. Vitulia IVONE

Associate Professor of Private Law

Lecturer of Fundamental Legal Concepts

email: vituliaivone@unisa.it

<http://www.unisa.it/docenti/vituliaivone/index>

- Chairmain of the Scientific Board of the *Fondazione Scuola Medica Salernitana* (<http://fondazione scuolamedicasalernitana.org/>)
- Founding Member of the Advisory Board of the *Observatory on Human Rights: Bioethics, Health, Environment*
- Co-director of the *International Summer School on Law, Bioethics and Health* (2nd edition, Salerno, July 2015)
- Member of the research group of the Italo-German VIGONI Programme 2011-2012: *Legal and ethical questions raised by end-of-life decision-making in Germany and Italy: a comparative and international law perspective*

Research interests: right to health and bioethical/legal issues concerning the beginning and end of life, informed consent, medically assisted procreation, pre-implantation genetic tests, advance directives and living wills, palliative care, dignity and human rights at the end of life, medical responsibility

Kirstin Jalink

MD (GP and elderly care)

PhD student Advance Care Planning

VU medical center Amsterdam, The Netherlands



Think before you start...

Celia Kitzinger, Sociology, University of York

healthtalk.org + 'coma'



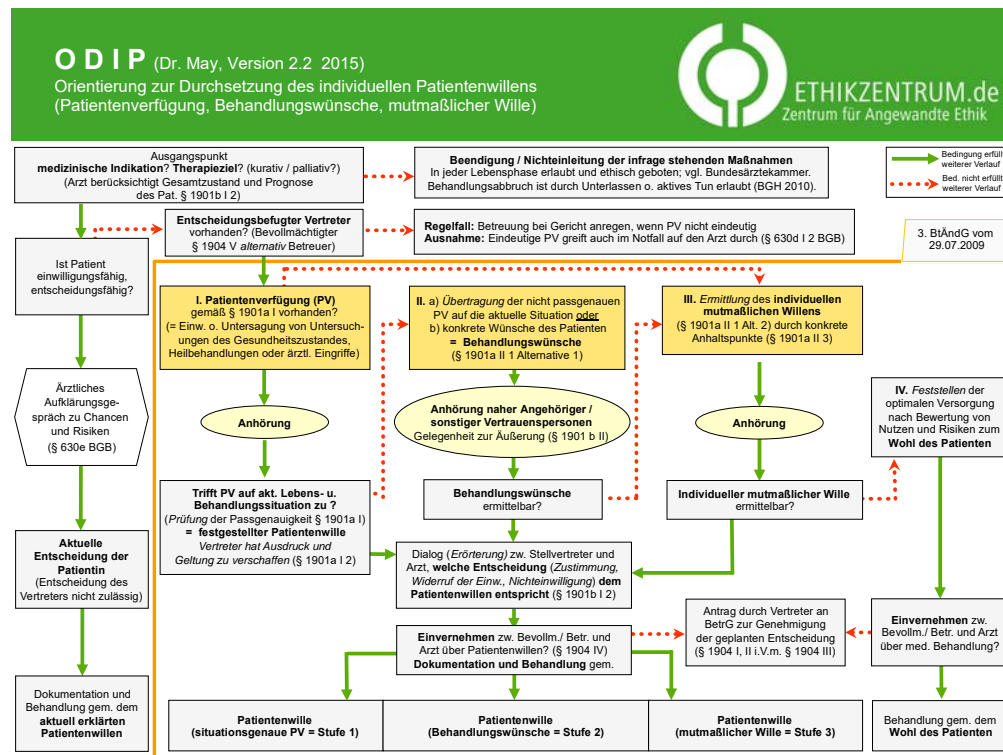
Guardian "Impact Award" (Runner up)

Arnd T. May PhD

Ethicist in the field of clinical ethics consultation

Centre of Applied Ethics, Recklinghausen GER

- Interpretation of an Advance Directive to provide treatment in accordance to patients wishes





UNIVERSITY OF SALERNO - SCHOOL OF LAW



Prof. Stefania NEGRI

Associate Professor of International Law

Lecturer of International Human Rights Law

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<http://salerno.academia.edu/StefaniaNegri>

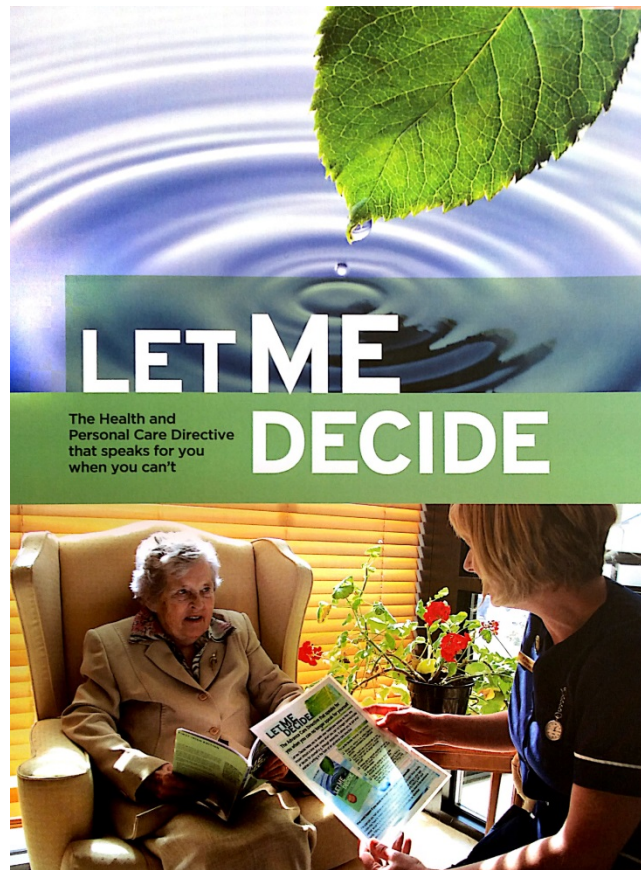
- Founder and Director of the *Observatory on Human Rights: Bioethics, Health, Environment* (www.odubsa.unisa.it - odubsa@unisa.it)
- Member of the Scientific Board of the *Fondazione Scuola Medica Salernitana*
- Director of the *International Summer School on Law, Bioethics and Health* (2nd edition, Salerno, July 2015)
- Director of the Italo-German VIGONI Programme 2011-2012: *Legal and ethical questions raised by end-of-life decision-making in Germany and Italy: a comparative and international law perspective*

Research interests: human rights in international and European law, right to health, informed consent, advance directives in European perspective, bioethical/legal issues concerning the end of life, euthanasia and assisted suicide, palliative care, global public health, food safety

Professor Jean McHale

- Jean McHale is Professor of Health Care Law at the University of Birmingham and Director of the Centre for Health Law, Science and Policy. She is the author and co-editor of a number of books and articles in this area including Health Care Law Text and Materials ((2nd ed) Sweet and Maxwell, 2007), Principles of Medical Law (Oxford: OUP, 2010) co-edited with Grubb and Laing and Principles of Mental Health Law Science and Policy (Oxford, OUP, 2010) (co-edited with Gostin, Bartlett, Fennell and McKay. Her new books European Health Law, Themes and Implications (Cambridge: CUP), with Hervey and the Routledge Handbook of Complementary and Alternative Medicine, Perspectives from Social Science and Law , co-edited with Gale, will be published in 2015.

Professor Willie Molloy

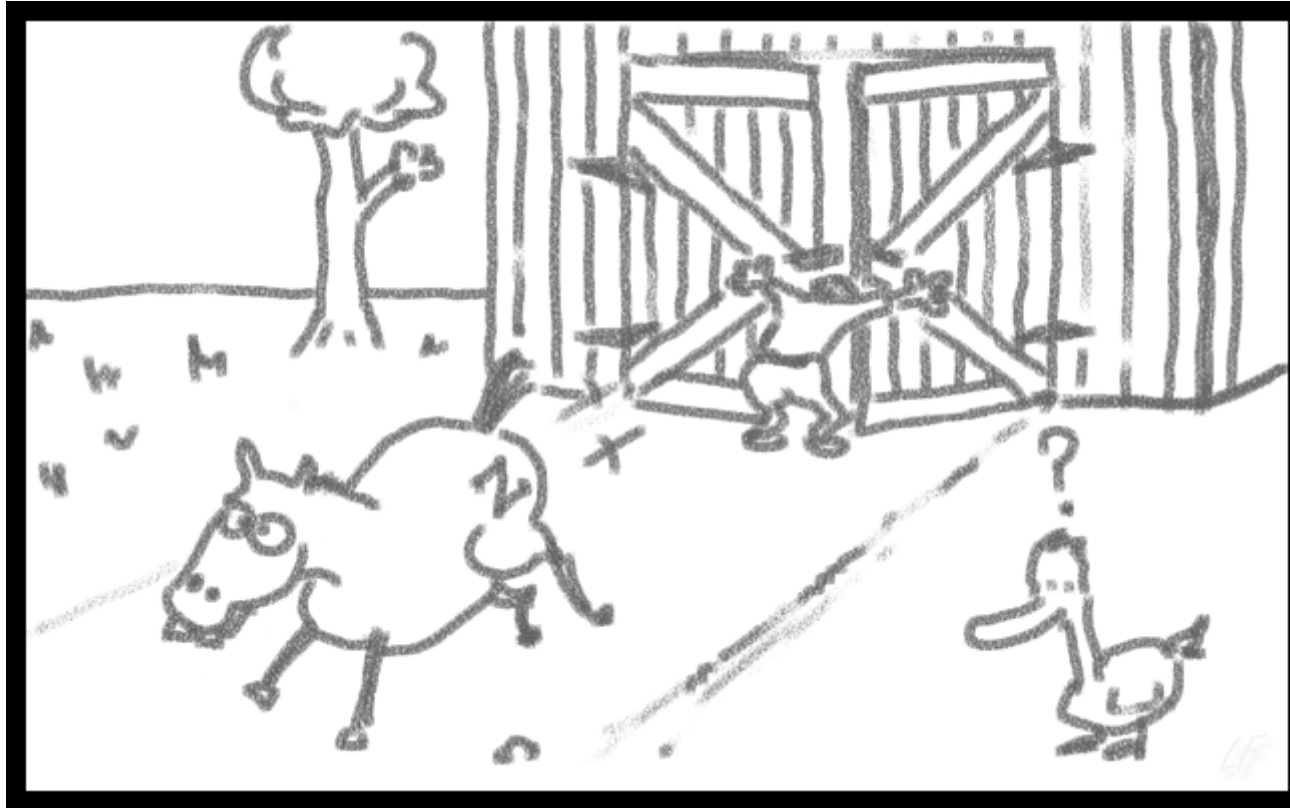


Alex Louise Pearl

2nd Year PhD student based in School of
Law

A.Pearl@leeds.ac.uk





**Andrea Prescott, Court of Protection and
Public Law Solicitor, Cartwright King**



Prof. Dr. Jörg Richter, University of Rostock & University of Hull, clinical psychologist & psychotherapist

Motivation – like everybody, I am a potentially aggrieved party, I gained some experience with medical paternalism in more than 25 years clinical practice in a psychiatric university hospital, and I would like to have a say when my time comes

One of the first persons who studied doctors' and nurses' attitudes towards advance directives in end-of-life decisions in Germany already from 1995 in collaboration with Prof. Dr. Martin Eisemann (Umeå/Tromsø) and Prof. Dr. Willie Molloy (Hamilton/Cork) in cross-cultural comparisons (Sweden, Russia, Austria, Germany)

selected publications:

- EISEMANN, M., ERICSSON, M., NORDENSTAM, M., *RICHTER, J.* & MOLLOY, D.W. (1999) Attitudes towards self-determination in health care - A general population survey in northern Sweden. European Journal of Public Health 9(1)41-44.
- EISEMANN, M., & *RICHTER, J.* (1999) Relationships between attitudes towards self-determination in health care with special reference to an advance directive. Journal of Medical Ethics 25(1)37-41.
- RICHTER, J.*, EISEMANN, M., BAUER, B. & KREIBECK, H. (1999) Entscheidungen und Einstellungen bei der Behandlung inkompetenter, chronisch kranker, alter Menschen. Ein Vergleich zwischen Krankenschwestern und Ärzten - oder: Warum fragt keiner die Krankenschwester? Zeitschrift für Geriatrie und Gerontologie, 32(2)131-138.
- EISEMANN, M., *RICHTER, J.*, BAUER, B., BONELLI, M. & PORZSOLT, F. (1999) Doctors' decision-making in incompetent elderly patients. A comparative study between Austria, Germany (East, West), and Sweden. International Psychogeriatrics 11(3) 313-324.
- RICHTER, J.* & EISEMANN (1999) Compliance with do-not-resuscitate orders. A cross-cultural comparison of doctors and nurses from Germany and Sweden. Resuscitation 42(3)203-209.
- RICHTER, J.* & EISEMANN, M. (2000) Attitudinal patterns determining decision-making in the treatment of the elderly: A cross-cultural comparison between physicians and nurses. Intensive Care Medicine, 26(9)1326-1333.
- RICHTER, J.*, EISEMANN, M. & ZGONNIKOVA, E. (2001) Doctor's authoritarianism in end-of-life treatment decisions. A comparison between Russia, Sweden and Germany. Journal of Medical Ethics, 27(3)186-191.
- RICHTER, J.*, EISEMANN, M. R. & ZGONNIKOVA, E. (2001) Personality Characteristics of Physicians and End-of-Life Decisions in Russia. Medscape General Medicine July 12. Available at:
http://www.medscape.com/Medscape/GeneralMedicine/journal/2001/v03.n04/mgm0712.01_rich/mgm0712.01_rich-01.html
- RICHTER, J.*, EISEMANN, M. & ZGONNIKOVA, E. (2002) Doctors' attitudes and end-of-life decisions in the elderly: a comparative study between Sweden, Germany and Russia. Archives of Gerontology and Geriatrics, 34(2)107-115.

ACP in dementia in UK

Newcastle: Louise Robinson, Cath Exley, Julian Hughes

Research (NIHR funded)

Effectiveness? (*Robinson et al 2010*)

Use and feasibility in practice? (*Robinson 2012*)



ADVANCE DECISIONS TO REFUSE TREATMENT
A Guide

Messages for practice *Living for the present*

- No one's responsibility
- Best interests decision making trump ACP
- Levels of acceptability
 - LPA: acceptable to all stakeholders
 - DNH/DNR orders - *AVOID ADRT*

Kevin de Sabbata

- PhD student, University of Leeds.

Dr Maria Stuttaford



- Social scientist working across disciplines including law and public health
- Health as a human right, focusing on:
 - how civil society organisations (CSOs) use a human rights approach to tackle health inequalities
 - the right to health in the context of plural health seeking behaviour
 - the right to health and participation
- Honorary Research Fellow, Cardiff University, UK
- Honorary Senior Lecturer, University of Cape Town, SA
- Associate Fellow, University of Warwick, UK

Professor Sue Wilkinson

- Professor of feminist & Health studies, University of Loughborough.
- Sue is a Professor in the Department of Social Sciences at Loughborough University. She has worked with Compassion in Dying and Dementia UK to evaluate their telephone helpline services, and is a befriender for Friends at the End (FATE).