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## European Understandings of Advance Decision-making: Implications for Policy and Research

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## Advance decisions, the Law Commission and the Mental Capacity Act 2005: 13 years on are we really any further forward?

Jean McHale, Professor of Healthcare Law, University of Birmingham.

In 1995 the Law Commission published its Mental Incapacity Report. This document provided recommendations for a comprehensive structure for the care and treatment of persons lacking mental capacity. The political ramifications of various aspects of the report— notably the recommendations around advance decisions resulted in delayed implementation. It was not until 2005 that the Mental Capacity Act was finally passed. The Act placed advance decisions on a statutory basis providing a structure both to safeguard protection of individual rights and also to safeguard the position of health care professionals respecting those rights. Yet 13 years on the take up of advance decisions remains very low and major uncertainties remain concerning their implementation. This paper examines the current regulatory structure, what went wrong and what could be done to improve the situation.

Jean McHale is Professor of Healthcare Law and Director of the Centre for Health Law Science and Policy at the University of Birmingham. Her recent books include *Principles of Medical Law* (OUP, 2017) edited with Judy Laing and *European Health Law: Themes and Implications* (CUP, 2015) with Tamara Hervey. She is currently the PI on an ESRC Project “Health Law Outside the EU: Immediate, Intermediate and Long-Term Impacts”.

## Notes

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## Difficult conversations: how policy meets practice in Advance Care Planning for the end of life.

Kristian Pollock, Professor of Medical Sociology, University of Nottingham.

Advance Care Planning (ACP) is key component of health policy goals to improve quality and equity in end of life care, reduce costs and ‘empower’ patients as informed and autonomous decision makers, even as they approach the most fraught and vulnerable experience in life. This paper presents evidence from two qualitative studies of how ACP is implemented in different settings. Professionals are broadly positive about ACP, but often lack adequate training and resources to support confident and skilful practice. Even in specialist programmes, implementation tends to reflect professional agendas. ACP emerges as a ‘co-construction’ rather than expression of patients’ autonomous decision making. In reinforcing a commitment to the ideological construct of ‘the good death’ models of ACP ignore social and cultural diversity. They reinforce a cultural script about the ‘best’ or appropriate way to die and consequently risk raising expectations, and also a sense of failure, among those who cannot or prefer not to comply. Patient responses to ACP are variable and complex. Some welcome the opportunity to formulate and document their preferences for care. Many others, however, resist formalising future options, within a perspective that is uncertain, shifting and pragmatic. In particular, the emphasis on autonomous decision making does not resonate with many patients who situate themselves within a network of relationships and decision making made with reference to mutual interests and consequences, rather than personal choice and control.

Kristian Pollock is Professor of Medical Sociology in the School of Health Sciences at the University of Nottingham. She has carried out qualitative research in a wide range of health care settings. Her current research interests include medicines management and Anticipatory Prescribing at the end of life, Advance Care Planning, death, dying and dementia. She is a member of the Nottingham Centre for the Advancement of Research into Supportive, Palliative and End of Life Care (NCARE).

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## Lasting powers of attorney, advance decisions and statements of wishes: an optimal triumvirate for advance care planning?

Jo, Samanta, Professor of Medical Law.

Advance care planning is promoted extensively as a mechanism to influence and inform health and welfare decisions following loss of capacity. This paper focuses on the main forms of advance care planning in England and Wales: namely advance decisions to refuse treatment and the appointment of attorneys under Lasting Powers of Attorney for Health and Welfare. It also considers the often neglected option of including statements of wishes and beliefs. It suggests ultimately that in English law, all three options have some recognised limitations when used in isolation on theoretical and practical grounds. A paradigm for the future is suggested using a combined approach to best reflect what medical treatment people would like to receive when they can no longer make healthcare decisions for themselves.

Professor Jo Samanta has recently left De Montfort University where she was Professor of Medical Law. She now works as an independent scholar on a variety of projects and collaborations for Innovate UK and the British Academy. She is currently collaborating on a clinical guidelines project for consent, advance care planning and information disclosure for the Legal and Ethical Policy Unit of the Faculty of Intensive Care Medicine.

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# Mental Illness and Pregnancy: Can Birth Plans Offer an Alternative to Court Authorised Obstetric Intervention?

Samantha Halliday, Professor of Law, University of Huddersfield.

The last six years have seen a resurgence of the issue of court authorised obstetric intervention, in almost all cases the women were suffering from a mental illness. Having established that the woman lacks capacity to make her own decisions in relation to the management of her pregnancy and delivery, the way in which best interests have been assessed in the latest tranche of cases will be addressed, focussing upon the centrality of the achievement of a successful delivery and the notion that a safe delivery will negate any harm suffered.

It will be argued that more thought is needed regarding how such cases can best be managed in such a way as to facilitate the woman's ability to make decisions and that positive steps should be taken to facilitate anticipatory decision-making, ensuring that her wishes, rather than her welfare, or indeed that of the foetus, are prioritised. To that end it is argued that much greater use needs to be made of advance decisions for obstetric treatment and care (as opposed to the more aspirational birth plan), enabling a woman to set out her wishes at a time where there can be no question of her lacking capacity, where there is no stress, pain or emergency situation detracting from a calm discussion of the available options.

Sam Halliday is a Professor of Law and Head of the Law School at the University of Huddersfield. Her recent book *Autonomy and Pregnancy: A Comparative Analysis of Compelled Obstetric Intervention*, Routledge, 2016, focuses upon the permissibility of encroachment on the pregnant woman's autonomy in the interests of the foetus. It adopts a comparative approach, drawing on the law in England and Wales, the United States of America and Germany in analysing the tension between a pregnant woman's autonomy and obstetric intervention undertaken to protect the foetus. She is the Principal Investigator an ESRC Research Seminar Series grant for "Towards a European understanding of advance decision-making: a comparative, interdisciplinary approach" (co-investigators: Gillian Hundt (Professor of Social Science in Health, University of Warwick) and Jörg Richter (Professor in Psychology, University of Hull)).

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## What does a lawyer know about my medical needs? Exploring the role of the lawyer in preparing a modern Lasting Power of Attorney for Health and Welfare.

Catherine Stanbury, Senior Lecturer, University of Huddersfield.

For centuries, lawyers have helped people choose and appoint appropriate guardians to look after their financial affairs where it is anticipated that they may not be able to do this for themselves. In particular, such appointments (facilitated by the creation of a ‘power of attorney’ document) have enabled older clients to confidently plan for the possible loss of mental capacity by ensuring that, in these circumstances, their financial affairs would be overseen by a trusted surrogate. Modern concerns about ensuring control over future healthcare when self-determination is not possible have, however, challenged lawyers to provide advice for a very different style of decision-making. Lawyers are now frequently engaged in advising their clients upon the appointment of surrogates to make future health, rather than financial, decisions on behalf of their principals. Since 2007, it has been possible to appoint health surrogates under the new-style Lasting Power of Attorney for Health and Welfare document (‘the LPA for Health’). The LPA for Health is almost identical in form to its counterpart, the Lasting Power of Attorney for Property and Financial Affairs but, in substance, its reach is far more profound. The person appointing a surrogate under an LPA for Health is not simply delegating authority over financial investments but is devolving their power, during periods of incapacity, over the course of their own life and death. Through interviews with lawyers and their clients my research explores the extent to which lawyers have the necessary knowledge, skills, experience and courage to guide their clients through this new territory.

Catherine Stanbury is a Senior Lecturer at the University of Huddersfield. Catherine joined the University after ten years in practice as a solicitor specialising in Private Client and Property matters. Inspired by her insights into the role of a lawyer in supporting clients to appoint attorneys as their financial agents to act during times of future incapacity, Catherine is currently engaged in PhD research which considers the new and less familiar role of the lawyer as advisor to clients appointing surrogates for future medical decision-making.

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Andreas Dimopoulos joined the School of Law University of Huddersfield on 3rd September having previously worked at Brunel University London. His research focuses on the rights of persons with (intellectual) disability, with an emphasis on how these fit into the overarching context of [international human rights law](#).

# Attitudes Towards Patient Autonomy in End-of-Life Decisions: A Systematic Comparative Review from the UK, the Netherlands, and Germany.

Jörg Richter, Professor of Psychology, University of Hull.

Knowledge about attitudes of the involved parties (doctors, nurses, patients, individuals from the public) is needed in order to accomplish the individuals' autonomy in end-of-life decisions. Advance treatment decisions could be one way to achieve this. The law relating to advance decision-making, as well as its cultural background, varies significantly between the UK, the Netherlands, and Germany raising the question of whether these differences are reflected by the people's attitudes? During the last 30 years an increasing number of individuals (more or less severely ill patients as well as rather healthy individuals) uses the opportunity of advance treatment decisions for the end of life in the three countries. The idea of self-determination of the time to die is increasingly discussed even by individuals living within the two jurisdictions where euthanasia is unlawful. Lay people, patients, and relatives in all three countries seem to expect a more binding effect of ADs in practice compared to the doctors' attitudes, their willingness to follow the patient's wishes, and how they do comply with available ADs. Doctors in all the three countries increasingly express more openness related to the patients' wishes and their willingness to consider ADs within their medical decisions. More and more doctors express that an available AD would make their decision process easier. However, the majority of doctors are still reluctant to follow an AD when the patient's wish doesn't match their medical or moral evaluation. Taking into account the development of the position of the doctors' profession from a healing profession towards a service providing profession, further attitude changes should be developed.

Jörg is professor of psychology at the University of Hull. He worked in large psychiatry university hospital in Germany as a clinical psychologist and psychotherapist for more than 25 years. He was one of the first researchers in Germany to empirically investigate attitudes towards end of life treatment decisions in collaboration with colleagues from Sweden, Canada, Russia, and Austria. His research findings and its cross-cultural focus have provided significant information for medical and political bodies. He is the Co-Investigator an ESRC Research Seminar Series grant for “Towards a European understanding of advance decision-making: a comparative, interdisciplinary approach”

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