Institution: Cardiff University		
Unit of Assessment: Communication, Cultural and Media Studies, Library and Information Management (34)		
Title of case study: Improving decision-making for patients in vegetative and minimally conscious states		
Period when the underpinning research was undertaken: 2010- ongoing		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	**Role(s):**	**Period(s) employed by submitting HEI:**
Jenny Kitzinger	Professor	27/01/2003 - present
Julie Latchem-Hastings	Research Associate	03/08/2015-02/08/2016 01/10/2016-present
Period when the claimed impact occurred: August 2013 – December 2020		
Is this case study continued from a case study submitted in 2014? Yes		

1. Summary of the impact (indicative maximum 100 words)

There are estimated to be up to 64,000 patients maintained in prolonged disorders of consciousness in the UK. Cardiff research identified failures in best interests decision-making for these patients and highlighted the lack of support available for their families. It also showed the unintended negative consequences of the legal requirement to obtain court authorisation for withdrawing life-sustaining treatment. Through an action-research approach, the team created new cultural representations of these conditions; translated research findings into practical support for families and staff; influenced legal changes increasing the emphasis on patients' own values in treatment decisions (including a landmark Supreme Court judgment); and impacted on new British Medical Association and Royal College of Physicians guidelines.

2. Underpinning research (indicative maximum 500 words)

Modern medicine can keep people alive indefinitely in entirely unconscious ('vegetative') or minimally conscious states. There is no register for these patients and many have become lost in the system. Jenny Kitzinger (hereafter Kitzinger) co-founded and co-directs the Coma and Disorders of Consciousness Research Centre, initially a collaboration with the University of York but now run solely at Cardiff since 2017. She led the Cardiff team, was PI on all main grants **[G3.1-G3.5]** and conducted most of the data collection. She worked on professional training needs with Latchem-Hastings. She conducted the analysis and the impact work around legal issues with Celia Kitzinger (hereafter CKitzinger; York until 2017, now Honorary Professor at Cardiff). This case builds upon and expands Kitzinger's earlier work in this field - the subject of a Cardiff case study in REF 2014 (Id=3653).

The research involved examining media representations of 'coma' and conducting in-depth interviews with over 50 relatives of patients **[3.1-3.4]** alongside case studies with 30 families focusing on decisions about life-sustaining treatment, and real-time tracking of patient pathways through the healthcare and legal system **[3.5, 3.6]**. The team also interviewed clinicians and lawyers, carried out observation in care homes **[3.2–3.5]** and in court hearings **[3.5, 3.6]**, and conducted a review (commissioned by Welsh Government) on understanding and uptake of Advance Decisions ('living wills').

Findings identified two main areas in which there were obstacles to patient-centred care.

2.1 Skills gaps, misunderstanding and misinformation

- People lacked understanding of vegetative and minimally conscious states and how to ensure their own wishes would be respected in the event of losing capacity, partly due to cultural misrepresentations (e.g. around the extent and nature of 'coma recovery') **[3.1-3.6]**.
- There was a lack of support and information to help patients' families navigate their contribution to decision-making **[3.2-3.6]**; a problem compounded by both clinical misapprehensions and misleading media coverage (e.g. promoting the myth that 'next of kin' have decision-making authority) **[3.1]**.
- Clinicians were often unclear about their own decision-making responsibilities, had difficulties communicating with families and were sometimes failing to explore patients' past

wishes about treatment, in contravention of the Mental Capacity Act 2005 (the Act supposed to guide person-centred practice) **[3.2-3.6]**.

2.2 Legal obstacles

The research also found that the presumption that withdrawing feeding tubes from patients in disorders of consciousness always needed judicial authorisation was creating unintentional harms. For example:

- It led to patients in permanent vegetative states being treated by default, sometimes for decades, without consideration of whether such ongoing life-sustaining treatment was in their best interests.
- It contributed to long delays in stopping such treatment – even in cases where families and clinicians had discussed the patient's likely wishes and agreed that it was not in the patient's best interests to continue **[3.5, 3.6].**
- In some cases, clinicians or families felt pressure to stop life-sustaining treatment before the patient entered the 'permanent' state (at which the legal requirements became applicable) – leading to the *premature* withdrawal of treatment in intensive care units, denying some patients the chance of any meaningful recovery that they might have wanted **[3.2].**
- Infections were sometimes left untreated in an effort to allow death without needing a court hearing; this can result in more traumatic deaths compared to those following withdrawal of a feeding tube **[3.2, 3.4]**.

The research provided a 360 degree insight into the cultural, clinical and legal barriers to effective patient-centred care for people in prolonged disorders of consciousness, as well as highlighted the lack of support available for their families and gaps in guidance for staff.

3. References to the research (indicative maximum of six references)

[3.1] Kitzinger, J (2014) 'Media representation of science and health: the case of coma' in Miller, T (ed) *The Routledge Companion to Global Popular Culture*, Routledge pp 333-342
[3.2] Kitzinger, J and Kitzinger, C (2012) 'The "window of opportunity" for death after severe brain injury: Family experiences', *Sociology of Health and Illness,* 35(7): 1095-1112 http://dx.doi.org/10.1111/1467-9566.12020
[3.3] Latchem J, **Kitzinger J**, Kitzinger C. Physiotherapy for vegetative and minimally conscious state patients: family perceptions, *Disability and Rehabilitation*, 2016; 38(1): 22-9 https://doi.org/10.3109/09638288.2015.1005759
[3.4] Kitzinger, C and **Kitzinger, J** (2016) 'Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state', *Journal of Medical Ethics,* 42: 11-17 http://dx.doi.org/10.1136/medethics-2015-102777
[3.5] Kitzinger J and Kitzinger C (2016) 'Causes and consequences of delays in treatment-withdrawal from PVS patients: a case study of *Cumbria NHS Clinical Commissioning Group v Miss S and Ors* [2016] EWCOP 32' Journal of Medical Ethics, 2017; 43: 459-468 http://dx.doi.org/10.1136/medethics-2016-103853
[3.6] Kitzinger J and Kitzinger C (2017) 'Why futile and unwanted life-prolonging treatment continues for some patients in permanent vegetative states (and what to do about it): Case study, context and policy recommendations', *International Journal of Capacity & Mental Health Law,* 23: 129-143 http://dx.doi.org/10.19164/ijmhcl.v2017i24.687

Selected grants:

[G3.1] Coma, consciousness and serious brain injury: Medical humanities and decision making, Wellcome Trust, 28/03/2011 - 27/09/2011, £5,000 (PI: Kitzinger)
[G3.2] Creating a 'Healthtalk' resource on family experiences of disorders of consciousness, ESRC, 11/2/13 - 10/8/14, £23,921 (PI: Kitzinger, Co-I: CKitzinger)
[G3.3] Bridging the 'best interest' gap: decision-making for vegetative and minimally conscious patients, ESRC, 01/03/2016 - 31/08/2016, £14,162 (PI: Kitzinger)
[G3.4] Improving best interests decision-making, Ourtree Trust, 1/2/2017 - 31/1/2018, £41,000 (PI: Kitzinger, Co-I: Latchem-Hastings)
[G3.5] Supporting and accelerating change through an online training resource, ESRC, 01/02/2018 - 31/07/2018, £21,497 (PI: Kitzinger)

4. Details of the impact (indicative maximum 750 words)

The Cardiff research achieved impact as part of a collective movement (working alongside families and practitioners) that led to legal and clinical practice reform. The research impacted on these reforms through: cultural interventions (art and mass media); creation of resources for families; patient advocacy and support for families facing court cases; delivering training; membership of working parties and professional guideline development groups. Through this work, Kitzinger ensured that the research – according to Victoria Butler-Cole QC, a leading barrister in the field – *“directly contributed to the dramatic and positive evolution of the law and practice over the last seven years concerning the treatment of people with prolonged disorders of consciousness”* **[5.1]**.

4.1 Media coverage and new cultural representations

Kitzinger worked with five artists to develop research/art collaborations about prolonged disorders of consciousness, including a theatre performance dramatizing the interview materials, art installations, and digital stories. Evaluation of a touring exhibition of this work combined with talks (six venues across England and Wales, events attended by over 600 people) showed increased knowledge of end-of-life decision-making (on average from 3.3 to 4.6 – an average increase of 1.3 points on a 5 point scale), as well as enriched understanding of emotional and ethical complexities **[5.2**, p.10**]**.

In addition, Kitzinger worked with the media to help contextualise the legal and medical ramifications of disorders of consciousness and to increase public understanding of preparing for the end-of-life. For example, she was interviewed on main evening news bulletins (BBC and Channel 4), the Today programme and the Victoria Derbyshire show; co-produced/presented a BBC Radio Wales programme on Advance Decisions (‘living wills’); and gave a 20 minute interview for Radio 4’s *PM* programme on end-of-life planning. Compassion in Dying, the charity which supports people to write Advance Decisions, report that the interview for Radio 4’s *PM* led to a 400% increase in calls to their helpline and over 10,000 visits to their website **[5.2,** p.21**]**.

Kitzinger also co-produced and presented BBC Radio 3’s *Coma Songs* – a combination of family testimony, especially commissioned poetry and soundscapes (broadcast 2014 and 2015, attracting over 100,000 listeners **[5.3]**). Co-producer Llinos Jones stated that it *“established new forms of cultural representation”* and was *“entirely prompted and shaped by Jenny’s research into prolonged disorders of consciousness…Jenny’s expert knowledge of a wide range of families’ experiences allowed sterile issues to be brought to life…[Coma Songs] opened up new ways of thinking for our audiences by challenging understanding of what it means to be in a vegetative or minimally conscious state,…contextualising Hollywood romanticisation and media stereotypes of these conditions, and sharing insight into families’ journeys and the social, clinical and legal context”* **[5.3]**.

4.2 Supporting families

Funding from the ESRC **[G3.2]**, enabled the expansion and translation of the initial research into an online resource for families of vegetative and minimally conscious patients on the Healthtalk.org site. This website – a collaboration between the Dipex charity and Oxford University – supports new data collection and the translation of research into ‘Information Standard’ certified and accessible information to help patients and families to understand a wide range of health conditions (and to counteract problematic online sources). The resource on disorders of consciousness (launched in September 2014) addresses 39 topics (from initial injury to end-of-life decisions) and includes 90,000 words and 250 video clips. Professor Derick Wade, a consultant in neurological rehabilitation, described it as a combination of *“medically/legally accurate information with the vividness, intimacy and honesty of the research interview material, all framed systematically through the themes identified in your [Kitzinger’s] research”* **[5.4]**.

Within a year of launch the resource made Cardiff joint-runner up for the Guardian’s University 2015 awards in the ‘Research Impact’ category. It also won the 2015 ESRC award for ‘Outstanding Impact on Society’ and the British Medical Association award for ‘Information about Ethical Issues’ **[5.5]**. The resource is promoted as the go-to support for families by major rehab/care centres across the UK and more widely **[5.4, 5.5]** and has been used by over 42,700 unique users, repeat visiting the site over 420,000 times. Three quarters of users come from the UK, USA, India, Canada and Australia, with others from 100 countries across Europe, Asia, and Africa **[5.5]**.

Feedback from families and clinicians who used the site demonstrates that the resource promoted improved decision-making and staff-family communication **[5.5]**. For example, the wife of one patient wrote that healthcare staff *“don't really know what we go through emotionally and practically. Research like this not only helps the families but gives the professionals the opportunity to look beyond the patient to the whole family”* **[5.5]** Professor Wade, routinely recommends the resource in his clinical practice as he found it *“enabled families to find new ways of understanding”*; *“is crucial in reaching patients in non-specialist care homes, who would otherwise lack any expert input”* and helps clinicians *“to gain insights into family experiences and to realise what a partial view they may gain from relying on their clinical experience alone”* **[5.4]**.

4.3 Influencing legal and practice reform

The Cardiff research impacted on law and clinical practice through top-down and bottom-up interventions. Examples of ‘top down’ include the researchers being invited to present at the annual training day for High Court judges responsible for these types of cases. ‘Bottom up’ interventions include how the Healthtalk resource empowered families to advocate for relatives. For example, a patient’s wife who had struggled over four years to get clinicians to engage with strong evidence that her husband would not want to be kept alive indefinitely commented that the Healthtalk resource helped her understand the process and push for a proper clinical review, and was: “*fundamental in making sure that Chris’ best interests were realised. Without Professor Kitzinger’s research and dedication to sharing her expertise, Chris would still be lying in that care home in PVS [permanent vegetative state], being turned every four hours”* **[5.6]**.

Similarly, the sister of a woman in PVS for 33 years, found the research invaluable **[5.5]**. Having gone over three decades without guidance for decision-making, she stated that: *“Finding the Cardiff University resource was a huge relief; we felt understood and it provided so much information and context…This empowered us to act – to channel our utter devotion to Cathy to ensure decisions were taken in her best interests, considering her as an individual. She is now finally at peace”* **[5.5]**.

Wade, an expert medical witness in legal cases, stated that the accessibility of the research was *“essential in bringing some of these cases to fruition in the Court of Protection…many of these cases would not have happened without you [Kitzinger and the team]”* **[5.4]**. The Cardiff team linked families to pro bono expertise, supported them with getting the cases to court, and provided research evidence to legal and clinical teams. Cases influenced by this work, as evidenced by testimonials from a practicing barrister **[5.1]** and the British Medical Association **[5.7a]**, include:

- a case in which the judge made a clear declaration that delays in cases reaching court were inimical to patient’s best interests (*Cumbria NHS Clinical Commissioning Group v Miss S and Ors [2016] EWCOP 32)* **[5.7a]**;
- a case where no best interests review of a patient in a permanent vegetative state had been held for over two decades (*Health board v CL)* **[5.7a]**;
- a high-profile judgment in which priority was given to the patient’s prior expressed wishes (as reported by family and colleagues) over the wishes of his clinical team (*Briggs v Briggs [2016] EWCOP53)* **[5.1, 5.7a]**;
- the first ever hearing for court-approved withdrawal of a feeding tube from a patient in a minimally conscious state (*Re N* [2015] EWCOP 34) **[5.7a]**.

These were an important part of sustained challenges to how patients were being treated and created an environment in which the requirement for mandatory court applications was debated by stakeholders, including health professionals, barristers, and judges. This increased recognition of the problems and culminated in a Supreme Court hearing*: Mr Y (An NHS Trust v Y – [2018] UKSC 46* **[5.1]**. Cardiff research on the unintentional harms caused by mandatory judicial scrutiny was cited in formal written submissions to the Court, and part read out by the Counsel for the Official Solicitor. The Court judgment removed the mandatory requirement to obtain court authorisation to withdraw feeding tubes from patients in vegetative or minimally conscious states.

Dr John Chisholm, British Medical Association, said that the judgment *“removed the stigma around and barriers to families raising the question of whether continuation of clinically-assisted nutrition and hydration was what their relative would have wanted”* and highlighted that clinicians must ensure that treatment is *“in their patients’ best interests”* **[5.7b]**. It also *“exposed the extent of* *conscientious objection among clinicians and allowed the profession to address the problem"* and *"allowed funds that were going to court cases to revert to healthcare"* **[5.7b]**.

Victoria Butler-Cole QC, a barrister involved in many of these cases, confirmed that without the input of the researchers, the Supreme Court judgment would *"not have happened at all"* and that the research led to *"radical improvements in timely and robust best interests decision making for the tens of thousands of patients currently in a prolonged disorder of consciousness"* **[5.1]**. The *"change in the legal landscape...will ensure that this positive impact is realised for all future such patients, their families and clinical teams*" **[5.1]**.

4.4 Improving clinical practice

The research led to *"cultural transformation"* among clinicians and *"a sea change in how therapy teams now approach treatment"* **[5.4]**. This has been achieved partly through making the work accessible to healthcare professionals, e.g. giving invited lectures to over 5,000 professionals in this REF period and delivering online training to over 1,300 trainee or practicing professionals with documented impact on knowledge and understanding **[5.2]**. It was also achieved by impacting on policy documents and briefings e.g. the research informed a House of Lord's report on the Mental Capacity Act 2014 and a Parliamentary Office of Science and Technology briefing sent to all MPs in 2015 **[5.2]**. In parallel with this the research helped shape new clinical guidance.

Kitzinger served on the core editorial team for the revised Royal College of Physicians (RCP) national clinical guidelines (2020) on 'prolonged disorders of consciousness following sudden onset brain injury' **[5.8]** and wrote an appendix on the role of families. The guidelines recommend the Healthtalk resource and cite six of Kitzinger's research outputs. These outputs **[**including **3.2, 3.4, 3.6]** informed the RCP recommendations including the importance of: training staff on the law around best interests decision making; providing high quality information and support to families; and holding regular reviews of treatment decisions. Professor Wade, a member of the development group, confirmed that the Cardiff research *"has been an evidential goldmine"* and noted that *"the rigour with which you've [Kitzinger] documented patterns of outcome and what these mean for people's lives has countered reliance on personal experience, helped shape professional guidelines…and meant we've all had to reassess our practice"* **[5.4]**.

Kitzinger also sat on the expert consultative group for the British Medical Association (BMA)/RCP to develop 2018 guidance for decision-making about feeding tubes for adults who lack the capacity to consent. Dr Chisholm, Chair of the BMA's working party on Clinically Assisted Nutrition and Hydration, said: *"The Cardiff research has been important not just for the typical vegetative state or minimally conscious state patients … but also for a broad spectrum of patients, including frail patients with multiple co-morbidities who suffer a severe stroke or patients with a progressive neurodegenerative condition – all of whom are covered by the BMA/RCP (2018) guidance. The direct impact of their research, and its impact via the court cases building on their work, thus has both deep significance and a scope that expands well beyond the original focus*" **[5.7]**. The research and impact trajectory of this work is continuing to expand including via a 2021 ESRC studentship (supervised by Kitzinger) on **"***The Role of Journalists in Reporting End of Life Decisions: Questions of Ethics, Law and Democratic Citizenship"*.

5. Sources to corroborate the impact (indicative maximum of 10 references)

[5.1] Testimonial from Victoria Butler-Cole QC
[5.2] Evidence summary on impact of research through formal submission of evidence, online training, media work, lectures and events
[5.3] Testimonial from Llinos Jones, co-producer of *Coma Songs*
[5.4] Testimonial from Professor Derick Wade, leading rehabilitation consultant and member of the RCP working party on disorders of consciousness
[5.5] Summary evidence re impact of the Healthtalk.org online resource
[5.6] Testimonial from the wife of a man in a Permanent Vegetative State
[5.7] a. British Medical Association (BMA) guidance; **b.** testimonial from John Chisholm, Chair of the BMA working party on Clinically Assisted Nutrition and Hydration
[5.8] Royal College of Physicians (2020) 'Prolonged disorders of consciousness following sudden onset brain injury: national clinical guidelines'