

Research with Impact

Jenny Kitzinger
Cardiff University

**Interdisciplinary social science research:
Dialogue with policy-makers, practitioners &
“real people”**

For:
Health and Care Research Wales
SWALEC
13th October 2016



Structure of talk

1. Briefly introduce my particular research
2. Highlight 3 areas to consider for impact:
 - foundations for research project
 - collaborations in developing the work
 - outputs and engagement to ensure impact of findings
3. Conclude with questions for you



Research focus: long-term vegetative or minimally conscious state

■ Context:

- No register, estimated to be up to 64,000 patients
- Most people say (in advance) would not want to have life-prolonging treatment in such situations but patient has 'lost capacity' to make decision once in situation
- Modern medical technologies sustain indefinitely
- Complex social, ethical, legal and communication issues

■ Core question:

- how is specialist care provided? What decisions about treatment are made, when, how, by whom?

Where we ended up (so far)

- Impact on national guidelines & inquiries
- Impact on medical and legal practice
- Impact on families going through this situation
- Impact cultural representation and public understanding.

Awards (ESRC. BMA ++)

But how did we get there.....?





Core research activities

- Interviews with family members with relatives in a vegetative or minimally conscious state
- Interviews with practitioners in the field
- Observations/ethnography

Includes tracking trajectories for individual patient over time - over years & across institutions (e.g. hospital, care home, court)



Core impact activities

1. Laying strong **foundations**
1. Building **collaborations** and partnerships
(‘patients’, ‘publics’ ‘practitioners’,
‘policymakers’)
1. Creating diverse **outputs and engagement**
(diverse audiences, diverse formats/outlets)

1. Laying strong foundations

- Classic academic (lit review & scoping conversation)
- +
- Grassroots (what's happening 'on the ground')
- +
- Expert consultation event (briefing paper & seminar, over 2 days)

'bottom up' & 'top down'
'Inside out' & 'outside in'





Strong foundations - outcomes

- Know what was already known, and what was not known (in, and beyond, published work) + what underway
- Understand diverse perspectives on issues
- Network of advisors who became project allies within their fields

2. Building collaborations

Collaborations across:

- Universities (Universities of York + Cardiff)
- Disciplines (e.g., Philosophy, Health Sciences, Biosciences, Law etc)
- Sectors (e.g. health care professionals)
- And alongside 'service users' (families)

Collaboration - outcomes

- allow multi-dimensional examination of a multi-dimensional problem
- productive data mining and speed up publication
- Later allowed us to talk to different audiences/networks ...and joint working is good for logistics (can be in 2 places at once!)



Example of sectors implicated

– e.g. by 'patient's trajectory' through health service

Ambulance
A&E

Intensive
care

Neuro-
surgery

Rehabilitation

Care
homes

Courts

CDoC Research Questions include...

(26 publications since 2013)

- Decision making processes (CK + JK)
- Family experience in social context (CK + JK)
- Advance Decisions to Refuse Treatment (CK + JK)
- Media representations of 'coma' (JK)
- Media representation of brain imaging (Gabby Samuel)
- Construction of diagnosis (Sarah Nettleton)
- Autobiography and the vegetative state (Alice Hall)
- Cost to the NHS? (Richard Cookson)
- Legal status of treatment withdrawal (Simon Halliday)
- Role of advocates (with David Menon, Jakki Cowley, Dot Chatfield)
- Allied Health Professionals role/training needs (Julie Latchem)
- Ethics, data collection, data management (Ben Saunders)

3. Creating diverse outputs

Journal publications

(Open access)



Social Science & Medicine
Volume 116, September 2014, Pages 134–141

A diagnostic illusory? The case of distinguishing between "vegetative" and "minimally conscious" states
Sarah Nettleton^a, Jenny Kitzinger^a, Celia Kitzinger^a

SOCIOLOGY OF HEALTH & ILLNESS
Sociology of Health & Illness Vol. 35 No. 7 2013 ISSN 0141-9889, pp. 1095–1112
doi: 10.1111/1467-9566.12020

The 'window of opportunity' for death after severe brain injury: family experiences
Jenny Kitzinger¹ and Celia Kitzinger²

¹School of Journalism, Media and Cultural Studies, Cardiff University
²Department of Sociology, University of York

Abstract This article builds on and develops the emerging bioethics literature on the 'window of opportunity' for allowing death by withholding or withdrawing treatment from severely brain injured relatives. These interviews were a larger study on the basis of interviewees' reports that have wanted to be kept alive in their current condition (minimally conscious states). Our analysis tracks the decision led to the situation in which life-sustaining treatments 'these patients – maintaining them in a state that some 'rise than death'. We show how the medico-legal following the patient to die structures family

Editorial

Grief, anger and despair in relatives of severely brain injured patients: responding without pathologising
Celia Kitzinger¹ and Jenny Kitzinger²

CLINICAL REHABILITATION
Journal of Evaluation in Clinical Practice ISSN 1360-2753
International Journal of Public Health Policy and Health Services Research

Interpreting chronic disorders of consciousness: medical science and family experience
Andrew Edgar DPhil,¹ Celia Kitzinger PhD² and Jenny Kitzinger PhD³
¹Reader in Philosophy, Centre for Applied Ethics, Cardiff University, Cardiff, UK
²Professor, Department of Sociology, Wentworth College, University of York, Heslington, UK
³Professor, JOMEC, Cardiff University, Cardiff, UK

Journal of Medical Ethics
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J Med Ethics 2015;41:157-160 doi:10.1136/medethics-2013-101799

Law, ethics and medicine

Paper

Withdrawing artificial nutrition and hydration from minimally conscious and vegetative patients: family perspectives

OPEN ACCESS Editor's choice

Celia Kitzinger¹, Jenny Kitzinger²

Disability and Rehabilitation
An international, multidisciplinary journal

<http://informahealthcare.com/dre>
ISSN 0963-8288 print/ISSN 1464-5165 online

Disabil Rehabil, Early Online: 1–8
DOI: 10.3109/09638288.2015.1005759

infor healthcare

RESEARCH PAPER

Physiotherapy for vegetative and minimally conscious state patients: family perceptions and experiences
Julie Latchem¹, Jenny Kitzinger², and Celia Kitzinger³

Policy briefings/interventions

- Serving on Working parties (Royal College of Physicians; Nuffield Council for Bioethics)
- Evidence to House of Lords Scrutiny Committee and to POST
- Set up working party re law



Accessible versions



**Evidence submitted to:
The Law Commission 2015
Consultation on the Law on Mental
Capacity and Deprivation of Liberty**

Professor Jenny Kitzinger, Cardiff University
Co-director of the Centre and Disorders of Consciousness Research Centre
(Universities of Cardiff and York)

A. About me and the research

I am professor of communications research at Cardiff University, specializing in healthcare communication. My research has focused on decision-making for people with neurological brain lesions. I worked on the Brain Collage brain lesions' walking party on 'spiraloid'.

Physicians' walking party on 'spiraloid'

Physicians' walking party on 'spiraloid' on the Boulevard.

neuroscientist's team responsible to Co-director Celia Kitzienger of the Centre and Disorders of Consciousness Research Centre – which carries out research on social, ethical and legal issues around coma,

Serious medical decisions regarding people in vegetative or minimally conscious states

The role of family and friends




Timeline on administering and withholding/withdrawing treatment from severely brain injured patients:

The law and professional guidance




Centre and Disorders of Consciousness Research Centre

www.cdcc.org.uk


Centre and Disorders of Consciousness Research Centre

Serious Medical Treatment and the Law Concerning Patients in a Permanent Vegetative State

EXECUTIVE SUMMARY

Purpose of this document

To summarise key research findings relating to Court of Protection Practice Direction 9e which requires court approval before a feeding tube can lawfully be withdrawn or withheld from a patient in a permanent vegetative (or minimally conscious) state.

Contact: Professor Celia Kitzienger, Co-Director, Coma and Disorders of Consciousness Research Centre.
Email: celia.kitzinger@york.ac.uk

Background

People who suffer profound brain injuries – e.g. through accidents, assaults, strokes, falls and infection – are sometimes left in a permanent vegetative state (PVS): they have a functioning brain stem and can usually breathe on their own but they have no awareness of themselves or their environment. And the longer they remain unconscious the less likely it is that they will ever become conscious again.

...emergency and intensive care, treatments for severely brain-injured ... tech. Keeping them alive requires good basic care (such as ... manage skin integrity), a feeding tube, intermittent antibiotics ... ongoing mechanical ventilation support (such as oxygen at ... that there are between 4,000 and 16,000 PVS patients and it has ... prolonging treatments indefinitely.

... often agree on "ceilings of intervention" – for example, that the ... ed if they have a cardiac arrest – many PVS patients are medically ... continue to be kept alive via hydration and nutrition delivered through a ... is often referred to as either 'artificial nutrition and hydration' (ANH) ... tion and hydration' (CANH) (these terms are used interchangeably): we ... more common term) in this summary.

Online + also hard copies

Key in NHS contexts - Access to internet is often limited + unreliable

Social media - Blogs, tweets. 'The Conversation'

(Timely, brief, emphasis on inviting dialogue)

The screenshot shows the homepage of the Bioethics Forum. At the top, the title "BIOETHICS FORUM" is displayed in a large, teal, serif font, with the subtitle "DIVERSE COMMENTARY ON ISSUES IN BIOETHICS" in a smaller, rounded box below it. Navigation links include "Forum Home", "Articles by Date", "Articles by Subject", and "Articles by Author". A search bar is located on the right side of the header. The main content area features a featured article titled "U.K.'s Landmark Case on Withholding Treatment Affirms the Importance of Patients' Values" by Celia Kitzinger and Jenny Kitzinger, dated 12/03/2013. The article text discusses a recent Supreme Court decision in the U.K. regarding end-of-life decision-making for a patient in a minimally conscious state. To the left of the main article, there is a sidebar with a "The Hastings Center Report" section for July-August 2015, a "Highlights" section with a link to "Drifting Away from Informed Consent in the Era of Personalized Medicine", and a "Subscribe" section. To the right of the main article, there is a "See also" section with links to "Caution on Diagnosing Preclinical Alzheimer's Disease", "New York's Palliative Care Information Act: Flawed but Needed", "Legal Moralism and Restrictions on Abortion", and "The View from Stage IV: Personal Stories in the Public Square".

BIOETHICS FORUM
DIVERSE COMMENTARY ON ISSUES IN BIOETHICS

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The Hastings Center Report
July - August 2015
Vol. 45, No. 4

Highlights

Drifting Away from Informed Consent in the Era of Personalized Medicine
Whose Risks and Benefits?
[VIEW COMPLETE ISSUE](#)

Subscribe
[Order the Hastings Center Report](#)

U.K.'s Landmark Case on Withholding Treatment Affirms the Importance of Patients' Values

BIOETHICS AND THE LAW
Celia Kitzinger and Jenny Kitzinger, 12/03/2013 [Tweet](#)

"Family Lose Right-to-Life Case at U.K.'s Highest Court." "Judges 'Right' to Allow Man to Die." "Widow Loses 'Withdrawn Treatment' Case." These were the headlines on a recent Supreme Court decision in the U.K. about end-of-life decision-making for a patient in a minimally conscious state: Aintree University Hospitals NHS Foundation Trust v James [2013] UKSC 67. This is a particularly significant decision because it is the first case to come before the U.K.'s highest court under the Mental Capacity Act 2005.

It's a long, sad, complicated story about disagreement between a family and a hospital about whether or not particular medical treatments were appropriate.

See also

- [Caution on Diagnosing Preclinical Alzheimer's Disease](#)
- [New York's Palliative Care Information Act: Flawed but Needed](#)
- [Legal Moralism and Restrictions on Abortion](#)
- [The View from Stage IV: Personal Stories in the Public Square](#)

Mass media



Between the Ears

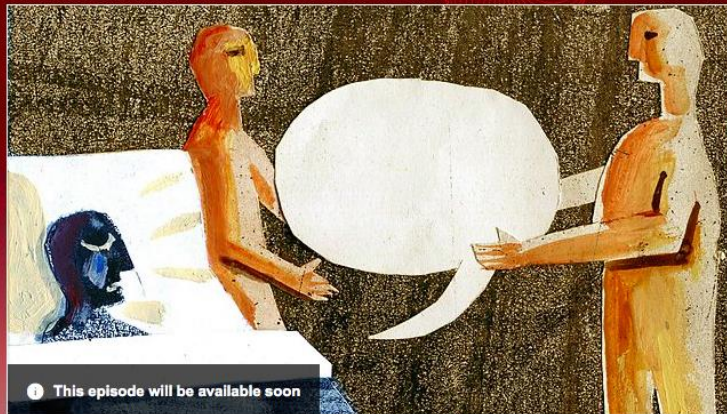


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This episode will be available soon

Coma Songs

A meditation on the cultural representation of comas through music, poetry and interviews with the families of people who have a suffered brain injury.

There are several thousand people in vegetative or minimally conscious states in the UK and, as medical interventions to save the body improve, numbers are growing. 'What is it like being in such as state?', 'Is she in there?', 'Does he recognize me?' 'What should I do for the... > [SHOW MORE](#)

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Family experiences of decision-making

The law about the role of the family in decisions, and how to act in a patient's 'best interests' is clear (see 'Decision-making: the legal situation and clinical practice '), but there was a widespread misconception among many of those we talked to that 'next of kin' were responsible for consenting, or refusing, treatment. In addition, although people had often come across 'Goal setting meeting' or 'Discharge meetings' they sometimes had not been invited to anything called a 'Best Interests' meeting and it was rare to have discussions with health care professionals where it was clear that 'best interests' and considering what the person would have wanted were the main focus of the discussion.

Some families thus experienced a lack of opportunity to represent their relative's own wishes in relation to serious medical treatment. They had very little communication with treating clinicians at all – or meetings which did happen were simply focused on practicalities of delivering care and going through the system (e.g. move from hospital to care home).

Now Playing [view profile](#)

David and Olivia say the 'best interests' of David's mother was not discussed. Meetings simply focused on delivering care, rather than reflecting on the purpose of interventions and what the patient herself would have wanted.

[view profile](#)

Kevin and Miggy wish they'd had regular opportunities to be given more information and to discuss their son's prognosis.

00:17 03:24

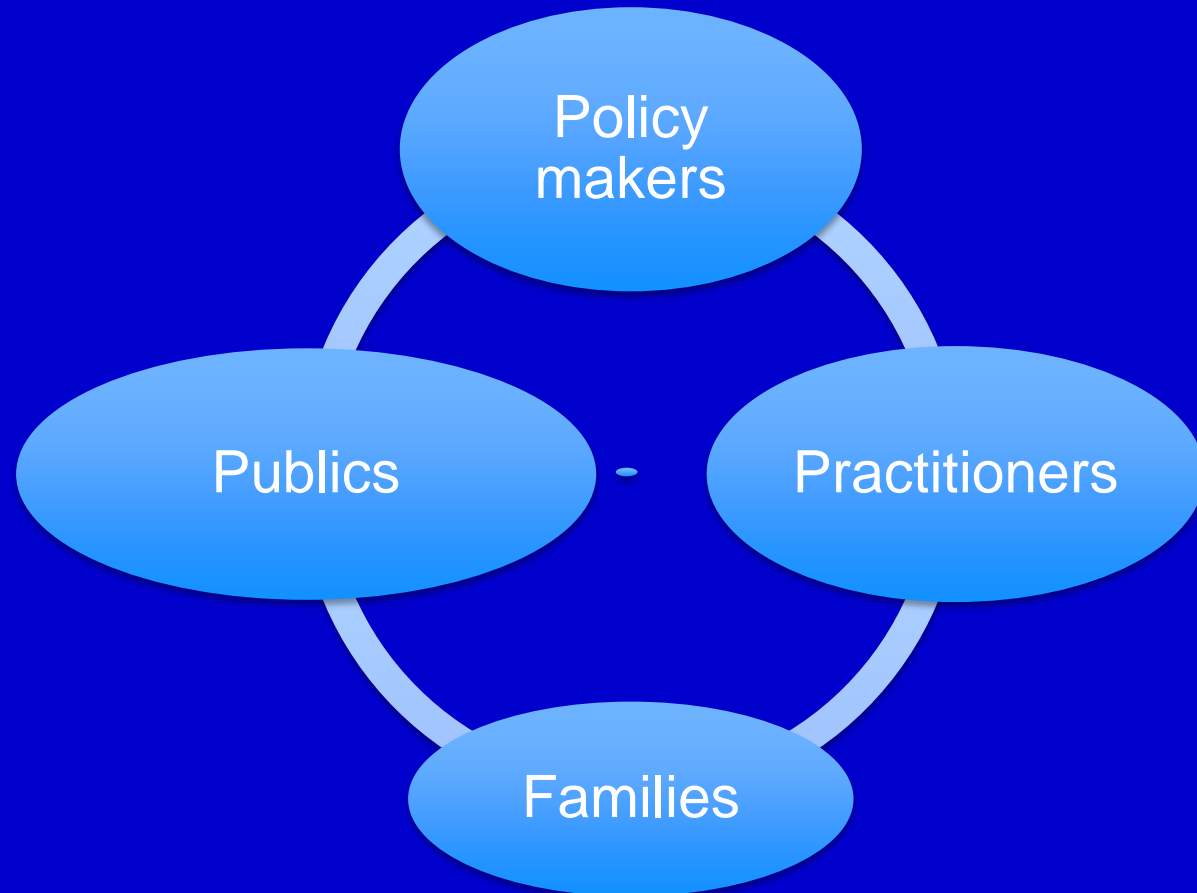
Show Text Version Print transcript

Art

Exhibition events of art, postcard exhibition, shadow puppet theatre, digital stories,



Different outlets, formats and...different audiences



Conclusion

Do you need an impact plan? Yes (and no!) ...start early, integrate impact, identify audiences/allies/networks. Care about outcome? Document impact. Recognise who else (or nobody else) is going to do it.

Balancing costs and benefits of impact work:

- **Costs:**
 - can take you away from 'pure theory' (but see 'benefits')
 - time demands can be huge
 - other priorities slip
- **Benefits:**
 - more theoretically challenging/interesting;
 - impact work *informs* (rather than simply results from) your research
 - can make a difference.

**





A set of question for you -

What *have you/could you* be doing

1. to ensure strong foundations?
2. to build collaborations and partnerships?
(With whom? Pros/cons?)
3. to create diverse outputs and engagement
(Who are your diverse potential audiences,
what formats/outlets)



Thank you

Questions for me??

@JennyKitzinger