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**Supporting families involved in court cases about life-prolonging treatment:
Working as academics, advocates, and activists**

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ABSTRACT

This article explores the links between our roles as academics, advocates and activists, focusing on our research on treatment decisions for patients in vegetative and minimally conscious states. We describe how our work evolved from personal experience through traditional social science research to public engagement activities and then to advocacy and activism. We reflect on the challenges we faced in navigating the relationship between our research, advocacy and activism, and the implications of these challenges for our research ethics and methodology – giving practical examples of how we worked with research participants, wrote up ‘case studies’ and developed interventions into legal debates. We also address the implications of the ‘impact agenda’ - imposed by the British Research Excellence Framework (REF) - for our actions as ‘scholar-activists’. Finally, we ask how practicing at the borders of academia, advocacy and activism can inform research – helping to contextualize, sensitise and engage theory with practice, leading to a more robust analysis of data and its implications, and helping to ensure dialogue between research, theory, ‘lived experience’, front-line practice, law, and public policy.

It’s August 2017 and we’re sitting in Courtroom 43 in the Royal Courts of Justice in London waiting for the hearing to begin. The case concerns withdrawal of clinically assisted nutrition and hydration from a patient in a vegetative state. Celia is towards the front on a long wooden bench with a sloping shelf in front for holding court bundles, laptop, and notes. Jenny is balancing her notebook on her knees from a bench at the back. Apart from us, everyone present is a lawyer.

It’s a familiar environment for us by now – we’ve attended a dozen similar hearings about life-prolonging treatment for patients in vegetative or minimally conscious states. In addition to our academic study of such processes we have, over time, developed a role in supporting families in getting to, and through, the court system. In several cases, we’ve helped to ensure the case actually got to court - at least in the time frame that it did. Usually we are in court with the family – who ask us to sit with them, sometimes requesting an ‘interpretation’ service, explaining the legal language and procedures, and often asking us to support them with the aftermath (ranging from dealing with media coverage to visiting the hospice, or attending any subsequent inquest).

On this occasion, the family chose not to come but Jenny, who has got to know the parents well, has promised to ring them the moment the hearing concludes. The parents first met Jenny about a year ago, at a research 'engagement' evening (involving a book reading and theatre performance based on our research)¹. Several months later they rang asking for help in trying to get their son's case to court. Jenny attended best interest meetings with the parents, helped draft letters to inform the process, found a specialist unit that would conduct a new expert assessment on their son and sat with them while a conclusive diagnosis was given which confirmed that he has been completely unconscious for over twenty years. Jenny is in court as an informal observer (as members of the public are entitled to be) and will let the parents know afterwards what was said, and the judgment (if we get one today).

Unusually, Celia has a formal role in this case. The application for withdrawal of this patient's feeding tube has been made by the Health Board responsible for his care. At the suggestion of the Health Board's solicitor, and with the support of the family, Celia applied to be the patient's litigation friend - a formal role whereby the patient has someone to instruct lawyers on their behalf. Celia took this on rather than the Official Solicitor (conventionally appointed in this role) so as to prevent further potential delays in what has already been a very protracted process. She has appointed a solicitor and barrister and worked with them to produce a position statement - the formal court document laying out the argument and conclusions of any party to the case. The position statement argues that continuing clinically assisted nutrition and hydration (CANH) is not in the patient's best interests. This same position is asserted by the Health Board, and nobody has applied to the court with a contrary view.

All the discussions have happened to get the case ready, the documentation is in place, the barristers are ready to present. The judge enters, we rise. The hearing begins.

How did we – two University professors originally trained in Social Anthropology (Jenny) and Psychology (Celia) – end up in this place betwixt and between academic, advocate and activist? We have documented elsewhere² the long and tortuous journey towards this court application for this particular patient and his family – a journey which dragged on over two decades. Here we focus on our *own* role in cases like this, and explore how our engagement with 'research participants' developed far beyond the conventional research relationship to become a process of working together to inform, and perhaps to change, outcomes for some patients and their relatives.

¹ The book reading was by Cathy Rentzenbrink, author of *The Last Act of Love*, a memoir about her brother's brain injury. Discussion covered the way the family cared for him at home for several years and their subsequent decision to advocate for the withdrawal of his feeding tube (the 'last act of love' of the book's title). Cathy Rentzenbrink has also contributed as an interviewee to our research (and written about that process within her memoir) and done book readings at a series of events organised by our research centre. The artistic collaborations presented that day (visual art and shadow puppet theatre) were funded, in part by a variety of 'impact' funding initiatives and the exhibition event itself was supported by the Arts and Humanities Research Council. A short film about the sort of events we organise showcasing our academic-artistic collaborations can be seen here: www.youtube.com/watch?v=LEuplCcJGj4

² Kitinger, J. & Kitinger, 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 Mental Health and Capacity Law*. 24: 129-143. <http://www.northumbriajournals.co.uk/index.php/IJMHMCL/article/view/687>

In the sections that follow we first briefly introduce ourselves and our research. Second, we present an account of how our work evolved from the personal, through traditional social science research to public engagement activities and then to advocacy and activism. In the third section we address the implications of the ‘impact agenda’ (imposed by the British Research Excellence Framework (REF) for navigating our way between our academic ‘day jobs’ and our advocacy and activism. We then (in the fourth section) reflect on ethical challenges we faced in the course of our research and advocacy, and their implications for our research methodology, and share some of the resources developed while navigating the ethical issues we faced. Finally, we ask how practicing at the borders of academia, advocacy and activism can inform, possibly *transform*, academic understanding of what we can do – helping to contextualize, sensitise and engage our theory with practice, leading to a more robust, challenging and challenged, analysis of data and its implications, and helping to ensure dialogue between research, theory, ‘lived experience’ and policy.

1. Introducing the researchers and the research

We are academic social-science researchers who study the treatment of patients in prolonged disorders of consciousness (coma, vegetative and minimally conscious states) and the experience of their families. We are also sisters with family experience of catastrophic brain injury because our sister, Polly Kitzinger, was injured in this way in a car crash in 2009. It was this personal experience which first catapulted us into a focus on this area of enquiry - building on our pre-existing academic expertise which included research on medical communication, social change, evolving technologies and medical/science ethics. As we began to move into this new research area we sought out new collaborations with colleagues from other disciplines within academia (e.g. law, philosophy, economics) and with practitioners in relevant areas of law and medicine with whom we formed early professional alliances and collaborations that have been crucial to the success and development of our research and practice.

Our research can be described as ‘empirical bioethics’ insofar as it ‘seek[s] to use social scientific data [...] to inform and enhance ethical analyses of topics of bioethical interest’³. The core social scientific data we’ve collected consists of 85 narrative interviews with family members of severely brain injured patients – like the patient whose court hearing we’ve described above - who have (or have had) a relative in a long-term coma, vegetative and/or minimally conscious state. (We have also interviewed healthcare and legal practitioners.) The topic of bioethical interest we seek to ‘inform and enhance’ concerns end-of-life decision-making for patients with severe acquired brain injuries who were, or remain, in prolonged vegetative or minimally conscious states. We’ve examined our data to explore in particular decision-making about the ‘feeding tube’ (Clinically Assisted Nutrition and Hydration [CANH]) from the early weeks through to long-term care settings. On the basis of our findings we’ve made a range of suggestions for improvements/changes in law, practice and social policy.

³ Davies, R., Ives, J. & Dunn, M. (2015) A systematic review of empirical bioethics methodologies, BMC Medical Ethics. 16(15). <https://bmcmedethics.biomedcentral.com/articles/10.1186/s12910-015-0010-3>

Three key concerns identified by our research findings are as follows.

- (a) **Failures when initiating life-prolonging treatment in the early weeks and months after injury to consider the patient's own likely wishes and/or establish time-limit treatment trials.** Our research found that while most families believed that their relative *would* have wanted the feeding tube (and other life-sustaining treatments) to begin with this was not true for every patient – and yet most families of patients whose disorders of consciousness were very *prolonged* (with the patient surviving in such states for months or years) had encountered no discussion of the options in the early days/weeks after the initial brain injury, nor were they invited to contribute any information about the patients' likely wishes, or informed about the 'window of opportunity' for death at this point - a 'window' which might close as the prognosis became clearer⁴. There was also usually no discussion of CANH as a possible time-limited trial – a treatment that might be in the best interests of many patients for a time (allowing them to be sustained while they were stabilised and assessed) but might not have any long-term benefits (e.g. if it was used to sustain them long after it was clear that they were not going to recover to a condition they would have wanted).
- (b) **Continuation of CANH and replacement of feeding tubes once patients have stabilised without following best interests decision-making procedures in long-term care settings.** We found vegetative and minimally conscious states are being 'warehoused' in long-term care homes with no reassessment of their clinical condition, and no reflection on their best interests. Although some families come to the view that their relative would not want this (and survey evidence shows the vast majority of people report that they would not want to be sustained in a 'permanent' condition such as VS/MCS⁵), patients are being kept alive like this for years on end. They are often treated 'by default' without taking into account their past wishes, values, feelings and beliefs. Although many people say they would not want to be kept alive in such conditions is very rare for people (in England and Wales) to make 'Advance Decisions' recording these wishes in a legally binding form. Once they have lost capacity (in the absence of such an Advance Decision) these patients then cannot give or withhold their consent to medical treatments (because they are unconscious or virtually so) and the law then requires that all treatments given should be in their best interests (s. 1(5) Mental Capacity Act 2005). But both the Mental Capacity Act 2005 and the National Clinical Guidelines on Prolonged Disorders of Consciousness⁶ which should guide proper 'best interests' decision making for these patients are widely ignored, misunderstood, or openly flouted in relation to decision-

⁴ Kitzinger, J. & Kitzinger, C. (2012) The 'window of opportunity' for death after severe brain injury: Family experiences. *Sociology of Health and Illness*. 35(7): 1095–1112. <https://onlinelibrary.wiley.com/doi/full/10.1111/1467-9566.12020>

⁵ Demertzi, A et al. (2011). Attitudes towards end-of-life issues in disorders of consciousness: A European survey. *Journal of Neurology*. 258: 1058-1065.

⁶ Royal College of Physicians (2013). Prolonged Disorders of Consciousness: National Clinical Guidelines. (One of us – Jenny – served on Core Executive and Editorial Group of the working party for these guidelines and our research also informed a guide about the role of the family to accompany the main document.) The 2013 RCP Guidance and associated appendices can be downloaded here: <https://www.rcplondon.ac.uk/guidelines-policy/prolonged-disorders-consciousness-national-clinical-guidelines>

making concerning clinically assisted nutrition and hydration⁷. Our research highlights the importance of implementing current law and practice guidelines and suggests ways in which this compliance might be improved.

- (c) **Delays in getting cases to/through the courts for decisions about CANH:** Until very recently in England and Wales, decisions about withdrawing feeding tubes from patients in PVS or MCS were widely understood to require an application to the Court of Protection. After continuing CANH was found (by the patient's treating clinician and family) not to be in the patient's best interests there were often long delays before court applications to withdraw CANH were initiated and they were taking months or years to reach court. These delays – and the apparent need to make a court application in the first place – could be deeply distressing for families and did not always serve (indeed could run directly counter to) the best interests of patients. We analysed the causes of delays⁸ and documented the harm caused by mandatory court applications (not only to the minority of patients for whom cases were started, but the majority who never reached court). Our findings led us to conclude that it should not be mandatory to apply to the Court of Protection before withdrawing CANH from patients in vegetative and minimally conscious states⁹.

In foregrounding the experience of families, our findings complement the work of many clinical and legal experts working on serious medical decision-making and mental capacity and including the excellent analyses of those working specifically on prolonged disorders of consciousness (e.g. Wade, Turner-Stokes, Ruck Keene)¹⁰ as well as in broader issues relating to death and dying (e.g. Marsh, Gwande, Mannix)¹¹ – and of course the moving autobiographical accounts of families themselves (e.g. Spinney, Rentzenbrink)¹²

In addition to publishing academic articles highlighting these research findings we delivered Continuing Professional Development training to a wide range of professionals (including judges) developed booklets, and created on-line training¹³ to try to improve the way the system operated. We also suggested changes to law and practice via submissions of evidence¹⁴, and served on professional committees

⁷ In December 2018, new Guidance on Clinically Assisted Nutrition and Hydration was published jointly by the British Medical Association and the Royal College of Physicians. (One of us – Celia – was on the core group that authored this Guidance). At time of writing, it remains to be seen whether it will effectively influence practice. The Guidance and associated information leaflets and training materials can be downloaded here: <https://www.bma.org.uk/advice/employment/ethics/mental-capacity/clinically-assisted-nutrition-and-hydration>

⁸ Kitzinger, C. & Kitzinger, J. (2016) Court applications for withdrawal of artificial nutrition and hydration from patients in a permanent vegetative state. *Journal of Medical Ethics*. 42(1): 11-17.

⁹ Kitzinger, C. & Kitzinger, J. (2015). Family perspectives on proper medical treatment. In S Fovargue & A. Mullock (eds) *The Legitimacy of Medical Treatment: What Role for the Medical Exception?* London: Routledge. (Also fn 7)

¹⁰ For example: Wade DT (2018) 'How many patients in a prolonged disorder of consciousness might need a best interests meeting about starting or continuing gastrostomy feeding?' *Clinical Rehabilitation* 32 11): 1551-1564; Turner-Stokes, L. (2017) A matter of life and death: Controversy at the interface between clinical and legal decision-making in prolonged disorders of consciousness, *Journal of medical ethics* 43:469-475; Ruck Keene, A et al 2019 Taking capacity seriously? Ten years of mental capacity disputes before England's Court of Protection, *International Journal of Law and Psychiatry* 62: 56-76.

¹¹ Marsh, H. (2014) *Do No Harm*. Orion Books; Gawande A. (2014) *Being Mortal*. Macmillan; Mannix, K. (2017) *With the End in Mind*. Little Brown and Co.

¹² Spinney, L (2016) *Beyond the High Blue Air* Atlantic Books; Rentzenbrink, C. (2015) *The Last Act of Love*. Picador.

¹³ <http://cdctraining.org.uk>

¹⁴ Kitzinger, J, Kitzinger, C (2014) *Evidence to: House of Lords Select Committee on the Mental Capacity Act 2005* (Evidence

including the British Medical Association and the Royal College of Physicians. Over and above such activities, over the last few years, we found families approaching us directly for help. It is this last phase of work - our voluntary support of families in relation to decisions about life-sustaining treatment and the research we are publishing on the basis of it – that we focus on here.

2. Four phases: Personal; Academic Social Science; Public Engagement; Advocacy and Activism

We did not set out, at the beginning of our research, to provide support for families struggling with end-of-life decision making – nor would we, back then, have been well-placed to do so. What we wanted initially was to learn from families about what the challenges were of having a relative in a vegetative or minimally conscious state and we saw the process of ‘giving back’ something to our participants (or to others in their situation) as a much more long-term enterprise – one that would perhaps find expression in policy changes as our findings, and the implications of them, filtered from the academic literature into policy and practice. But the more we learnt, the more we found ourselves in situations where it would have felt wrong to simply listen to our interviewees’ stories without at some point (e.g. after the formal interview had ended, or when they approached us for help later) offering to explain medical information they didn’t understand, giving them names of rehabilitation consultants who would be able to provide the definitive diagnosis they craved, or offering to come along to a meeting with medical professionals to support them in articulating their views. After we had published work, and presented some of it in accessible formats, we were also increasingly approached by families (and indeed health care professionals) suggesting that their experience could contribute to our research and actively *seeking* such support.

Our work with families - and then the case studies based on some of that work - emerged as a result of our increasing expertise in this area (and the visibility of that expertise in accessible formats). It also developed out of the changing experience of research participants who got back in touch (sometimes years after their initial interview) to tell us about their shifting views and experiences and, often, to ask for help. We sought to identify other professionals to assist them, but often ended up doing this ourselves, because of a clear gap in service provision that we were able to fill.

For clarity we present our research in four phases – capturing in broad brush strokes how the research evolved over time, although in fact it is less discrete and linear than this summary makes it appear.

Phase 1 (2009-2011): Personal Case Study

We launched our research as a direct result of our own family experience. In 2009, our sister, Polly Kitzinger, was catastrophically brain-injured in a car accident and was in a prolonged disorder of consciousness for around two years. This led to an intense engagement in the ethical, medical, legal and practical issues. We assumed

submission, 2014); Kitzinger, J, Kitzinger, C (2015) Evidence to: [The Law Commission 2015 Consultation on the Law on Mental Capacity and Deprivation of Liberty](#) (Evidence submission, 2015); Kitzinger, J, Kitzinger, C (2017c) Evidence to: [Parliamentary Select Committee Investigation into Continuing Healthcare Funding](#) (Evidence submission, 2017); Evidence to: [NICE](#) (submitted 2018)

from the outset that, since Polly was unable to speak for herself, the most important ethical consideration was to establish what Polly would have wanted in this situation – and that the role of those who knew and loved her would be to speak on her behalf and represent her views. We were shocked by our experience of how the evidence we presented to clinicians about what Polly’s views would have been were ignored and over-ridden. The first year following her accident was focused on Polly as we fought to have her voice heard, consulting widely with experts in the field, reading extensively about disorders of consciousness (including the ethical, philosophical, sociological, historical and legal literatures to help inform our thinking), documenting the existing law/guidelines (e.g. the Mental Capacity Act 2005) and seeking to gain what influence we could on how she was treated (e.g. Jenny applied to become Polly’s court-appointed welfare deputy).

In the following year, we also put in a complaint against the Health Board - and eventually received an acknowledgment and apology that there had been a failure to comply with the Mental Capacity Act. We were also involved in two court hearings about Polly’s treatment (details of which we cannot publish without being in contempt of court) and we went on to write up (part of) our experiences in academic form positioning our experience within a broader historical, philosophical, ethical, medico-legal context. We gave a series of talks (e.g. to history, philosophy, and clinical audiences – each chosen to help us learn from inter-disciplinary and cross-sector perspectives), and we made international contacts and also began to explore ways in which end of life decisions for patients in prolonged disorders of consciousness were managed internationally (e.g. Celia spent a term in the US as a visiting scholar at the Hastings Bioethics Centre and Yale University Centre for Interdisciplinary Bioethics). We also published a blog post on a leading bioethics site.¹⁵ In writing and speaking about Polly we have had to navigate legal constraints (contempt of court) and ethical issues (e.g. Polly’s inability to consent, and the effect on other family members) and the effect on ourselves (e.g. absorption into a deeply painful issue). This will be explored as part of a paper we plan to develop about ‘insider research’ (building off our earlier poster presentation¹⁶).

Personal stories are a powerful way of communicating the issues involved and we are still frequently asked to talk about Polly in conjunction with our presentation of research findings and policy implications (e.g. most recently – in 2018 - the BBC1 ethics discussion program ‘The Big Questions’ and on Radio 4’s flagship ‘PM’ program in an interview with Eddie Mair¹⁷). These, in turn, seem to effect public understanding and action – e.g. the interview on Radio 4’s PM programme led to a huge spike in calls to the Charity ‘Compassion in Dying’ and downloads of Advance Decision forms from their website.¹⁸

¹⁵ www.thehastingscenter.org/m-polly-and-the-right-to-die/

¹⁶ <http://cdoc.org.uk/wp-content/uploads/2014/05/Insider-Outsider-poster-HQP-2-2.pdf>.

¹⁷ <http://www.bbc.co.uk/programmes/p05sk9qh>

¹⁸ Two days after the interview was broadcast, the Chair of the Trustees of Compassion in Dying wrote to inform us that it had led to a 400% increase in calls to their help line compared to January 2017, more than 10,000 website page views and 200 Advance Decision downloads. (email 4th January 2017)

Phase 2 (2010-2013): Social Science Research: Large-scale in-depth narrative interview study

At the time of Polly's accident we were both university professors and we'd worked on a range of policy-relevant topics throughout our careers: child sexual abuse, HIV/AIDS, and emerging medical technologies (Jenny); lesbian and gay psychology, same-sex marriage rights, and trauma after childbirth (Celia). We both feel strongly that research can play a part in contributing to social change and that it should challenge human rights abuses and injustice. Both of us had embodied in our scholarship and in our activism the feminist maxim that 'the personal is political'. For example, Celia's doctoral research on 'the social construction of lesbianism'¹⁹ was a feminist response to psychology's attempts to pathologise and/or depoliticise her lesbian identity; later she campaigned for the formation of the Lesbian and Gay Psychology Section (now the Psychology of Sexualities Section) of the British Psychological Society²⁰, and was a litigant, with her wife, in a test case at the High Court for the recognition of overseas same-sex marriage²¹. Jenny's doctoral research on child sexual abuse followed her feminist activism in helping to set up one of the first 'incest survivors' refuges in the UK; her research projects on HIV/AIDS were closely linked with her social and political commitments in the early stages of the epidemic; and this link between the personal and the political continued through her work on issues such as cancer, genetic research and nanotechnologies. The long-standing intersections between our personal lives, our activism and our scholarship, and the ways in which these played out in public arenas, meant that we had engaged seriously from an early stage in our research careers with questions of 'objectivity' (vs 'subjectivity') in science, considering the relationship between researcher and researched, and exploring the challenges and affordances of both 'insider' and 'outsider' research (and the murky boundaries between them)²².

There was a sense of inevitability in our choice (though it didn't really feel like a 'choice') to work together to research how treatment decisions are made for patients in prolonged disorders of consciousness, to find out whether what had happened to Polly was commonplace or an exception (had she/we just encountered particularly poor practice?), and what could be done to prevent this kind of harm happening to other patients and their families. Around a year after our sister's accident we decided we felt able to conduct formal research looking at other families' experience of the treatment of their relative. We engaged policy maker, clinical and legal stakeholders (e.g. in a Wellcome Funded two-day seminar at the outset of this phase) and started to audio-record interviews with other people with experience of having a relative in a long term vegetative or minimally conscious state. Our research has, from the outset, involved connections with research participants that went beyond the research context – e.g. our first research participants were people we met via our own social contacts after our sister's accident, including 'at the bedside' in wards (see 'method' section, fn 4). Recruitment was then expanded (clearly

¹⁹ Kitzinger, C. (1987). *The Social Construction of Lesbianism*. London: Sage.

²⁰ <https://www1.bps.org.uk/networks-and-communities/member-microsite/psychology-sexualities-section/history-psychology-sexualities>

²¹ *Wilkinson v Kitzinger* [2006] EWHC 2022 (Fam). See also Kitzinger, C. & Wilkinson, S. (2004). Social advocacy for equal marriage: The politics of 'rights' and the psychology of 'mental health'. *Analyses of Social Issues and Public Policy*. 4(1): 173-194.

²² Wilkinson, S. & Kitzinger, C. (Eds.) 1996. *Representing the Other*. London: Sage.

declaring the fact of our own family experience) such that most of our subsequent interviewees were encountered for the first time in interview and there was no on-going relationship with most of them beyond the formal research processes. However, some chose to stay in touch e.g. updating us about developments, approaching us for advice and/or requesting second, or even third interviews – sometimes years later - to talk about changes in the patient's condition or in their own thinking and experience. We developed a fairly standard protocol for informed consent and research ethics for this project – approved by our respective Universities (then, York and Cardiff) – and standard information and consent forms for our participants.

Phase 3 (2013-2014): Public Engagement: Filming interviews and developing the healthtalk.org resource

Our 'healthtalk.org' initiative (collaborating with Oxford University)²³ introduced a new approach to interviewing. We video-recorded interviews and asked for consent to use selected video-clips as part of this on-line resource. At this point our earlier ethics permission/protocol (from our own universities) was supplemented by the ethics protocol initially developed at Oxford University's Department of Primary Care Health Sciences approved by NHS Berkshire Research Ethics Committee. Working to this new ethics protocol we ensured that interviewees had an appropriate level of informed consent and control over how their interviews appeared and how they were described (e.g. signing off on a summary of their story). Interviewees reviewed not just the use of their own material, but also often commented on the site as a whole, and several came to the launch event for the resource and have stayed in touch, with a clear interest in our evolving work. Two family members (previous interviewees) were important members of the Steering Group for this project, which also included a leading brain surgeon and neurorehabilitation consultant, and a representative of a national brain injury charity. Our online resource won a number of awards (from the ESRC, the British Medical Association and from Cardiff University) and these facilitated further applications for (mostly internal) 'impact funds' helping us to develop online learning tools, run events (e.g. book readings, art exhibitions) and other translations of our work into 'engagement' materials/events which reached out to families, publics and practitioners. We also spoke about our work on the media (appearing on radio programs such as 'Inside the Ethics committee'²⁴).

Phase 4 (2016-ongoing): Advocacy and Activism 'Case work' and 'case studies':

The fourth (current) phase of our work was not planned. In some cases it evolved spontaneously out of the interview research and our ongoing contacts with interviewees. In other cases it was initiated by families who approached us volunteering their stories and asking for support (sometimes on the advice of doctors or lawyers, sometimes because they had encountered our work through our online resources, 'engagement' activities or via open-access academic publication or media work). The majority of families who've contacted us believed their relative would NOT want ongoing treatment and that clinicians were failing to take this into account in 'best interests' decisions about them. However, we have also been contacted by family members who believe life-sustaining *should* continue and that 'best interests' procedures were not being followed in *that* direction. We were happy to support

²³ <http://www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/topics>

(This was supported by impact funding from the Economic and Social Research Council and support in kind from the Oxford University Health Experiences Research Group and the Dipex charity)

²⁴ <http://www.bbc.co.uk/programmes/b07m7n0g>

families in either case – our focus always being on ensuring good practice (i.e. following the law and, in particular, ensuring that information about the patient’s values, wishes, feelings and beliefs was properly considered in making treatment decisions about them). In practice, we ended up working as volunteer advocates and developing ‘case work’ with a wide range of families.

The support we’ve provided as part of our case work has been in large part determined by the shape and size of the ‘service gap’ for these families. It includes a wide range of activities ranging from supporting families to write letters, through to helping their relative get appropriate assessments or treatment – see box 1.

Box 1: Examples of the support we have provided to families via ‘case work’

- listening empathetically to the anger, frustration, grief and despair often expressed by these families, and showing that we understand (sometimes through reflecting on links with our own personal experience);
- asking questions that might challenge assumptions (e.g. concerning family members’ guilt about having ‘made the decision’ for life-prolonging treatment to continue or stop);
- exploring with families how much of the distress associated with having a relative in a prolonged disorder of consciousness is common across families’ experience – not linked to individual psychology – and how much of its source lies in systemic failings in the system.
- identifying, celebrating and building on families’ strengths as they try to do the ‘right thing’ by their relative;
- informing families of the patient’s legal rights (something they were often unaware of before – with their initial position coming from a ‘moral’ sense of the patient’s rights rather than necessarily knowing the legal framework);
- explaining the procedures that should be followed to determine the ‘best interests’ for the patient (a term families have sometimes never heard before), including the importance of considering the patient’s own wishes;
- explaining the families’ role and responsibilities in relation to determining ‘best interests’ (including explaining that ‘next of kin’ have no special legal status to ‘make decisions’ for their relative);
- making contact (at families’ request) with commissioners and providers of care for the patient, and raising issues with policy makers, in order to inform them of their legal obligations (or supporting clinicians to do so) and chasing up delays and trying to progress appropriate best interests decision-making processes;
- engaging with diverse family members to help explore or explain issues (including mediating for family members in conflict with one another);
- supporting family members in their input into, and understanding of the processes involved (including accompanying them to sessions where diagnostic tests were conducted on their relative, results given, or decisions about treatment made);

- outlining options and talking about palliative care (often we found families had not been told there were options or, even if they had been, little (or sometimes misleading) information had been given about palliative pathways and the dying process)²⁵;
- signposting families and professionals to expert legal/medical input as necessary (including putting families in touch with pro bono legal support and putting care providers/commissioners in touch with independent expert medical assessors);
- signposting family members to counselling/psychology resources (e.g. via GP, Stroke Association);
- signposting family members to religious/ethical advice e.g. putting one family in touch with a hospital Imam from another city with experience of advising families on end of life decisions;
- reviewing and giving feedback on documentary evidence for the court (e.g. letters about the patient's prior expressed views) and offering guidance on how to process applications to court as efficiently as possible (a novel and intimidating procedure for many involved);
- providing support for family members in preparation for and during court hearings (explaining the procedures, translating technical terms into 'lay' language; helping them manage potential journalistic interest);
- supporting families as their relative dies (with both practical and emotional aspects e.g. as they accomplish their relative's move to an appropriate hospice, witness a sometimes uncertain and protracted dying process, experience mixed feelings about the death, or go through the funeral and the coroner's inquest);
- supporting families when they talked to journalists or appearing alongside them to provide research context in discussions of their case (e.g. on the BBC2 'Victoria Derbyshire Show', 23 Sept 2016)²⁶.
- providing practical guidance to families who want to use their experience to create change for the future – to help other families others like them e.g. via social media campaigns, fundraising, or making representation to the professional medical or government bodies about the changes needed²⁷

²⁵ Kitzinger, J. & Kitzinger, C. (2018). Deaths after feeding tube withdrawal from patients in vegetative and minimally conscious states: A qualitative study of family experience. *Palliative Medicine*. Online First <http://journals.sagepub.com/doi/10.1177/0269216318766430>.

²⁶ For an example of a discussion of this case see <https://www.bbc.co.uk/news/magazine-37444379>

²⁷ For example, we wrote to the Welsh Cabinet Secretary for Health, Wellbeing and Sport and provided a pre-publication copy of our case study of one family's experience (their son was kept in PVS for over two decades without a review of his best interests) see Kitzinger, J. & 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 Mental Health and Capacity Law*. 24: 129-143. www.northumbriajournals.co.uk/index.php/IJMHMCL/article/view/687 This led to a meeting with the Deputy Chief Medical Officer, followed by the Minister making a public commitment to ensuring that the care of VS/MCS patients in Wales was reviewed, instructing the Chief Medical Officer to write to every Health Board in Wales to assess the potential number of cases in Wales and to seek assurance that their diagnosis, care and treatment was being undertaken in their best interests. This also led to the setting up of a Task group to make recommendations for improvements in practice in Wales. See Statements on the Welsh Government website by Vaughan Gething on 1st October 2017, 30th Jan 2018 and 8th December 2018) (e.g. <https://gov.wales/about/cabinet/cabinetstatements/2018/diagnosis-treatment-care-permanent-vegetative-state/?lang=en>)

We recognize that elements of this work can - and maybe should - be done by others, including case managers, Independent Mental Capacity Advocates (IMCAs)²⁸, counsellors/psychologists, neuro-navigators, brain injury charities, doctors, and lawyers. In practice, families are left without many elements of this support and where such support is offered it is often fragmented and poorly designed for this group of families, who need joined-up support usually over months or years.

Our published case studies (so far there are three) emerged out of the case work we were doing. They were not part of a formally defined 'research project'. We had no funding, and no predefined research questions or protocols. We simply wanted to write about these cases because we learnt a lot from them and they have important implications. Working on and writing about cases in which we have been involved in this way has raised challenges, since they did not fit straightforwardly into our 'day jobs' as academics (section 3), nor did they fit traditional ethics protocols (section 4).

3. Advocacy, Activism and the Impact Agenda

The effect of the 'impact agenda' in British universities, and the increasing expectation that our research should have relevant and measurable social or policy outcomes, means that more academics are likely to find themselves involved in research of this type. This involves some practical challenges – for example, what is the responsibility of academics to follow through when members of the public approach them for support as a result of their university-funded engagement activities? Where do the boundaries of 'university approved' academic impact end and one's own commitment to advocacy/activism begin? How do we navigate the value (or not) placed on such activities and our relationship with colleagues and our universities?

Most of the case work we carried out (until October 2017 when Celia resigned from University of York) was 'on top of' our full-time academic professorial jobs. Our university managers were/are enthusiastic supporters of our work insofar as it results in high quality outputs and can be used for REF impact case studies, but the amount of time and energy devoted to supporting individual families in the ways described above does not fit straightforwardly with an academic job. We defined most of it as 'voluntary work' to be done outside our paid employment – but, to be done effectively, we needed flexibility to attend key events (court hearings, for example, are not scheduled with reference to our university teaching schedules). We found ourselves working extremely hard, juggling externally scheduled support work activities (like the need to be in court on particular dates) with competing commitments timetabled in the workplace and we were both dependent on the understanding and respect for our work from our colleagues and employers. Jenny was met with full support from both her immediate colleagues and from senior management within Cardiff University, but Celia had a very different experience at York. Indeed, this situation was particularly detrimental to Celia who was assessed for and refused promotion (in the same year that she was awarded a Lifetime Achievement Award by the British Psychological Society) on the grounds of

²⁸ We benefitted from an ESRC IAA award allowing the secondment of an Independent Mental Capacity Advocate (IMCA), Jakki Cowley, who was able to work alongside us for six months (with much mutual learning and support). She took on some of the labour that we might otherwise do (e.g. in the Briggs case, supporting family members to write statements, accompanying them to 'best interests' meetings, supporting them at court cases, and going with them to TV studios).

insufficient “citizenship” activity - attendance at Departmental meetings having taken second place to attendance at best interests meetings and court hearings. Unfortunately, “advocacy seems a poor fit with prevailing metrics for evaluating academic performance”²⁹ – at least with the way in which some University managers interpret it. Celia resigned from University of York as a direct result of being refused promotion and is now an Honorary Professor in the Law School at Cardiff University and delighted to be connected with a School with so many other clearly socially-engaged projects (e.g. the Transparency Project³⁰).

4. Practical Ethics at the Boundaries of Research, Advocacy and Activism

The ethics of working at the borders of academia/advocacy/activism means developing ethical practice in ways that go well beyond those currently formulated by professional bodies such as the British Sociological Association or British Psychological Society, or by university-wide ethics committees or review boards. Others have commented on the distinction between ‘procedural ethics’ (approval from relevant research ethics committee) and ‘ethics in practice’ – the everyday ethical issues that arise in the course of doing research³¹, including the blurring of role boundaries and management of multiple identities³² when one is not only a researcher, but also a member of the group being researched and a support-person for families. In this section of the article we try to articulate some of the nuts and bolts of ethics-in-practice in our research.

4.1. Self-care

Despite commitment to our case work, and the sense of being useful it brings, it can also leave us feeling emotionally drained and exhausted – and it often means we are ‘on call’ at evenings and weekends. Like ‘sensitive’ research more generally the work can be demanding and stressful³³. There are additional costs and benefits – and complex dynamics - for us as ‘insider researchers. We are aware of the need for ‘self-care’ and each of us has put strategies in place. At different points in our research we’ve both received counseling. We also debrief with, and support, each other. We are massively sustained through the research process by evidence that we are making a difference – to individual patients and their families, and to law and social policy. Researchers in other areas have commented on the extent to which ‘making a difference’ is a key coping strategy e.g. for researchers investigating sexual violence this included: breaking the silence around sexual abuse, assisting research participants in accessing services, working with participants and communities for safer environments, developing policy and programs, and writing³⁴.

²⁹ Rogers, W., Draper, H., Leach-Scully, J. & Moorlock, G. (2017). Bioethics, advocacy and activism, Australasian Association of Bioethics and Health Law. <http://www.aabhlconference.com/1524>

³⁰ <http://www.transparencyproject.org.uk/about-us/>

³¹ Guillemin, M., & Gillam, L. (2004). Ethics, reflexivity, and “ethically important moments” in research. *Qualitative Inquiry*. 10: 261-280.

³² Ledger, A. (2010). Exploring multiple identities as a health care ethnographer. *International Journal of Qualitative Methods*. 9(3): 291-304.

³³ McGarrol, S. (2017) The emotional challenges of conducting in-depth research into significant health issues: Reflections on emotional labour, fieldwork and the life course. *Area*. 49(4): 436-442. Dickson-Swift, V., James, E. L et al. (2009) Researching sensitive topics: Qualitative research as emotion work. *Qualitative Research*. 9: 61-79.

³⁴ Coles J, Astbury K et al. (2014). A qualitative exploration of researcher trauma and researchers’ responses to investigating sexual violence. *Violence against Women* 20(1): 95-117.

More recently we have sought out non-managerial supervision from an experienced counsellor to help to ensure that we deliver the best support possible, and that our focus remains firmly on what is right for each individual patient and family, and that our work is sustainable and we do not 'burn out' after what is now, almost a decade of working in a very difficult field.

4.2. Managing multiple roles: personal involvement, advocating for patients and/or families, being researchers, being activists

Families who approach us for support often know a lot about us before making contact with us (e.g. from what they've been told by whoever referred them and/or by looking at our website and the online open access academic publications or resources we've produced). We try to make sure they know, where relevant, that we have personal experience of fighting for our sister's life-sustaining treatment to be withdrawn and have written extensively on other families' experiences of this and we always refer them to our *cdoc.org.uk* website to get a more rounded picture of what we do, as well as to the *healthtalk.org* resource if they've not already found it. In response to feedback from a Cardiff Ethics Committee about our emerging research ethics, we adapted and consolidated the individual emails we had developed 'on the hoof' when family members approached us for help, and used these to create a standard document in which we explicitly spell out the kind of support we can offer and the terms on which we are offering it³⁵.

We've also developed our own guidelines to manage issues of confidentiality, making it clear that we will share information with each other but will seek written permission before sharing the views or experience of one family member with others in the same family. Confidentiality is especially crucial when we are also discussing the case with the treating clinician or family lawyer (who may have been the person who put the family in touch with us in the first place) – or with other members of the clinical team, independent experts, and so on. We are also clear that we will not use any information shared with us in our privileged support role without the consent of the person who gave it to us. We make explicit to families that we are offering support with 'no strings attached' in the sense that our support is not contingent on any expectation that they would be willing to participate in our research. At the same time, we want to reserve the right to comment on cases in the public domain. Serious medical treatment cases in the Court of Protection are heard in public and can be attended and reported (usually subject to reporting restriction orders which require confidentiality) by journalists, academics and anyone else who wishes to attend. This means it is open to us to write up a case study based only on publicly available information without the consent or involvement of the family – and we also make this clear to them. Latterly we've also learnt that it is important to make clear that we don't have time to write up *all* the cases we work on: some families have been disappointed that we have not reported their stories.

4.3. Publishing case studies and what information we use (and don't use)

In point of fact we have not published anything about most of the 'case work' we've been involved in – in part because we've not had time to do so given the intense time pressures on us as a result of the case work. Ironically this has meant watching others analyse and publish cases about which we have much more information.

³⁵ www.cdoc.org.uk/your-info/

When we have published case studies, we've always also interviewed the family (and sometimes professionals involved in the case as well) and negotiated with families and with professionals involved whether and how to use the information we've gained from non-public sources. We have also engaged in extensive pre-publication consultation with the parties involved. Each of our published case studies draws from different sources as follows:

- Case Study 1: “When ‘Sanctity of Life’ and ‘Self-Determination’ clash: Briggs versus Briggs [2016] EWCOP 53 – implications for policy and practice”³⁶ This article is about the Paul Briggs case. Along with the IMCA, Jakki Cowley (seconded to Cardiff University for 6 months thanks to ESRC Impact funding) we were involved in helping the patient’s wife, Lindsey Briggs bring this case to court (and, with Lindsey Briggs’ full support, we live-tweeted the court case). However, this article draws *only* on the publicly available published judgment. It does *not* use our experience of the prolonged and difficult process of getting the case to court – we simply have not had time to write such an article (although we have the family’s support to draft such a piece). The existing published paper does not draw on any knowledge or context from our support work – and could have been written about any publicly heard case by anyone attending it, without the involvement or consent of the family. As we say in the article, we simply use our “*experience of supporting families, advocating for patients and training healthcare professionals in similar situations*” to give context to our reading of the judgment. We argue that it helps us “*to consider the implications of the published judgment for policy and practice with patients in prolonged disorders of consciousness and their families*”.
- Case study 2: “Causes and consequences of delays in treatment-withdrawal from PVS patients: a case study of Cumbria NHS Clinical Commissioning Group v Miss S”³⁷. This article, unlike the Briggs article draws not only on the published judgment, ‘*but also on the two authors’ involvement in supporting the family (before, during and subsequent to the court hearings) as a result of their academic and policy-related work in this area. This includes conversations with the family and with members of the clinical and legal teams, and observations in court*’. Our prior work with the mother of Miss S followed the approach outlined above (e.g. early on mentioning the possibility of writing about her case and later asking her for an interview). She, and everyone else involved, was “*provided with the opportunity to give feedback on it and consent has been obtained for all direct quotations.*” In addition: “*Because we draw on detailed notes made during our attendance at the [public] court hearings, we shared a draft with the two judges involved in the case, neither of whom has objected to its publication. The family members involved (S’s mother, brother and daughter) fully support the publication of this article and the use of their words. Miss S’s brother, for example, wrote: “I am more than happy for my quotes to be used”, adding, “I really appreciate the fact that you have used [a particular quote]” [email to authors] and Miss S’s mother stated: “I seriously hope that the whole case is eventually in the public domain as [we] have nothing to hide or be ashamed of [and, without public discussion] nothing will change and other families will probably experience some*

³⁶ Kitzinger, J., Kitzinger, C. & Cowley, J. (2017). When ‘sanctity of life’ and ‘self-determination’ clash: Briggs v The Walton Centre NHS Trust & Ors [2016] EWCOP 53. *Journal of Medical Ethics*. 43(7): 446-449. <http://jme.bmj.com/content/43/7/446>

³⁷ Kitzinger, J. & Kitzinger, C. (2017). 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*. 43: 459-468. <http://jme.bmj.com/content/43/7/459>

of the devastating aspects we had to endure” [email to authors]. The patient herself, ‘Miss S’, lacked capacity to give consent—but members of her family believe she would have wanted it made public.”

- Case study 3: “Why futile and unwanted life-prolonging treatment continues for some patients in permanent vegetative states (and what to do about it)”³⁸

This article is “[b]ased on interviews with the patient’s parents, and the court decision” (this is the court case described at the beginning of this article). In addition, “We contextualize this in relation to our work with 85 family members of patients in disorders of consciousness and ask why, despite guidelines, policies and statute concerning ‘best interests’ decision-making, thousands of PVS patients are similarly maintained in England and Wales without any formal review of whether CANH is in their best interests”. In the ‘Methods’ section we describe how we supported the patient’s parents in bringing the case to court but state explicitly: “Although this much broader experience undoubtedly informs our understanding and approach to this research, we have not explicitly drawn on it in this article and we have not used any privileged information gained as part of our role in advocating for the patient or his family.” The parents would have preferred that their son’s name had not been used in the published court judgment, and were very concerned about media publicity. In negotiating publication of our article with them, we agreed not to use their son’s name, notwithstanding that it was already in the public domain.

4.4. Navigating dialogue and pressures at pre-publication stage

In each case study the families involved have been very supportive of publications – and where any deletions were requested by family members (e.g. as outlined above) we’ve fully understood and complied with their requests. We have found it harder to navigate some less supportive reactions from professionals - academic reviewers, editors, legal/clinical practitioners or policy-makers – and found some of their comments less easy to understand. In the article about the Briggs case, for example, our original submission to the journal included interview and fieldwork data – but on the basis of feedback from the editor and reviewers (for whom this seemed to be unfamiliar data), we excluded this material from the published version, at the cost of some important analytic and policy-relevant points. In the case study of Miss S, our statement that the judges did not ‘object’ to the articles publication obscured the difficulties we had with one of the judges involved in this case who responded (via his clerk) to our email quoting what he’d said in court and explaining that we intended to publish it with a suggestion that we might be in contempt of court. We were only able to resolve this by seeking help from our legal contacts in the Transparency Project, who confirmed that the hearing was held in public and we were permitted to quote from it. In the third case study, we express our gratitude towards the key figures involved who provided valuable comment on the draft – and describe how seriously the case was taken by practitioners and policy makers; we do not write about the fact that sharing the draft led to some criticisms and pressure not to publish from those indirectly implicated in some of the problems the analysis exposed. It is instructive that each case study encountered at least one challenge at the point of sharing the draft (or sections of it). This is a further consideration when

³⁸ Kitzinger, J. & 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 Mental Health and Capacity Law*. 24: 129-143. <http://www.northumbriajournals.co.uk/index.php/IJMHMCL/article/view/687>

developing work at the borders of academia and activism: these challenges are time-consuming, anxiety-provoking, and can be difficult to resolve.

5. From advocacy to activism: Pushing forward case law and legal change.

Our advocacy for individual families taught us a great deal about the practical problems in the way the medico-legal system operates in practice for patients in prolonged disorders of consciousness – the sticking points where ‘best interests’ breaks down, nobody is identified as a decision-maker for a particular patient, responsibilities are diffused and denied, and the system falters and fails. A great many of the problems, as we’ve described in our published work, were ‘unintended consequences’ of the apparent requirement that patients in PVS or MCS must be referred to the court before life-prolonging treatment can be withdrawn in their best interests. We documented the delays and obstructions associated with the legal process – and we contributed to policy discussion about necessary changes (e.g. via a Working Party on Practice Direction 9E, chaired by Celia which reported to the Court of Protection Rules Committee – and PD9E was eventually withdrawn in December 2017).

The cases we’ve been involved in include some of the key case law in this area which have helped to clarify and move forward the way in which such cases are dealt with. We provided information and support to the daughter (and attended the court hearing) in the first case in which a judge declared that it was not in the best interests of a minimally conscious (as opposed to vegetative) patient for CANH to be continued (*Re N* [2015] EWCOP 34). (The daughter is also one of our research interviewees). This case was ground breaking but it was widely interpreted – in ways perhaps not intended by the judge – as limited to patients in MCS who were in deteriorating health as a result of a degenerative disease (multiple sclerosis in N’s case) and hence for whom there was no hope of ‘recovery’. The circumstances were very different in the case of Paul Briggs (*Briggs v Briggs* [2016] EWCOP53] – see our article on this case described above - since he had been injured in a road traffic collision and (in the view of the clinical staff) still had the possibility of recovering to higher level of consciousness, notwithstanding that he would still be severely physically impaired and reliant on others for all the activities of daily living. The judge’s decision that life-prolonging treatment could be withdrawn from a minimally conscious patient with the potential for further recovery, and the basis on which that judgment was made, was a landmark decision in the area of prolonged disorders of consciousness. We attended – and live tweeted – the court hearing, and one of our articles was handed by the family’s barrister to the judge at the beginning of the hearing.

We also supported the family in the case of Mr Y (*An NHS Trust v Y* – [2018] UKSC 46) which definitively settled the issue of whether there was a requirement for every decision about CANH- withdrawal from vegetative or minimally conscious patients to be approved by the court. In delivering the Court’s decision, Lady Black rejected the notion that there is no such mandatory requirement: “If the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court”³⁹. The earlier cases

³⁹ *An NHS Trust and other v Y* [2018] UKSC 46. 126.

– in which we had been involved – were cited in the Supreme Court as key case law. Our research was also cited in submissions to the Supreme Court, and specifically referred to (read out loud to the court) by Counsel for the Official Solicitor. Subsequently we were called on by journalists to comment on the final judgment (including appearing on the main evening news bulletins for BBC and Channel 4). In other cases, we've supported families in complaining about delays in cases reaching court, and –since the development outlined above – worked with families to ensure that it is possible to move ahead with treatment withdrawal in accordance with the guidelines, without making an application to the court.

We believe that our research and our involvement with families has supported the development of case law and improvements in the way that courts deal with these cases. It also specifically helped to inform the removal of Practice Direction 9E and the Supreme Court decision that the law does not require mandatory court applications in such cases. Through our work with the British Medical Association core group on CANH we've been able to provide positive input in shaping the new guidance, including contributing a training podcast (posted on the BMA website⁴⁰) which explains to doctors how families should be consulted. It is clear from the approaches we are now receiving from families and from clinicians that these developments are supporting timely and more patient-centred decision-making, with a proper focus on the best interests of the patient.

Our work as academics, advocates and activists is now inextricably linked. Our research questions arise out of the case work we are doing. For example, we're now talking with health care professionals about issues of 'conscience' and 'conscientious objection' – and developing e-learning tools about this⁴¹. We decided to do this as a direct result of having attended a 'best interests' meeting at which the treating consultant and a palliative care consultant informed the family that it would be 'unethical' and equivalent to 'euthanasia' to withdraw a feeding tube from a profoundly brain injured patient whose family believed he would not want life-prolonging treatment. These issues of conscience were rarely explicitly declared in the early days of our research and declaring conscientious objection appears to have become more common since law and policy have been more explicit about the fact that treatments can only be delivered to non-capacitous patients if they are in their best interests.

Although the ethical (and practical) issues of being academics thoroughly imbricated in advocacy and activism can sometimes be complex and challenging, it would seem to us impossible – even if we wanted to - to retreat now into an ivory tower of disengaged bioethics research! This does not mean that we think we should do this all the time in relation to all of our research, nor does it mean we think other academics should all do this! The aim of this article is not to be prescriptive – but we hope it may – in exploring some of the challenges and opportunities of working across these boundaries - invite dialogue with others working in this way and be of some support to those considering developing their work in such directions.

⁴⁰ https://www.youtube.com/watch?v=yw66KHs1g_0&feature=youtu.be

⁴¹ See the e-learning resources developed out of our research, informed by new guidelines and refined through the understanding 'case work' gave us of challenges on the ground: <http://doctraining.org.uk>