

**COLLABORATIVE DTP STUDENTSHIP 2018**

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| Pathway title | Journalism and Democracy |

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| Title of proposed PhD research project | **End-of-Life Decisions in the News: Medical Ethics, Law and Democracy** |
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| Anticipated main supervisor | Professor Jenny Kitzinger kitzingerj@cardiff.ac.uk |
| We have a formal partnership with ‘Advance Decision Assistance’ [ADA] - a charity devoted to promoting improved public understanding of Advance Decisions and improvements in Best Interests decision-making. ADA will provide 10 days free consultancy, including expert input into research design, implementation and working alongside Prof Jenny Kitzinger to support the student in translating research findings into useful materials for journalists. We have close links with other organisations including the charity ‘Compassion in Dying’ [CiD]and a wide range of palliative care groups. These organisations/experts are all keen to contribute to, learn from and implement findings from this work, developing their communications strategies to enhance media reporting and public understanding of end of life decision-making. Our advisory group includes the Director of Communications for CiD and the Chief Executive of Hospice UK.Professor Kitzinger’s established working with key organisations and her recent appointment to The LancetCommission on the Value of Death means that regular discussions are already integrated into her everyday working practice, and the student will be included in this. In addition our partners will help:* develop the project
* mentor the student in key research sites (including observation at court hearings around disputed end of life decisions)
* be involved in on-going discussion of findings as they emerge
* work alongside the student/supervisor in developing outputs (e.g. training materials) and impact and engagement activities

This project is anchored by JOMEC’s social science conceptual and methodological expertise in journalism and democracy and draws on interdisciplinary expertise in law and medicine. It will align scholarly enquiry with professional, real-world priorities, producing conceptual and empirical findings relevant across academia and to key stakeholders (e.g., news organisations, NGOs, policy-makers, clinicians) concerned with improving the quality of media representations of end-of-life issues – empowering citizens to have more understanding of end-of-life decision-making and more control over decisions for themselves – and to be involved in the wider democratic debates about palliative care and end-of life-support.This proposal seeks to enrich understandings how journalists and sources might better inform citizens about complex rights and choices at the end-of-life. The project builds on the pathway’s focus on journalism and democracy and the supervisor’s world leading expertise in this arena and the partner’s work promoting public understandings. Methodologically, it will extend journalism studies theory and methods of researching source activities, news values/practices/representation and offer a broader engagement with legal/ethical/clinical challenges and everyday practices of end-of-life decisions played out in public and private domains in the context of evolving technologies and institutional practices. **Context:** Modern medicine can sustain the body long after patients have lost the mental ability to participate in decision-making and after quality of life has become very poor. Decisions about whether life-sustaining interventions should continue are everyday occurrences but have received less scholarly or journalistic attention than high-profile topics such as ‘Assisted Dying’. This has resulted in a serious democratic deficit around such crucial decisions that will affect all of us as patients or as family members and citizens. **Aims**: This project will examine how journalists cover ‘best interests’ decision-making about treatment withdrawal for people unable to make decisions for themselves (e.g. patients with advanced dementia or in unconscious states) and how this compares to the range of source events/activities/statements. **Rationale:** How we engage with end-of-life decisions as individuals, families, social networks and professional carers is key to the quality of deaths experienced, the grief and memories of those left behind, and to social support for diverse policies of care. News stories are central to questions around democratic decision-making and the broader political fabric of our lives and relationships with one another and our own bodies.Death is a significant ‘life-event’ yet is something we are often ill-prepared to address. One in three of us will face the end of our lives unable to make choices for ourselves. Recently there has been a series of high-profile court cases and a growing social movement to ‘reclaim dying’ through establishment of ‘death cafés’, ‘festivals’ and promotion of advance care planning. These are important developments and journalism is well-positioned to make significant contributions toward citizen knowledge and understanding. **Research Questions**: When are end-of-life decisions covered in the news? What makes some stories more newsworthy than others and why? Whose voices are heard, what range of opinion is represented and how are source statements selectively used and what information is (or is not) included? How are key players represented, and what ideas about death, emotion, choice, rights, medicine, ethics, law and society play out in the news narratives?  **Methods/design**: Content and discourse analysis of news reporting of end-of-life decisions; journalist interviews, analysis of source statements and attending public court hearings. The interface between journalism, medical ethics and legal studies will be a key aspect of the student’s methods training and make a unique contribution to the field of journalism and democracy. |