



## **Caring for Critically ill Children in the Glare of Digital Media**

### **Rights Best Interests and Public Good in the Age of 'Generation Tagged'**

6<sup>th</sup> Winchester Conference on Trust, Risk, Information and the Law  
#TRILCon19

**Date: Wednesday 1 May 2019 9.15-5.15pm**

**Venue: West Downs Campus, University of Winchester, Winchester, UK**

#### **Speaker Biographies**

**Dr Liam Berriman** is a lecturer in Childhood and Youth Studies in the Department of Social Work and Social Care, University of Sussex. He is co-author of *Researching Everyday Childhoods: Time, Technology and Documentation in a Digital Age* published as an open access ebook by Bloomsbury in 2018: <http://dx.doi.org/10.5040/9781350011779>. His work currently focuses on how practices of care in childhood are transformed by technology and digital data.

**Claire Bessant** is Associate Professor in Law at Northumbria University, Newcastle. Her research interests relate to human rights and the family. She is particularly interested in the role of parents as guardians of their children's privacy, and the legal ramifications of parental sharenting. Currently Claire is working on a research project examining parental understandings of the law relating to their family's information privacy.

**Professor Jo Bridgeman** is Professor in Healthcare Law and Feminist Ethics at the University of Sussex. Jo's research adopts a critical feminist perspective informed by and developing the feminist ethics of care in consideration of parental, professional and state responsibilities to children. Jo has published widely on the medical treatment of children, including: the care of children with complex needs; parental responsibility for children undergoing treatment for cancer; withholding/withdrawal of life-sustaining treatment from a child; issues arising from the Bristol Royal Infirmary Inquiry.

**Peta Coulson-Smith** is a paediatric doctor in the Wessex region and is a Clinical Training Fellow and Senior Teaching Fellow in Clinical Ethics and Law at the University of Southampton. Peta is a member of the UHS Clinical Ethics Committee and has a specific interest in difficult decisions in medical practice for children. Peta is researching the ethical issues associated with the decision-making process and utilisation of medical technology for critically ill children on the intensive care unit.

**Dr Ranjana Das** is a Senior Lecturer in Media and Communication at the Department of Sociology in the University of Surrey - Guildford, UK. She has been co-author/editor of *The Future of Audiences* (Palgrave, 2018) and *Provocative Screens* (Palgrave, 2017). She has been funded by the Arts and Humanities Research Council, UK, the British Academy and the Wellcome Trust, and has directed the CEDAR network on the future of audiences (2015-2018). Her current work focuses on parenthood, intimacies and everyday life in platform societies.

**Katie Gollop QC** is a Barrister at Sergeant's Inn. Within her specialism of healthcare law, Katie has a broad practice. She is a highly experienced trial advocate. Well known for her ethical work, many of Katie's serious medical treatment cases in the Court of Protection attract national news coverage. She has represented families and healthcare providers at high profile inquests and is instructed in public enquiries. Katie represented Great Ormond Street Hospital in the Charlie Gard litigation.

**Dr Victoria Jaynes** is a Research Fellow in Digital Sociology and Humanities at the University of Sussex. Her current research focuses on 'sharenting', exploring how children and young people feel about having their information and images shared by family members. Previously her research has engaged with young people's everyday experiences of the digital from an interdisciplinary feminist perspective. Her research interests include: gendered experiences of technology, young people and youth culture, ethnographic methods and digitally mediated representational practices.

**Professor Anneke Lucassen** is an expert in Clinical Genetics within Medicine at the University of Southampton and combines key clinical, laboratory and ethico-legal expertise to research developments in genetic medicine and to effect improved delivery of genomic services to individuals and families. Her particular interest is the ethico-legal aspects raised by new genomic technologies. In 2001 she co-founded [the UK Genethics Group](#) which is a national forum for the analysis of ethico-legal issues arising in genetic practice, which has held nearly 50 national meetings to date. She co-leads the Clinical Ethics and Law unit in the Faculty of Medicine, Southampton (CELS: [www.soton.ac.uk](http://www.soton.ac.uk)). Her leadership role in national policy development and implementation of best practice is evidenced by appointment to the Human Genetics Commission until 2012; Nuffield Council of Bioethics 2009-2015; Member of HFEA scientific review of treatment of mitochondrial diseases 2011-2014 and Genomics England Ethics Advisory committee 2013 onwards. She was the inaugural chair of the British Society for Genetic Medicine Ethics and Policy committee, and plays a key role in the development, and running of, the Wessex Genome Medicine Centre. From 2017 she is Chair of the British Society for Genetic Medicine.

**Stephanie Nimmo** is an award-winning, London-based writer, freelance journalist, marketing consultant, trainer, public speaker and campaigner. She focused mainly on the health and social care sectors with an emphasis on issues around paediatric palliative care, disability, learning disability, autism and issues affecting carers. She also writes and speaks regularly on the subject of grief and bereavement. As well as writing a successful and highly influential blog, she has also authored two books, written for *The Guardian*, *The Independent*, *The Telegraph*, *The BMJ*, *Marie Claire*, *Woman & Home*, *The Sun*, *The Mirror* and many other publications. She is regularly called on to give comment in the media on both national radio and TV and has spoken at APPGs and receptions at the Palace of Westminster on numerous occasions. Stephanie is an

ambassador for the charity Together for Short Lives and also help train medical professionals at Great Ormond Street Hospital.

**Dr Emma Nottingham** is a Senior Lecturer in Law at the University of Winchester. Her research specialises in children's rights and medical law and ethics. She is particularly interested in the legal and ethical implications of medical decision-making concerning children. Currently, Emma is working on a research project examining the case of Charlie Gard and Alfie Evans to explore the impact of social media on the care of critically ill children. This research explores issues including children's rights to privacy and moral distress of medical professionals. Emma is the Editor of the blog Paediatric Bioethics and tweets @EmmaCNottingham.

**Mr Robert Wheeler** has been a Consultant Paediatric & Neonatal Surgeon in Southampton since 1994. His main surgical interest is in paediatric oncology, chairing the Surgical Section of the national Children's Cancer & Leukaemia Group (CCLG) until 2011. He has the largest presented single-surgeon series of Wilms' tumours, and a particular interest in the technicalities of tumour dissection. Mr Wheeler is an Intercollegiate Examiner in paediatric surgery, and a member of the Invited Review Mechanism of the Royal College of Surgeons. Mr Wheeler is also an academic lawyer, specialising in clinical law. An Honorary Senior lecturer at the University of Southampton since 2009, he in 2013 became the Director of the Department of Clinical Law at University Hospitals of Southampton, the first such department in the NHS: <http://www.uhs.nhs.uk/HealthProfessionals/Clinical-law-updates/Clinicallawupdates.aspx> He has a monthly column, 'Cross Examination' in the Bulletin of the Royal College of Surgeons. He contributes to Powers' Clinical Negligence, and has surgical and legal chapters in thirty-five medical textbooks; most recently, the Oxford textbook of surgical consent. He is an editor in the forthcoming OUP textbook on Medical Ethics and Law, and author of the forthcoming 'Clinical law for clinical practice'.

### **Helen Ryan**

Helen Ryan (nee James) is a senior lecturer in law at the University of Winchester specialising in medical law and mental health law. Helen's research also explores the ethical and legal implications surrounding the participation and depiction of very young children in broadcast productions and on social media platforms such as Facebook, Twitter, Instagram and YouTube. She was lead author (with Marion Oswald and Emma Nottingham) of the recent paper, *The not-so-secret life of five-year-olds: legal and ethical issues relating to disclosure of information and the depiction of children on broadcast and social media* published in the Journal of Media law was influential in a subsequent stakeholder workshop and report '*Have 'Generation Tagged' Lost Their Privacy? A report on the consultation workshop to discuss the legislative regulatory and ethical framework surrounding the depiction of young children on digital, online and broadcast media*' (with Oswald, Nottingham, Hendry and Woodman). Her book chapter 'Generation Tagged and the Global You Tube Family' in 'The Digital in Children's Early Years: Research, Design and Practice' is due out in late 2019. Helen provides consultancy in medico-legal education and is alternate Vice-Chair of the Health Authority Research Ethics Committee (Hampshire A). She is also Editor-in-Chief of the Journal of Information Rights, Policy and Practice (JIRPP).

**Dr Peter Wilson** has worked for the University Hospital Southampton NHS Foundation Trust since September 2003. He is a consultant in paediatric intensive care, and led the PICU retrieval service between 2003 and 2006. In 2007, he became director of the unit. Dr Wilson is now clinical division lead. He has previously worked at the Paediatric intensive care unit training at Great Ormond Street Hospital, Guy's Hospital and New Children's Hospital (Sydney, Australia). Dr Wilson was involved in the Channel 4 documentary 'My Dying Child'.