



UNIVERSITY OF
WINCHESTER
CENTRE FOR INFORMATION RIGHTS

Caring for Critically ill Children in the Glare of Digital Media Rights Best Interests and Public Good in the Age of ‘Generation Tagged’

6th Winchester Conference on Trust, Risk, Information and the Law
#TRILCon19

Date: Wednesday 1 May 2019 9am-5.15pm

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

In the recent cases of Charlie Gard and Alfie Evans, the parents of critically ill children advanced social media campaigns to overturn the decisions of the doctors and the courts to withdraw life-sustaining medical treatment. This fuelled a social media crusade which led to 'moral panic' against 'the State' (represented here by the NHS and its staff). This workshop explores the impact of social media on critically ill young children and their parents as well as professionals who work alongside them. It is of interest to a range of fields including, but not limited to, medicine, philosophy, law, sociology, anthropology, history, education, media and communication studies, medical humanities as well as those from the biomedical ethics community.

Aims of the day are to consider:

- the difficult ethical implications which arise when a critically ill child is the subject of a social media campaign.
- the impact of social media campaigns upon the care and privacy of critically ill young children.
- the ethical questions surrounding the exposure of intimate details about a child's health via social media
- the impact of social media on the confidence of parents in the ability of medical professionals
- the role of social media in facilitating parents to explore treatment options abroad
- the 'moral distress' of medical professionals
- the public perception of the medical profession and the NHS
- the competing rights of parents, children, the press, medical professionals and the NHS

Speakers

Liam Berriman, Lecturer in Childhood & Youth Studies, University of Sussex.

Claire Bessant, Associate Professor in Law at Northumbria University

Jo Bridgeman, Professor of Healthcare Law & Feminist Ethics, University of Sussex.

Peta Coulson-Smith, Senior Teaching Fellow in Clinical Ethics and Law, University of Southampton.

Ranjana Das, Senior Lecturer in Media and Communication, University of Surrey.

Katie Gollop QC, Barrister, Sergeant's Inn.

Victoria Jaynes, Research Fellow in Digital Sociology/Humanities, University of Sussex.

Anneke Lucassen, Professor of Clinical Genetics, University of Southampton. Honorary Consultant in Clinical Genetics.

Stephanie Nimmo, award-winning writer, freelance journalist, marketing consultant, trainer, public speaker and campaigner.

Emma Nottingham, Senior Lecturer in Child Law and Medical Ethics, University of Winchester.

Helen Ryan, Senior Lecturer in Medical Law, University of Winchester.

Robert Wheeler, University Hospital Southampton.

Peter Wilson, University Hospital Southampton.

Workshop Fee To book a place at the conference, please click here to visit the [Winchester University Store](#) and click on academic conferences. For more information, please contact the conference team at trilcon19@winchester.ac.uk

Nurses/AHP/students - £40

Doctors/Academics/lawyers/other - £60

(a small number of free places are available for those with no access to funds, email trilcon19@winchester.ac.uk for details)