

LITERATURE REVIEW

Disagreements in the care of critically ill children: emerging issues in a changing landscape

Dr Neera Bhatia¹

*Senior Lecturer in Law, Deakin University, School of Law,
Melbourne, Australia*

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¹ Correspondence to: neera.bhatia@deakin.edu.au. Dr Neera Bhatia undertook the review and provided the first draft; Dr Giles Birchley (University of Bristol, Centre for Ethics in Medicine) provided advice and comments on the first draft; Professor Richard Huxtable and Dr Jonathan Ives (University of Bristol, Centre for Ethics in Medicine) provided further edits to subsequent drafts.

Contents

Summary	3
Introduction	4
Methodology	6
Findings	7
A: The role and impact of the internet, social media, and crowdfunding.....	7
B: Parents seeking innovative medical treatments.....	13
C: Child medical tourism.....	18
Identification of gaps in research.....	20
Conclusion	21
References	22
Appendix 1: Recent high-profile cases in the UK.....	29

Summary

Disagreements between parents and healthcare professionals concerning the care and treatment of critically ill children in the U.K. have recently received considerable attention. Disputes of this nature are ethically, legally and socially fraught. A number of recent U.K. high-profile cases have received an unprecedented amount of national and international media attention and commentary from the public and the academic community.

This review of the literature aims to explore some of the challenges that are emerging in a changing healthcare landscape when disagreements occur between parents and healthcare professionals in the care and treatment of critically ill children. The key challenges for future legal, social and policy development that emerged from the literature are: (1) *the role and impact of social media/internet in treatment decisions*, (2) *innovative treatments*, and (3) *child medical tourism*.

The role that the internet and social media play in healthcare is a developing area of study and continued research in this area is vital. In light of recent high-profile cases in the U.K., it is especially important to attempt to understand how to mitigate the harm to all parties where treatment disagreement occurs and where the use of the internet and social media plays an integral role. There is a paucity of literature and empirical data regarding child medical tourism, and further research as to its legal and ethical impact is recommended. There is also a need for further research into a possible national and/or international framework(s) or guidance for appraising parental requests for innovative treatments for critically ill children.

The emerging challenges discussed in this report raise legal, ethical and social concerns that will impact, affect and influence the lives of many, including critically ill children, parents, healthcare professionals, and wider society. These are new challenges being faced in an era of rapidly advancing medical science and technology, and it is crucial that policymakers keep pace. Disagreements about the care and treatment of critically ill children are matters of life and death. They require the most critical attention and measured consideration by those involved in developing law, policy, research and appropriate governance.

Introduction

- 1 Care, treatment, and medical decision-making for critically ill children can be complex, protracted and distressing for all parties involved, including the child, parents, healthcare professionals and, increasingly, wider society.² Emerging technology and medical science continue to extend the lives of patients, including the lives of critically ill infants and children with life-limiting conditions.³ This has resulted in an increased expectation that modern medicine will be able to improve quality of life or offer complete cures to health conditions.
- 2 In most cases, medical treatment decisions for critically ill children are discussed and agreed upon through a 'shared decision-making' process.⁴ This generally involves the treating doctors and parents. In some instances, however, parents and healthcare professionals disagree on treatment decisions and may have divergent views on how best to treat critically ill children, and what is in their best interests. The most contentious disagreements often occur when limits to life-sustaining treatment are at issue.⁵ For example, parents of a critically ill child may request the continuation of life-sustaining medical treatment against clinical opinion that further treatment would no longer be in the child's best interests.⁶ Another example of when conflict may arise is where parents of a critically ill child seek to access innovative therapies where their effectiveness and risks are unproven. This uncertainty may cause healthcare professionals to advise against their use.⁷
- 3 Conversely, although occurring more rarely in court reports, parents may request that a specific type of medical treatment not be provided to a child, contrary to medical advice that the treatment is in the child's best interests.⁸ When disputes between parents and healthcare professionals about a child's medical treatment reach an impasse, court intervention is legally required to determine what is in the best interests of the child.⁹

² Sarah Barclay, 'Recognizing and managing conflict between patients, parents and health professionals' (2016) 26 *Paediatr Child Health (Oxford)* 314.

³ Lorna K Fraser and others, 'Rising National Prevalence of Life-Limiting Conditions in Children in England' (2012) 129 *Pediatrics* 923; Padmanabhan Ramnarayan, and others, 'Characteristics of Deaths Occurring in Hospitalised Children: Changing Trends' (2007) 33 *J Med Ethics* 255.

⁴ Giles Birchley and others, 'Best interests' in paediatric intensive care: an empirical ethics study' (2018) 102 *Arch Dis Child* 930.

⁵ Conflict arises in a range of healthcare situations both in adult and paediatric medical specialities. Disputes of all severity occur regularly. However, the most prominent types of disputes that require court intervention are those concerning end-of-life matters. See, Liz Forbat and others, 'Conflict in a paediatric hospital: a prospective mixed-methods study' (2016) 101 *Arch Dis Child* 23.

⁶ See Appendix 1.

⁷ See Appendix 1.

⁸ An example of when this occurs is where a parent refuses a necessary blood transfusion for a child due to their religious beliefs. See, Joe Brierley, Jim Linthicum and Andy Petros, 'Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?' (2013) 39 *J Med Ethics* 573, 576. For example, see the case of *Neon Roberts - An NHS Trust v SR* [2012] EWHC 3842 (Fam).

⁹ *Glass and another v United Kingdom* (2004) 39 ECHR 15.

The role of the Court

- 4 The law in this area has developed on a case-by-case basis, centrally premised on the concept of 'best interests'.¹⁰ While there is no legal definition to determine 'best interests',¹¹ it is a central principle in medical treatment decisions, including those that may be a matter of life or death for a critically ill child. For at least two decades, irresolvable disagreements between parents and healthcare professionals concerning medical treatment decisions for critically ill children in the U.K. have required court involvement. There have been an increasing number of cases since the 1980s in which the courts have been required to decide whether medical treatment is in the best interests of a child.¹²
- 5 English law states that the welfare of the child should be the 'paramount consideration' of the court.¹³ 'Welfare' has been held to be synonymous with 'best interests' in English case law.¹⁴ Additionally, factors including quality of life, futility of treatment, and burdens and benefits of treatment have developed over time through the body of English case law that may also inform the discussion as to what is in a child's best interests.¹⁵ Some of the literature has suggested that an exploration of other socio-economic factors that extend beyond the best interests approach taken by the courts warrant consideration, particularly in circumstances where survival is a possibility for a critically ill child. These include the likelihood of/or severity of disability, and the long-term impact of caring for a critically ill child on the wider family circle and broader society.¹⁶ A 2006 Nuffield Council on Bioethics report entitled: 'Critical care decisions in fetal and neonatal medicine: ethical issues' also explored a range of social, legal, ethical, and economic issues pertaining to the care and treatment of extremely premature and critically ill babies.¹⁷

Four recent U.K. high-profile cases

- 6 Legal academics have developed the concept of 'stigmata cases', noting five distinct features that are common to these types of cases. These five features relate to cases that: are relatively novel and ethically controversial; raise the balance of personal interests

¹⁰ Jo Bridgman, 'Gard and Yates v. GOSH, the Guardian and the United Kingdom: Reflections on the legal process and the legal principles' (2017) 17 *Med Law Int* 285, 287. The philosopher David DeGrazia has argued that the best interest principle is based on desire fulfilment, hedonism and objective-list theories of wellbeing. See, D DeGrazia, 'Value theory and the best interests standard' (1995) 9 *Bioethics* 50.

¹¹ Although not exhaustive, the English courts shall have regard to a number of factors under section 1(3) of *Children Act 1989*. These factors are often referred to as the 'welfare checklist', in determining a child's best interests. See, *Children Act 1989* s 1. See also, Neera Bhatia and Mirko Bagaric, 'Best Interests of Neonates: Time for a Fundamental Re-Think' (2013) 20 *J Law Med* 852.

¹² See, Richard Huxtable, *Law, Ethics and Compromise at the Limits of Life: To Treat or Not to Treat?* (Routledge 2013). See also, Margaret Brazier and Emma Cave, *Medicine and the Law* (6th edn, Manchester University Press 2016) 442.

¹³ *Children Act 1989* s 1. The same principle governs the law of Scotland and Northern Ireland. See S Elliston, *The Best Interests of the Child in Healthcare* (Routledge 2007).

¹⁴ Jo Bridgeman, *Parental Responsibility, Young Children and Healthcare Law* (Cambridge University Press 2007) 101.

¹⁵ See, Richard Huxtable, *Law, Ethics and Compromise at the Limits of Life: To Treat or Not to Treat?* (Routledge 2013).

¹⁶ Some of these issues have been discussed in Neera Bhatia, 'Tensions and Trauma in end of life decision making for (extremely) premature or critically impaired infants' in Ian Freckelton and Kerry Petersen (eds), *Tensions & Traumas in Health Law* (Federation Press 2017). See also, Neera Bhatia, *Critically Impaired Infants and End of Life Decision Making: Resource Allocation and Difficult Decisions* (Routledge 2015).

¹⁷ 'Critical care decisions in fetal and neonatal medicine: ethical issues' (Nuffield Council of Bioethics November 2006) <<http://nuffieldbioethics.org/wp-content/uploads/2014/07/CCD-web-version-22-June-07-updated.pdf>> accessed 15 September 2018.

and public interests; force us to consider the goals of medical practice; offer an opportunity to take stock of the boundaries between the anomalous and routine, the normal and the pathological; and require the courts to develop a social, even moral, vision to respond to the social and cultural revolution of contemporary medicine.¹⁸

- 7 In the last five years, there have been four high-profile cases in the U.K. where parents and healthcare professionals have disagreed on the withdrawal of life-sustaining treatment and/or the suitability and access to innovative therapies (Appendix 1). In the cases concerning Ashya King (hereafter *King*), Charlie Gard (hereafter *Gard*), Isaiah Haastrup (hereafter *Haastrup*) and Alfie Evans (hereafter *Evans*) the five distinct 'stigmata' features discussed above are identifiable.¹⁹ These cases received an unprecedented amount of media and public attention and challenged medical and legal decision-making processes. Each case was met with considerable media scrutiny, mass global attention and academic commentary. All raised broader questions about the factors that contribute to developing disagreements about the care and treatment of critically ill children.
- 8 Directed by the overarching brief, a sub-set of targeted questions guided a review of legal, social and policy studies. These questions were:
 - i. Which factors appear to contribute to the ways in which disagreements about the care of critically ill children develop between parents and health professionals (mainly doctors), hospitals and policy-setting bodies in the U.K.?
 - ii. Which of the above are identified as key challenges for future policy?
 - iii. Are there gaps in the research?

Methodology

- 9 A 'rapid review' methodology was implemented to appraise the literature in a short space of time. Rapid review is, '*a type of knowledge synthesis in which components of the systematic review process are simplified or omitted to produce information in a short period of time*'.²⁰ Initial searches of the *PubMed*, *JSTOR*, *HeinOnline*, *Project Muse*, *WestLaw (U.K.)*, *LexisNexis (U.K.)*, *Bailii (U.K.)*, and *Google Scholar* databases were undertaken for the high-profile case names. This enabled a focused review that captured current social and/or scientific factors influencing disagreements about the care and treatment of critically ill children. The rapid nature of this review means that formal quality appraisal was not conducted before papers were included. Where, however, there are obvious limitations to evidence and/or argument this has been highlighted.
- 10 Three key challenges for future legal, social and policy development emerged from the literature: (1) the role and impact of social media/internet in treatment decisions, (2)

¹⁸ Derek Morgan and Robert G Lee, 'In the Name of the Father? Ex parte Blood: Dealing with Novelty and Anomaly' (1997) 60 *Mod Law Rev* 840; Jonathan Montgomery, 'Law and the demoralisation of medicine' (2006) 26 *Legal Studies* 185, 186

¹⁹ See Appendix 1.

²⁰ Sara Khangura and others, 'Evidence Summaries: The Evolution of a Rapid Review Approach' (2012) 1 *Syst Rev* <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3351736/pdf/2046-4053-1-10.pdf> accessed 15 September 2018; Andrea C Tricco and others, 'A Scoping Review of Rapid Review Methods' (2015) 12 *BMC Med* 224.

innovative treatments, and (3) child medical tourism. To further inform the discussion of these challenges, further literature was carefully selected from the results of supplementary searches on the eight databases discussed above. Additionally, more targeted searches using Google accessed pertinent social media platforms and media articles.

Findings

A: The role and impact of the internet, social media, and crowdfunding

- 11 Access to the internet is changing the way parents of critically ill children are able to gain healthcare information and exchange ideas with others on social media.²¹ Parents may refer to the internet as their initial source of information when first informed of their child's medical condition. They may be unwilling to solely rely on, or accept, the medical diagnosis and/or opinion given to them at first instance. In which case, they may use the internet and the information obtained to challenge medical expertise or opinion, potentially bringing alternative medical treatment plans to the attention of treating healthcare professionals.²² Thus, easy access to internet may provide parents with a greater sense of empowerment in being self-informed, able to diagnose/re-diagnose, and educate healthcare professionals about their child's medical condition.²³
- 12 More recently, where disagreements about the care and treatment for critically ill children have arisen, parents have used social media to effectively mobilise support and create public awareness of the medical condition and the dispute at hand.²⁴ These high - profile cases have highlighted that public access to healthcare information via the internet,²⁵ and social media is providing a global virtual space for likeminded parents to gather support and challenge medical and legal decisions in the public arena.

²¹ Patients may use the internet, more specifically social media groups to 'crowdsource' answers to their health concerns. Tessa Richards, 'When doctors and patients disagree' (2014) *Br Med J* 349.

²²It has been found that in some cases, despite knowing that the internet can be an unreliable method of obtaining information relevant to the child's medical condition, some parents may still rely on it as a supplementary source of information, See, Vicki Xafis, Dominic Wilkinson and Jane Sullivan, 'What information do parents need when facing end-of-life decisions for their child? A meta-synthesis of parental feedback' (2015) 14 *BMC Palliat Care* <<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4424961/>> accessed 15 September 2018. See also, Brynn K Wainstein and others, 'Use of the Internet by parents of paediatric patients' (2006) 42 *J Paediatr Child Health* 528.

²³ Jerzy Konstantynowicz and others, 'What Do Children with Chronic Diseases and Their Parents Think About Pediatricians? A Qualitative Interview Study' (2016) 20 *Matern Child Health J* 1745; Teresa T Moro and others, 'Parent Decision Making for Life Support Decisions for Extremely Premature Infants: From the Prenatal through End-of-Life Period' (2011) 25 *J Perinat Neonatal Nurs* 52.

²⁴ Neera Bhatia, 'Three ways the Charlie Gard case could affect future end-of-life cases globally' *The Conversation* (25 July 2018) <https://theconversation.com/three-ways-the-charlie-gard-case-could-affect-future-end-of-life-cases-globally-81168>> accessed 15 September 2018. See also, Bernadette Richards, 'Social Media: The Unnamed Plaintiff' (2018) *J Bioeth Inq* <https://www.semanticscholar.org/paper/Social-Media%3A-The-Unnamed-Plaintiff_-Richards/572b1b5649d65c22738242c47250515880da4ca6> accessed 15 September 2018.

²⁵ See, Pierre Pluye, Roland Grad with Julie Barlow, *Look It Up!: What Patients, Doctors, Nurses, and Pharmacists Need to Know about the Internet and Primary Health Care* (McGill-Queens University Press 2017). See also, John Nosta, *The Internet Is Making Us Lose Trust in Our Doctors* (Forbes 2017) <https://www.forbes.com/sites/johnnosta/2017/05/08/the-internet-is-making-us-lose-trust-in-our-doctors/#270cf1b465fa>> accessed 15 September 2018; Aleks Krotoski 'What effect has the internet had on healthcare?' (*The Guardian* 9 January 2011) <https://www.theguardian.com/technology/2011/jan/09/untangling-web-krotoski-health-nhs>> accessed 15 September 2018.

Recent U.K. high-profile cases and social media

- 13 King²⁶ received public attention after Ashya King's family and supporters posted several YouTube videos.²⁷ These were intended to gather public support for Ashya to access an innovative treatment unavailable through the National Health Service (NHS) in the U.K. after specialists advised that this treatment would offer no benefits over conventional treatment.
- 14 More recently, *Gard*, *Haastrup*, and *Evans* all concerned critically ill infants where strong disagreement between parents and healthcare professionals about end-of-life treatment required the involvement of the court. These cases received international attention and global support, significantly bolstered by the sophisticated use of social media campaigns and the use of public relations teams.²⁸ These included websites, Facebook and Twitter accounts that attracted several thousand followers and supporters.²⁹ The social media strategies employed included the use of nuanced 'hashtags'³⁰ across all social media platforms that gained traction in the mainstream media after being frequently shared by supporters.
- 15 The administrators of the social media groups uploaded footage, news updates, and daily photographs, creating a system of almost entirely 'self-reported' news that allowed direct control of the narrative. This rallied support on a global scale,³¹ reaching influential figures including the Pope, President Trump and the President of Poland, Andrzej Duda, amongst

²⁶ See appendix 1.

²⁷ For example, Seek and You Will Find it, 'King: Information important for Ashya's case' (YouTube 31 August 2014) <https://www.youtube.com/watch?v=Q-QNz_EGloo> accessed 15 September 2018; Essex Watch, 'Update on Ashya King' (YouTube 30 August 2014) <<https://www.youtube.com/watch?v=F93RjILFOXk>> accessed 15 September 2018. See also Jo Bridgeman, 'Misunderstanding, threats, and fear, of the law in conflicts over children's healthcare: In the matter of Ashya King [2014] EWHC 2964' (2015) 23 Med Law Rev 477.

²⁸ Richard Hurley, 'How a fight for Charlie Gard became a fight against the state' (2017) 358 Br Med J <<https://www.bmj.com/content/358/bmj.j3675>> accessed 15 September 2018; Ranjana Das, 'Populist discourse on a British social media patient-support community: The case of the Charlie Gard support campaign on Facebook' (2018) 24 Discourse, Context & Media 76-84 <<https://doi.org/10.1016/j.dcm.2017.11.005>> accessed 15 September 2018; Alexi Mostrous 'Charlie Gard: publicity that was not always in the family's interests: an investigation raises questions over how well the parents were guided by three key figures' (The Times 29 July 2017) <<https://www.thetimes.co.uk/article/charlie-gard-publicity-that-was-not-always-in-the-family-s-interests-pjqtvwgz>> accessed 20 September 2018.

²⁹ There are a number of different Facebook groups. An example includes. Charlie Gard Facebook Group: <https://www.facebook.com/groups/265101867249571/members/>; Alfies Army Official Facebook Group: <https://www.facebook.com/groups/alfiesarmy/members/>. Since the death of the critically ill children, memorial Facebook groups have been created. Further international Facebook groups, fundraising groups, and groups to promote the recently established Charlie Gard foundation have also been established. There are also Twitter accounts that have been created.

³⁰ These included: #charliesarmy; #charliesfight; #alfiesarmy; alfieswar; #lifeforIsaiah.

³¹ The use of significant media and social media to attract global support is a novel phenomenon in high-profile cases in the U.K. paediatric context. It is somewhat presaged by the prominence of the media and public involvement in the U.S.A. and Italy. In the U.S.A. a dispute about the (non)treatment of an adult named Terry Schiavo in the early 2000's was prolifically reported in U.S. daily newspapers, garnering significant public attention and fuelling a national controversy, which included presidential intervention from (then) president George Bush Jr. See, ABC News, 'Terry Schiavo Timeline' (ABC News 6 January 2006) <<https://abcnews.go.com/Health/Schiavo/story?id=531632&page=1>> accessed 15 September 2018; Science Daily, 'The Schiavo Case: are Mass Media to Blame?' (Science Daily 8 August 2008) <<https://www.sciencedaily.com/releases/2008/08/080806161541.htm>> accessed 15 September 2018. See also, Sherrie Dulworth, 'From Schiavo to Death Panels: How Media Coverage of End-of-Life Issues Affects Public Opinion' (2013-14) 58 New York School Law Review 391. A similar phenomenon occurred in the case of Eluana Englaro in Italy in the latter part of that decade. See: Latronico N and others 'Quality of Reporting on the Vegetative State in Italian Newspapers. The Case of Eluana Englaro' (2011) 6 PLoS ONE.

others. The engagement of third-parties may change the decision-making dynamic and impact on the nature of the dispute. Pressure from religious communities or religious leaders has been argued to have an impact on family behaviour during end-of-life decision-making, inspiring behaviours ranging from praying for a cure to insistence on aggressive treatment at the end-of-life to align with the principles of their faith.³²

- 16 In *Gard and Evans*, social media campaigns were effective in gaining thousands of public supporters. A Facebook group³³ was created in spring 2017 by supporters of Charlie Gard's family, and by July 2017 had grown to over 60,000 members, over 10,000 posts, and over 12,000 commentators.³⁴ A similar page for Alfie Evans has attracted over 730,000 Facebook members to its group.³⁵ A Facebook page advocating medical treatment for Isaiah Haastrup created by supporters unconnected to his family attracted more than 1,000 followers.³⁶ At the time of writing, despite their deaths, the Charlie Gard and Alfie Evans Facebook groups remain active. Administrators of the groups only permit entry after specific questions are answered to determine support for the ongoing campaign.³⁷ This allows the growth of an echo chamber of a distinct group of like-minded followers, with little to no room for dissenting opinion.
- 17 In these cases, members of the public with easy access to the internet commented and challenged the views of healthcare professionals, regardless of whether they possessed all of the relevant facts, subject matter knowledge or expertise. Social media was used in these high-profile cases to influence public support and to challenge medical and legal decisions.³⁸ The power and influence of social media and the impact of public opinion in these cases was evident through the number of public protests, comments on newsfeeds on social media and backlash and abuse³⁹ that was experienced by those involved (directly or elsewhere) in the care or treatment of children.⁴⁰ Examples of those affected included not only the healthcare professionals within the hospitals caring for these particular children, but also the police officers tasked with managing protests outside the hospitals or the courts.

³² Joe Brierley, Jim Linthicum and Andy Petros, 'Should religious beliefs be allowed to stonewall a secular approach to withdrawing and withholding treatment in children?' (2013) 39 J Med Ethics 573, 574

³³ Charlie Gard Facebook Group: <https://www.facebook.com/groups/265101867249571/members/>.

³⁴ Ranjana Das, 'Populist discourse on a British social media patient-support community: The case of the Charlie Gard support campaign on Facebook' (2018) 24 Discourse, Context & Media 76 <<https://doi.org/10.1016/j.dcm.2017.11.005>> accessed 15 September 2018. By July, there had been in excess of 3,500 photos, 610 videos, 436 links and 5,500 new status updates posted to the Facebook page.

³⁵ Alfies Army Official Facebook Group < <https://www.facebook.com/groups/alfiesarmy/members/>>

³⁶ Life for Isaiah Haastrup: < https://www.facebook.com/groups/LifeForIsaiah/?ref=br_rs>

³⁷ Ranjana Das, 'Populist discourse on a British social media patient-support community: The case of the Charlie Gard support campaign on Facebook' (2018) 24 Discourse, Context & Media 76 <<https://doi.org/10.1016/j.dcm.2017.11.005>> accessed 15 September 2018.

³⁸ It is noteworthy that whilst parents and others are free to utilise social media as they wish, and harness its power for good or ill, health professionals do not seem to have that same freedom, possibly because they see involvement as risky, are bound by professional codes of conduct and, for those involved, have an obligation to maintain confidentiality. This may be a significant factor in the apparent one-sidedness of (social) media coverage. There has, however, been a call to encourage clinicians to engage publically with these debates. See Tom Sheldon, 'There will be another Alfie Evans. Experts need to engage' (*Science Media Centre* 10 May 2018) <http://www.sciencemediacentre.org/there-will-be-another-alfie-evans-experts-need-to-engage/>> accessed 28 September 2018.

³⁹ Clare Dyer, 'Alfie Evans case: Proposed law aims to prevent conflicts between parents and doctors' (2018) 361 *Brit Med J* <DOI:10.1136/bmj.k1895> accessed 15 September 2018.

⁴⁰ See, Natasha Hammond-Browning, 'When Doctors and Parents Don't Agree: The story of Charlie Gard' (2017) 14 *J Bioeth Inq* 461, 466-7.

18 It has been noted that the use of social media – in particular, the live tweeting of court decisions – led to misunderstandings and a “heightening frenzy”.⁴¹ The disagreement between the parents and the healthcare professionals played out on an international media platform. Justice Francis highlighted in *Gard* that while the era of the internet and social media has its advantages, it also has its drawbacks, stating:

“...when cases such as this go viral, the watching world feels entitled to express opinions, whether or not they are evidence based.”⁴²

19 The internet is generally available in most countries.⁴³ The size of the rally of supporters to the causes of the critically ill children, particularly in *Gard* and *Evans*, provided third-party, trans-national, actors with an opportunity to intervene. In these instances, third parties in different geographical locations may use the anonymity of the ‘virtual online world’ that the internet and social media groups provide to discuss, comment and advocate for causes and issues that are otherwise unlikely to have wide public support in the ‘real world’.⁴⁴ It has been suggested that these high-profile cases may have served as a springboard for social, political and religious activism via the internet.⁴⁵ It has been contended that social media in the *Gard* campaign was utilised ‘to misunderstand and misinterpret evidence, science and law, to malign public institutions’.⁴⁶ Some academics have noted that the involvement of third party activism, especially in *Gard* and *Evans*, was symptomatic of a broader movement involving a rise in populist campaigns that are critical of the National Health Service (NHS).⁴⁷

⁴¹ Ann Gallagher, ‘What can we learn from the case of Charlie Gard? Perspectives from an inter-disciplinary panel discussion’ (2017) 24 *Nurs Ethics* 775, 776.

⁴² *Great Ormond Street Hospital v Yates* [2017] EWHC 1909 (Fam) [11].

⁴³ There are some countries where internet censorship and surveillance occurs.

⁴⁴ Adam G Klein, ‘How online hate infiltrates social media and politics’ (*The Conversation* 16 March 2017) <<https://theconversation.com/how-online-hate-infiltrates-social-media-and-politics-74353>> accessed 1 September 2018; Julie Ebner, ‘The far right fights on global networks. They must be fought online and off’ (*The Guardian* 1 May 2017) <<https://www.theguardian.com/commentisfree/2017/may/01/far-right-networks-nationalists-hate-social-media-companies>> accessed 15 September 2018.

⁴⁵ This was particularly illuminated in *Gard* and *Evans*. See, Gaby Hinsliff, ‘Alfie Evans’ parents needed help. The vultures came instead’ (*The Guardian* 27 April 2018) <<https://www.theguardian.com/commentisfree/2018/apr/26/alfie-evans-parents-activists>> accessed 15 September 2018; Janet Street-Porter, ‘I know how Charlie Gard’s parents feel – but their trauma shouldn’t be exploited for political gain’ (*The Independent* 7 July 2017) <<https://www.independent.co.uk/voices/charlie-gard-gosh-great-ormond-street-hospital-ruling-pope-donald-trump-a7829351.html>> accessed 15 September 2018.

⁴⁶ Ann Gallagher, ‘What can we learn from the case of Charlie Gard? Perspectives from an inter-disciplinary panel discussion’ (2017) 24 *Nurs Ethics* 775, 775.

⁴⁷ Richard Hurley, ‘How a fight for Charlie Gard became a fight against the state’ (2017) 358 *Br Med J* <<https://www.bmj.com/content/358/bmj.j3675>> accessed 15 September 2018. This is also being seen in broader society, where a range of social issues such as climate change, and vaccinations for children have been the focal point media commentators and campaigns based on scepticism, or outright denial, of mainstream science. See for example, Neil T.Gavin, Tom Marshall ‘Mediated climate change in Britain: Scepticism on the web and on television around Copenhagen’ 2011 21 *Global Environmental Change* 3 1035; Christopher Booker ‘The climate change brigade are wrong again’ (*Daily Telegraph* 13th August 2016) <<https://www.telegraph.co.uk/news/2016/08/13/the-climate-change-brigade-are-wrong-again/>> accessed 18 November 2018; Chloe Lambert, ‘Measles is [sic] back with a vengeance – is the anti-vaccination movement to blame?’ (*The Telegraph* 20 August 2018) <<https://www.telegraph.co.uk/health-fitness/body/measles-back-vengeance-anti-vaccination-movement-blame/>> accessed 16 September 2018; Alex Matthews-King, ‘Good Morning Britain condemned for spreading anti-vaccination myths with ‘offensive’ canine autism debate’ (*The Independent* 25 April 2018) <<https://www.independent.co.uk/news/health/autism-vaccine-piers-morgan-gmb-dog-pets-good-morning-britain-a8322051.html>> accessed 15 September 2018; ‘What’s behind the ‘anti-vax’ movement?’ (*BBC News* 5 August 2015) <<https://www.bbc.co.uk/news/health-33774181>> accessed 15 September 2018.

20 Nonetheless, the aftermath of the robust social activism in these cases, where parents played an integral role in wanting to make treatment decisions for their children, has translated into legal advocacy. This is particularly notable in *Gard* and *Evans*, where the parents have used the support gathered via social media and other means to shift the focus towards law reform.⁴⁸

Private to public sphere

21 These high-profile cases⁴⁹ have highlighted that social media can play a significant role for parents where disputes about treatment arise. While previous cases concerning disagreements between parents and healthcare professionals have generally been conducted in a more private setting, those that have attracted media attention have generally been via traditional media avenues, and not at the invitation of the parents. However, the cases noted above have played out in a very public fashion, with the public at large playing the role of a fourth participant in the decision-making process.

Crowdfunding

22 The crowdfunding platform can be used for raising money for targeted campaigns via specific websites dedicated for this purpose. It is a method of raising money from a large number of people using the internet. It is increasingly being used as a means of raising money for medical treatment,⁵⁰ and consequently increases awareness of some healthcare issues.⁵¹ It is popular in countries such as the U.S.A., where the allocation of funds and access to healthcare differs from that in the U.K. The families in these four high-profile cases all set up crowdfunding accounts and were able to raise various amounts of money. The most considerable sum raised was in the *Gard* case, it raised over £1.2 million pounds (GBP) in a six month period to cover the cost of treatment and travel expenses for the child to travel overseas for treatment.⁵²

⁴⁸ Charlie's Law would necessitate mediation between parents and healthcare professionals before turning to the courts, mandatory access to advice of clinical ethics committees for parents and healthcare professionals in end-of-life decision-making situations and give parents the option to seek alternative treatment at a different hospital if they are dissatisfied with the decision of the initial admitting hospital. See: Catherine Burns, 'Charlie Gard's parents want 'Charlie's Law' (*BBC News* 20 June 2018) <<https://www.bbc.com/news/health-44334306>> accessed 16 September 2018; The Gard Foundation, 'Charlies Law' <<https://www.thecharliegardfoundation.org/charlies-law/>> accessed 18 September 2018.

Alfie's Law would allow parents access to an impartial advocate to represent their interests where disputes arose in treatments decisions for critically ill children, allow assistance for financial aid with legal appeals (where required), and give parents the right to a second medical opinion from a healthcare professional of their choice, independent of the National Health Service (NHS). See, Calvin Freiburger, 'Law aimed at protecting kids like Alfie Evans and Charlie Gard introduced in UK' (*Life Site News* 7 September 2018) <<https://www.lifesitenews.com/news/charlies-law-introduced-in-uk-to-protect-rights-of-sick-children-and-their>> accessed 15 September 2018.

⁴⁹ See Appendix 1.

⁵⁰ See, Michael J Young and Ethan Scheinberg, 'The Rise of Crowdfunding for Medical Care: Promises and Perils' (2017) 317 *J Am Med Assoc* 1623. Other types of crowdfunding include: reward based; equity crowdfunding and debt crowdfunding.

⁵¹ Conversely, crowdfunding has been used by fringe groups to raise funds for their causes. However, recently popular crowdfunding sites have banned some of these groups from accessing their sites. See, Blake Montgomery, 'PayPal, GoFundMe, And [sic] Patreon Banned A [sic] Bunch Of [sic] People Associated With [sic] The [sic] Alt-Right. Here's Why.' (*Buzzfeed News* 2 August 2017) <<https://www.buzzfeednews.com/article/blakemontgomery/the-alt-right-has-a-payment-processor-problem#.lx4z4ORxy>> accessed 15 September 2018.

⁵² In the *Gard* case, the funds raised were used to set up the Charlie Gard Foundation to invest in further research into mitochondrial disease, to support families of affected children (which includes some campaigning activities). See, 'The Charlie Gard Foundation' <<https://www.thecharliegardfoundation.org/>> accessed 15 September 2018.

Ethical considerations of crowdfunding

- 23 Advantages of crowdfunding, such as raising awareness of rare medical conditions, were evident in *Gard*.⁵³ Nonetheless, crowdfunding in healthcare has ethical and social implications.⁵⁴ A number of concerns have been identified with crowdfunding in relation to healthcare and critically ill children: issues relating to disclosure of children's private medical information by parents; fraudulent websites being created to raise funds; the costs, fees and waivers demanded for usage of crowdfunding websites; and the crowdfunding websites' power and control in choosing which causes and campaigns to support and/or reject, driven by market values and attitudes of the day.⁵⁵ It has been highlighted that the success of crowdfunding campaigns appears to be based on 'capitalising on emotionally appealing stories and evoking empathy'.⁵⁶ In this regard, appealing to members of the public to support and donate to the causes of critically ill children over the internet is likely to prove fruitful.
- 24 To summarise, access to more information via the internet and social media groups are contributing factors to parents challenging the prevailing orthodoxy, and parents are likely to become more self-informed, less willing to accept a medical diagnosis or advice at first instance, and less reliant on the treating clinicians as a single source of medical information.⁵⁷ The effective employment of social media was evident in some manner in all four high-profile cases. Although it is likely that social media did not directly affect the final court decision about the 'best interests' of the children in these cases, the decision-making process in general was nevertheless likely to have been affected by evident public support on a global scale, and the 'echo chamber' effect had the potential to inflate parental perceptions of the likelihood of resolution in their favour through the court system.⁵⁸ It has been posited that this results in lengthy court proceedings, more challenges to the court decisions and ever greater intervention from third party activists.⁵⁹

⁵³ Connie Yates, 'Help us to save our baby boy!' (*Gofundme* 30 January 2017) <<https://au.gofundme.com/please-help-to-save-charlies-life>> accessed 15 September 2018.

⁵⁴ Gabrielle Dressler and Sarah A Kelly, 'Ethical implications of medical crowdfunding: the case of Charlie Gard' (2018) 44 *J Med Ethics* 453; Jeremy Snyder, 'Crowdfunding FOR MEDICAL CARE: Ethical Issues in an Emerging Health Care Funding Practice' (2016) 46 *Hastings Cent Rep* 36; Amy L Gonzales, Elizabeth Y Kwon, Teresa Lynch, Nicole Fritz, 'Better everyone should know our business than we lose our house': Costs and benefits of medical crowdfunding for support, privacy, and identity' (2016) 20 *New Media Soc* 641.

⁵⁵ Gabrielle Dressler and Sarah A Kelly, 'Ethical implications of medical crowdfunding: the case of Charlie Gard' (2018) 44 *J Med Ethics* 453, 455.

⁵⁶ Trena M Paulusa and Katherine R Roberts, 'Crowdfunding a "Real-life Superhero": The construction of worthy bodies in medical campaign narratives' (2018) 21 *Discourse, Context and Media* 64 Gabrielle Dressler and Sarah A Kelly, 'Ethical implications of medical crowdfunding: the case of Charlie Gard' (2018) 44 *J Med Ethics* 453, 455.

⁵⁷ Honor Nicholl and others, 'Internet Use by Parents of Children With Rare Conditions: Findings From a Study on Parents' Web Information Needs' (2017) 19 *e51 J Med Internet Res*; Jerzy Konstantynowicz and others, 'What Do Children with Chronic Diseases and Their Parents Think About Pediatricians? A Qualitative Interview Study' (2016) 20 *Matern Child Health J* 1745.

⁵⁸ Gaby Hinsliff, 'Alfie Evans' parents needed help. The vultures came instead' (*The Guardian* 27 April 2018) <<https://www.theguardian.com/commentisfree/2018/apr/26/alfie-evans-parents-activists>> accessed 15 September 2018.

⁵⁹ Richard Hurley, 'How a fight for Charlie Gard became a fight against the state' (2017) 358 *Br Med J* <<https://www.bmj.com/content/358/bmj.j3675>> accessed 15 September 2018.

B: Parents seeking innovative medical treatments

- 25 Ongoing developments in medical research, particularly in the areas of stem cell and gene therapy, continue to offer hope of a cure to patients suffering progressive and/or incurable medical conditions such as Parkinson's disease⁶⁰ and Multiple Sclerosis.⁶¹ There have been recent debates about access to experimental therapies for children to treat spinal muscular atrophy (SMA), a potentially life-limiting genetic disease.⁶²
- 26 Disputes about treatment can arise when parents of critically ill children seek access to innovative medical treatments.⁶³ This may involve treatments that are still undergoing trial(s) and where their effectiveness remains unproven, and/or treatments that are not available in the U.K. Conflict may also arise when parents request the use of alternative/complementary treatments that lack scientific evidence of effectiveness, such as natural herbal therapies rather than conventional medicine. This is an issue that has confronted the courts in the U.K.⁶⁴ and overseas, most recently in Australia.⁶⁵

King: Proton Beam Therapy

- 27 In *King*, the parents of Ashya King requested access to proton beam therapy. They had researched the treatment on the internet as an alternative to radiotherapy that was required post-operatively after the removal of a brain tumour (medulloblastoma).⁶⁶ The request was referred by the treating hospital to the NHS England Proton Clinical Reference Panel, who denied it on the basis that it would not be beneficial in Ashya King's case. Ashya's parents then removed him from the hospital without the knowledge of hospital staff and travelled overseas, with the intention of obtaining the treatment at a private clinic in Prague. The parents and the child were detained in Spain and returned to the U.K. after intervention by the relevant authorities, and the matter went before the High

⁶⁰ Dr Beckie Port, 'Trials to treatments: gene therapy' (Parkinson's UK June 11 2018) < <https://medium.com/parkinsons-uk/trials-to-treatments-gene-therapy-143e6a1b4a24>> accessed 28 September 2018.

⁶¹ Alex Matthews-King, 'Stem cell transplant trial 'has miraculous effect' on multiple sclerosis sufferers' (*Independent* 19 March 2018) < <https://www.independent.co.uk/news/health/multiple-sclerosis-stem-cell-transplant-clinical-trial-ms-symptoms-improvements-sheffield-chicago-a8263126.html>> Accessed 28 September 2018.

⁶² NMP King and CE Bishop, 'New treatments for serious conditions: ethical implications' (2017) 24 *J Gene Ther* 534; Nancy S Jecker, 'Is There a 'Right to Try' Experimental Therapies? Ethical Criteria for Selecting Patients With Spinal Muscular Atrophy to Receive Nusinersen in an Expanded Access Program' (2017) 17 *Am J Bioeth* 70.

⁶³ Jo Bridgeman, 'Contested care: when disputes over child cancer treatment reach the courts' (*The Conversation* 18 August 2018) <<https://theconversation.com/contested-care-when-disputes-over-child-cancer-treatment-reach-the-courts-63004>> accessed 15 September 2018.

⁶⁴ See the case of case of Neon Roberts: *An NHS Trust and SR* [2012] EWHC 3842 (Fam). See also, Caroline Davies, 'Neon Roberts should not be subjected to 'unproven treatments' court told' (*The Guardian* 21 December 2012) <<https://www.theguardian.com/law/2012/dec/20/neon-roberts-unproved-treatments-court>> accessed 15 September 2018; Press Association, 'Boy whose mother tried to halt cancer treatment recovering well' (*The Guardian* 1 February 2014) <<https://www.theguardian.com/uk-news/2014/jan/31/neon-roberts-cancer-treatment-recovering>> accessed 15 September 2018.

⁶⁵ See the case of Oshin Kiszko: *Director Clinical Services, Child & Adolescent Health Services and Kiszko & Anor* [2016] FCWA 75; 'Oshin Kiszko: 6yo Perth boy at centre of legal battles over cancer treatment dies' (*ABC News* 28 December 2018) < <http://www.abc.net.au/news/2016-12-28/oshin-kiszko-boy-at-centre-of-legal-battle-over-treatment-dies/8151550>> accessed 15 September 2018. See also, Bernadette J Richards and Michaela E Okninski, 'The best interests of a child: a tragedy in three parts' (2017) 25 *Med Law Rev* 138; Ian Freckelton, 'Parents' Opposition to Potentially Life-saving Treatment for Minors: Learning from the Oshin Kiszko Litigation' (2016) 24 *J Law Med* 61.

⁶⁶ See Appendix 1.

Court.⁶⁷ The judge found the parents' request for proton beam therapy was 'reasonable'.
68

28 Ashya King received the proton beam therapy, funded by the National Health Service (NHS).⁶⁹ The treatment was successful. In 2018, his most recent MRI scan showed no signs of the cancerous tumour⁷⁰ and he had returned to school. Since the 2014 case, at least one study has been conducted on the effectiveness and side-effects of using proton beam therapy to treat medulloblastoma tumours.⁷¹ The results may indicate proton beam therapy has fewer side effects than conventional therapy,⁷² and were widely seized upon as a vindication of Ashya's parent's position.⁷³ Earlier this year, proton beam therapy was used for the first time in the U.K. to treat a cancer patient, and it is anticipated that around six proton beam therapy centres (including some NHS centres) will be established within the next three years.⁷⁴

Gard: Nucleoside Therapy

29 *Gard* again brought the issue of access to unproven innovative treatments to the fore. This case concerned a critically ill infant, Charlie Gard, with a rare degenerative condition known as mitochondrial DNA depletion syndrome. His parents sought to have him transferred to the U.S.A. to access nucleoside therapy. While the therapy had never undergone a clinical trial, nor been used in Charlie's disease, a U.S. neurologist believed it might offer a small chance of improvement to his quality of life, although no cure.

30 Charlie's medical treatment team considered that any further treatment would not be in Charlie's best interests due to the severity of the brain damage caused by his condition. Charlie's parents did not agree and the case was referred to the High Court. A number of judicial appeals were made by the parents and the court allowed fresh evidence to be given by the U.S. neurologist who offered the nucleoside therapy. However, as he

⁶⁷ See Appendix 1.

⁶⁸ *Portsmouth City Council v Naghmeh King* [2014] EWHC 2964 (Fam) [32]. The judge also stated that separating the child from his parents was not in his best interests.

⁶⁹ Clare Dyer, 'NHS will pay for boy's proton beam therapy in Prague' (2014) 349 *Brit Med* <https://doi.org/10.1136/bmj.g5944> accessed 15 September 2018.

⁷⁰ Joel Adams, 'Ashya King cleared of cancer three years after his parents abducted him from hospital for treatment abroad' (*The Telegraph* 3 March 2018) <<https://www.telegraph.co.uk/news/2018/03/03/ashya-king-cleared-cancer-three-years-parents-abducted-hospital/>> 15 September 2018.

⁷¹ Yock T and others, 'Long-term toxic effects of proton radiotherapy for paediatric medulloblastoma: a phase 2 single-arm study' (2016) 17 *Lancet Oncol* 287.

⁷² NHS 'Proton beam therapy 'effective' and 'causes fewer side effects' February 1st 2016 <<https://www.nhs.uk/news/cancer/proton-beam-therapy-effective-and-causes-fewer-side-effects/>> accessed 18 September 2018.

⁷³ Gianluca Mezzofiore 'So Ashya's parents were RIGHT: Proton beam cancer therapy that forced family to go on the run to Spain because they couldn't get it on the NHS is as good as chemotherapy - and has fewer side effects' (*Mail Online*, January 30 2016) <<https://www.dailymail.co.uk/news/article-3424058/So-Ashya-s-parents-RIGHT-Proton-beam-cancer-therapy-forced-family-run-Spain-couldn-t-NHS-good-chemotherapy-fewer-effects.html>> accessed 18 September 2018; Laura Mowat 'Ashya King's mother: Proton beam therapy saved my cancer child's life' (*Daily Express*, January 30 2016) <<https://www.express.co.uk/life-style/health/639463/Proton-beam-therapy-used-to-treat-Ashya-King-less-toxic-for-child-cancer-patients>> accessed 18 September 2018.

⁷⁴ 'Proton Beam Therapy' (*NHS The Christie Foundation Trust*) <<http://www.christie.nhs.uk/our-future/our-developments/protons/proton-beam-therapy.aspx>> accessed 15 September 2018; Sophie McIntyre, 'Radiotherapy alternative to be offered in UK after Ashya King's Proton therapy 'miracle recovery'' <<https://www.independent.co.uk/news/uk/home-news/radiotherapy-alternative-to-be-offered-in-uk-after-aysha-king-s-proton-therapy-miracle-recovery-10155796.html>> accessed 15 September 2018.

conceded that Charlie's brain damage made it unlikely the treatment would have any effect, the court was unconvinced. The parents withdrew their opposition and treatment was withdrawn.⁷⁵

Considerations in relation to innovative treatments

- 31 While innovative treatments may offer hope of cure, or some improvement to the quality of life, some treatments lack evidential basis, such as in *Gard*. The question of whether parental requests for unproven innovative treatments to be provided to their critically ill children should be heeded engenders polarised views, both in the academic literature and wider public discourse.⁷⁶
- 32 One suggestion made in the literature is for a shift in the communication approach between healthcare professionals and families seeking treatment for critically ill children. It has been posited that ongoing conversations with parents could be improved where 'longshot treatment' efforts provided to critically ill children with extremely low chances of success are transitioned to being termed as 'fantasy treatment' where there is no hope of success. It has been contended that such language would assist parents and families in managing their expectations and hope.⁷⁷
- 33 Critics have, however, argued these terms are too simplistic. In cases where a child has a rare condition, a clear transition from 'longshot' to 'fantasy' treatment is not always possible. Further, where parents and healthcare professionals disagree on treatment, the innovative treatment being sought might be considered 'fantasy treatment' by the healthcare professionals, but an acceptable 'longshot treatment' by the parents.⁷⁸
- 34 Other issues, such as the potential harms and benefits of innovative treatments and whether they should be offered despite the uncertainty of their effectiveness, also deserve consideration. Some of the commentary has focused on the balance between harms and benefits of innovative treatments. Some commentators have noted that a "commitment not to put a child at more than minimum risk is intensified when the proposed procedure involves experimental therapy".⁷⁹
- 35 It has been noted that a threshold for what may be considered to cause significant harm to a critically ill child may play a role in determining whether parents should be able to access innovative treatments. As has been discussed earlier, in *King*, the court determined that proton beam therapy was in Ashya King's best interests because it

⁷⁵ See, Emma Cave and Emma Nottingham, 'Who Knows Best (Interests)? The Case of Charlie Gard' (2017) 26 Med Law Rev 500.

⁷⁶ Robert D Truog, 'The United Kingdom Sets Limits on Experimental Treatments: The Case of Charlie Gard' (2017) 318 JAMA 1001; Iain Brassington, 'Never Let an Ill Child Go to Waste' (*Journal of Medical Ethics Blog* 7 July 2017) <<https://blogs.bmj.com/medical-ethics/2017/07/07/never-let-an-ill-child-go-to-waste/>> accessed 15 September 2018.

⁷⁷ Elliott Mark Weiss and Autumn Fiester, 'From "Longshot" to "Fantasy": Obligations to Pediatric Patients and Families When Last-Ditch Medical Efforts Fail' (2018) 18 Am J Bioeth 3.

⁷⁸ Aaron Rothstein and Ariane Lewis, 'The Challenges of Discussing "Longshot" and "Fantasy" Treatments' (2018) 18 Am J Bioeth 27.

⁷⁹ John J Paris and others, 'The Charlie Gard case: British and American approaches to court resolution of disputes over medical decision' (2017) 37 J Perintol 1268, 1270.

offered him the best possible chance, with little detrimental effect.⁸⁰ In contrast, in *Gard*, nucleoside therapy was determined not to be in Charlie Gard's best interests. The judge found that the trial of the innovative therapy that Charlie's parents sought would have caused him 'significant harm' and no benefit.

- 36 The use of unproven innovative treatments highlights the fact that there is no clear line between proven and unproven treatments. Indeed, standards of proof may be relative rather than absolute.⁸¹ As one commentator postulates, in *Gard* at least, a "catch 22 situation" existed, as Charlie was one of only a handful of children in the world to have the rare medical condition.⁸² In the wake of *Gard*, it has been contended that innovative treatments in future cases should be considered where all conventional treatment options have been expended and death is inevitable. In these cases, the innovative treatments should be utilised without any delay, however, factors such as the side effects of such treatments should be taken into account, and as such a time-limited trial should be considered.⁸³
- 37 It has been posited that a trial of experimental treatment would be reasonable, particularly in the case of a critically ill patient, such as in the *Gard* case. The rationale for this, even in the case of largely unproven treatment is that in the case of a dying or severely ill patient, trialling innovative treatments could not put the patient in a 'worse' position.⁸⁴
- 38 An opposing view argues that such patients can be made worse off, and where the potential benefits of the innovative treatment are outweighed by the harms, the parents' request should be overruled.⁸⁵ Some commentators contend that parents must make decisions that have the child's welfare as the paramount consideration, promoting the child's best interests, not their own,⁸⁶ whilst others note that parents cannot make the same treatment decisions for children that they might make for themselves.⁸⁷ Arguably, parents cannot refuse life-sustaining treatment, or demand the continuation of life-sustaining treatment, when healthcare professionals are of the opinion that it is/is no longer in the best interest of the child⁸⁸ – but this relies on the assumption that healthcare professionals are in the best position make that best interest judgement.

⁸⁰ Jo Bridgeman, 'A Threshold of significant harm (f) or a viable alternative therapeutic option?' (2018) 44 J Med Ethics 466, 469.

⁸¹ Broberg CS and others, 'Emergence of the arterial switch procedure for transposition of the great arteries and the potential cost of surgical innovation' (2017) 154 J Thorac Cardiovasc Surg 1047.

⁸² Dominic Wilkinson and Julian Savulescu, 'Hard lessons: learning from the Charlie Gard case' (2018) 44 J Med Ethics 438, 438.

⁸³ Dominic Wilkinson and Julian Savulescu, 'Hard lessons: learning from the Charlie Gard case' (2018) 44 J Med Ethics 438; Dominic Wilkinson and Julian Savulescu, 'After Charlie Gard: ethically ensuring access to innovative treatment' (2017) 30 The Lancet 540 .

⁸⁴ Julian Savulescu, 'The Moral of the Case of Charlie Gard: Give Dying Patients Experimental Treatment ... Early' (*Practical Ethics, University of Oxford* 5 July 2017) <<http://blog.practicaethics.ox.ac.uk/2017/07/the-moral-of-the-case-of-charlie-gard-give-dying-patients-experimental-treatment-early/>> accessed 15 September 2018. See also, 5 News, 'Charlie Gard's parents message to doubters' (*YouTube* 20 June 2017) <<https://www.youtube.com/watch?v=EjcS3eN40w8>> accessed 15 September 2018.

⁸⁵ Dominic Wilkinson, 'Debate Response: Charlie Gard, Interests and Justice – an alternative view' (*Journal of Medical Ethics Blog* 26 April 2017) <<https://blogs.bmj.com/medical-ethics/2017/04/26/debate-reponse-charlie-gard-interests-and-justice-an-alternative-view/>> accessed 15 September 2018.

⁸⁶ Eliana Close, Lindy Willmott and Benjamin P White, 'Charlie Gard: In defence of the law' (2018) 44 J Med Ethics 476

⁸⁷ Richard David, 'Voices of moral authority: parents, doctors and what will actually help' (2018) 44 J Med Ethics 458.

⁸⁸ For an Australian perspective, see, Lindy Willmott, Ben White and Neera Bhatia, 'When Is It in a Child's Best Interests to Withhold or Withdraw Life-sustaining Treatment? An Evolving Australian Jurisprudence' (2018) 25 J Law Med 944

- 39 Considerations about the fair distribution of limited healthcare resources in a public healthcare system are generally not a focal point when determining end-of-life treatment decisions. As has been discussed earlier, the core principle is whether the treatment is in the best interests of the child. One view is that where resources to access innovative treatments are not at issue, and such treatment(s) are affordable, they should be available and not denied, as they do not deny other patients access to public healthcare and treatment.⁸⁹ This was a point of contention in some of the cases where parents had raised substantial funds through crowdfunding, yet nonetheless, it was held that treatment was not in the best interests of the child.⁹⁰ Some commentators have argued that this analysis is too simplistic and does not properly account for the costs of maintaining a healthcare infrastructure.⁹¹
- 40 As highlighted earlier, concerns have been raised about the potential exploitation of parents of critically ill children by the intervention of third parties representing fringe groups or groups with particular agendas.⁹² Vulnerability⁹³ and unrealistic expectations of a cure or improved health are also contributing factors to parents seeking innovative treatments. It has also been posited that patients with life-limiting conditions are more likely to view innovative treatments with unwarranted optimism,⁹⁴ and it seems likely that parents of critically ill children view innovative treatment with the same optimism.
- 41 This, in turn, raises a potential concern about how and when innovative treatments are offered to critically ill children, given the willingness of parents to seek the use of these treatments even when unproven and/or in the early clinical trial stage.⁹⁵ Fewer than 10% of medicines in early clinical trials ultimately prove safe, efficacious and cost-effective enough to be marketed,⁹⁶ and some academics have raised public interest arguments in support of limiting access to innovative treatments. It has been argued that easy access to such treatments may lead to providers bypassing clinical trials and making unproven treatments widely available due to increasing public demand, eroding the evidence basis of emerging medicines.⁹⁷

⁸⁹ Dominic Wilkinson, 'Debate Response: Charlie Gard, Interests and Justice – an alternative view' (*Journal of Medical Ethics Blog* 26 April 2017) <<https://blogs.bmj.com/medical-ethics/2017/04/26/debate-reponse-charlie-gard-interests-and-justice-an-alternative-view/>> accessed 15 September 2018.

⁹⁰ John Lantos, 'The tragic case of Charlie Gard' (2017) 171 *JAMA Pediat* 935

⁹¹ Truog RD, 'The United Kingdom Sets Limits on Experimental Treatments: The Case of Charlie Gard' (2017) 318 *JAMA* 318

⁹² Dan Bilefsky, 'For Parents of Children Like Charlie Gard, Learning to "Redefine Hope"' (*New York Times* August 7 2017) <<https://www.nytimes.com/2017/08/07/world/europe/for-parents-of-children-like-charlie-gard-learning-to-redefine-hope.html>> accessed 15 September 2018.

⁹³ Valerie Shilling and Bridget Young, 'How do parents experience being asked to enter a child in a randomised controlled area?' (2009) 10 *BMC Med Eth* <<https://doi.org/10.1186/1472-6939-10-1>> accessed 16 September 2018.

⁹⁴ Arthur Caplan, 'Is it sound public policy to let the terminally ill access experimental medical innovations?' (2007) 7 *Am J Bioeth* 1; Shira Bender, Lauren Flicker and Rosamond Rhodes, 'Access for the Terminally Ill to Experimental Medical Innovations: A Three-Pronged Threat' (2007) 10 *Am J Bioeth* 3; John J Paris and others, 'Approaches to parental demand for non-established medical treatment: reflections on the Charlie Gard case' (2018) 44 *J Med Ethics* 443.

⁹⁵ Katharine Wright, 'Making unbearable decisions about the care and treatment of a seriously ill child – ethical reflections' (*Nuffield Council on Bioethics* August 7 2017) <<http://nuffieldbioethics.org/blog/making-unbearable-decisions-care-treatment-ill-child>> accessed 15 September 2018.

⁹⁶ David W. Thomas, Justin Burns *et al.*, 'Clinical Development Success Rates' 2006-2015, Oregon /California /Washington DC: BIO, BioMedTracker, Amplion, 2016 <http://bit.ly/22o5TGf?_ga=2.36002406.793786953.1537274314-1585100987.1537274314> Accessed 18 September 2018.

⁹⁷ Giles Birchley, 'Charlie Gard and the weight of parental rights to seek experimental treatment' (2018) 44 *J Med Ethics* 448

- 42 A 2013 Nuffield Council on Bioethics report considered the development, regulation, use, and promotion of novel neurotechnologies.⁹⁸ Of particular note was that “the awareness that the pursuit of an intervention solely because it represents a patient’s ‘last best hope’ is likely to be too cavalier to justify an experimental intervention”. Additionally, an “emphasis on the primacy of patient interests, entail[s] a duty of care that persists beyond the period of experimentation”.⁹⁹ Whether these principles may apply equally to innovative treatments sought by parents is unclear,¹⁰⁰ however, some of the literature discussed earlier in this section would support this view.
- 43 To sum up, medical research continues to offer hope of a cure or improvement in health to those suffering debilitating and/or life-limiting health conditions, and the prospect of innovative treatment may amplify hope, but consequently vulnerability, for parents seeking to access them. Views and opinions as to whether parents of critically ill children should be given access to innovative treatments are polarised, with some of the literature suggesting that ‘some chance is better than no chance’. This is opposed by arguments that medical consensus should determine which treatments are in the best interests of the child, and those raising public interest concerns. Strategies for managing unrealistic parental expectations have also been advanced.

C: Child medical tourism

- 44 The definition of ‘medical tourism’ is widely contested in the literature, with varying descriptions offered. Differences in its definition stem from the international media and social media hyperbole and over-exaggeration about the aims and objectives of medical tourism.¹⁰¹ Child medical tourism has been defined as: “bi-directional movement of children (<18 years of age) to and from a country to seek advice, diagnosis and treatments”.¹⁰² Parents may opt to travel overseas to obtain healthcare that may not be available in the U.K., or is unavailable under the National Health Service (NHS), or are simply seeking better healthcare options. Parents may also opt to travel to lower healthcare resource environments for cultural reasons.¹⁰³
- 45 There has been considerable growth in medical tourism, providing individuals from varying socio-economic backgrounds, including those from developed and less developed countries, with the opportunity to obtain better healthcare.¹⁰⁴ Some of the factors that have been identified as contributing towards the growth of medical tourism

⁹⁸ ‘Novel neurotechnologies: intervening in the brain’ (Nuffield Council of Bioethics). <<http://nuffieldbioethics.org/project/neurotechnology>> accessed 16 September 2018.

⁹⁹ Katharine Wright, ‘Making unbearable decisions about the care and treatment of a seriously ill child – ethical reflections’ (Nuffield Council on Bioethics August 7 2017) <<http://nuffieldbioethics.org/blog/making-unbearable-decisions-care-treatment-ill-child>> accessed 15 September 2018.

¹⁰⁰ Giles Birchley, ‘Charlie Gard and the weight of parental rights to seek experimental treatment’ (2018) 44 J Med Ethics 448.

¹⁰¹ John Connell, ‘Medical tourism – concepts and definitions’ in Neil Lunt, Daniel Horsfall and Johanna Nanafeld (eds), *Handbook on Medical Tourism and Patient Mobility* (Edward Elgar Publishing 2015). See also, generally, Glenn Cohen, *Patients with passports: medical tourism, law and ethics* (Oxford University Press 2015).

¹⁰² Charlotte Hamlyn-Williams, Monica Lakhanpaul and Logan Manikam, ‘Child medical tourism: a new phenomenon’ in Neil Lunt, Daniel Horsfall and Johanna Nanafeld (eds), *Handbook on Medical Tourism and Patient Mobility* (Edward Elgar Publishing 2015).

¹⁰³ Lorraine Culley and others, ‘Children travelling for treatment: what we don’t know’ (2013) 98 Arch Dis Child 442

¹⁰⁴ Johanna Hanefeld and others, ‘Medical Tourism: A Cost or Benefit to the NHS?’ (2013) 8 PLOS one <[doi:10.1371/journal.pone.0070406](https://doi.org/10.1371/journal.pone.0070406)> accessed 15 September 2018.

include abundant marketing via the internet and social media and low-cost treatment that in turn is supported by cheaper travel.¹⁰⁵

- 46 In the high-profile cases discussed in this report, the parents of critically ill children sought to either travel overseas and/or obtain second opinions from overseas specialists in order to obtain putatively better treatment options against U.K. medical opinion. In *King*: Prague, *Gard*: U.S.A., *Haastrup*: Germany and Poland, and *Evans*: Italy.¹⁰⁶ These cases illuminated the issue of child medical tourism in the public arena and opened up social and academic debate about whether parents should be allowed to take their children overseas for treatment. Notwithstanding the significant press and social media spotlight on these cases, they are not the first cases in which parents have sought access to treatment for their children overseas.¹⁰⁷
- 47 Despite this, there is a paucity of detailed empirical data or analysis that explores child medical tourism. The limited literature has discussed the different forms of medical tourism.¹⁰⁸ Most pertinent to this discussion relates to parents in high income countries seeking innovative treatments unavailable in their home country (e.g. *King*: proton beam therapy,¹⁰⁹ *Gard*: nucleoside therapy, and stem cell tourism¹¹⁰). These types of cases have received considerable media coverage.¹¹¹
- 48 Travel overseas for innovative treatments was a central point of disagreement between the parents and healthcare professionals in *King* and *Gard*. This may be related to varying attitudes of parents towards their perceived rights towards, and obligations to, their children. Some commentators have asserted that the intention to remove critically ill children from conventional treatment, in order to undergo unproven innovative treatments overseas, may be tantamount to child neglect or maltreatment.¹¹² This challenge becomes more acute in cases where a child cannot express his/her wishes. Other factors to consider in relation to child medical tourism include: privacy and confidentiality of medical

¹⁰⁵ Lorraine Culley and others, 'Children travelling for treatment: what we don't know' (2013) 98 Arch Dis Child 442

¹⁰⁶ See Appendix 1.

¹⁰⁷ Corey Ashcroft, 'Corey sets off for cancer treatment in USA' (*Chorley Guardian* 30 November 2011) <<https://www.chorley-guardian.co.uk/news/corey-sets-off-for-cancer-treatment-in-usa-1-4014701>> accessed 15 September 2018; Liz Little, 'Little girl with cerebral palsy able to walk thanks to miracle treatment' (*Nine Honey* August 2018) <<https://honey.nine.com.au/2018/08/19/16/36/stem-cell-treatment-cerebral-palsy-isabella>> accessed 15 September 2018.

¹⁰⁸ Lorraine Culley and others, 'Children travelling for treatment: what we don't know' (2013) 98 Arch Dis Child 442; Charlotte Hamlyn-Williams, Monica Lakhnpaul and Logan Manikam, in Neil Lunt, Daniel Horsfall and Johanna Nanafeld (eds), *Handbook on Medical Tourism and Patient Mobility* (Edward Elgar Publishing 2015). Other forms of medical tourism include: Parents travelling overseas to access healthcare for their children with a reciprocal NHS arrangement to seek access to treatment that the U.K. cannot provide; Parents from low resources countries travelling overseas funded by humanitarian organisations to access healthcare for their children; Parents travelling overseas to access elective surgery for their children (e.g., gastric band surgery for obesity); and parents (resident migrants) travelling to their 'home countries to access diagnostics, second opinions or treatment to their 'home' countries.

¹⁰⁹ Sam G Cockle and Jane Ogden, 'The 'radiation vacation': Parents' experiences of travelling to have their children's brain tumours treated with proton beam therapy' (2016) 3 Health Psychol Open 1.

¹¹⁰ Aaron D Levine and Leslie E Wolf, 'The Roles and Responsibilities of Physicians in Patients' Decisions about Unproven Stem Cell Therapies' (2012) 40 J Law Med Ethics 122.

¹¹¹ See for example, Hayley Dixon, 'Terminally ill boy denied 'potentially life-saving' treatment by NHS 'would be given it in any US hospital'' (*The Telegraph* 3 April 2017) <<https://www.telegraph.co.uk/news/2017/04/03/terminally-boy-denied-potentially-life-saving-treatment-nhs/>> accessed 15 September 2018.

¹¹² Amy Zarzeczny and Timothy Caulfield, 'Stem cell tourism and doctors' duties to minors--a view from Canada' (2010) 10 Am J Bioeth 3; Bryn Nelson, 'A trip to remember, with strings attached: Researchers begin sorting through the tangled ethical and legal implications of medical tourism' (2014) 122 Cancer Cytopathol 787.

information, as well as timely sharing of such information between countries, issues of medical negligence, variation in regulation and governance of medical procedures, and differing standards of care, amongst others.¹¹³

- 49 Although not fitting squarely within the scope of ‘child medical tourism’, the weight of an independent second opinion from a medical expert in a second country may also be a prominent issue in cases where disagreement about treatment arises between parents and healthcare professionals.
- 50 The status of claims from other jurisdictions was also raised in *Gard*. Charlie Gard was granted U.S. permanent residence in order to expedite the much sought-after travel to the U.S.A. to receive the nucleoside therapy.¹¹⁴ Similarly, in *Evans*, Alfie Evans was granted Italian citizenship during the court proceedings with the objective of allowing him to leave the country to travel to Rome to continue treatment.¹¹⁵ Nonetheless, in both cases, the (domestic) courts ruled that the critically ill children could not be removed from the hospital, despite the readiness of other jurisdictions to accept legal responsibility for them.
- 51 To conclude, there is a considerable amount of literature that discusses the growing industry of medical tourism in different contexts broadly. However, there is a paucity of research in the academic literature concerning child medical tourism, and more specifically child medical tourism where parents are seeking innovative treatments. Recent high-profile cases have underlined the need for further research and discussion of innovative treatments in this context. It would be appropriate for the discussion to extend to situations where second opinions are offered by international experts, particularly where the international experts provide the opinion remotely and do not examine the child first hand.¹¹⁶

Identification of gaps in research

- 52 The increasing role of the internet in healthcare is a developing area of study. While the ability of the internet to (mis)inform decision-making is increasingly discussed, the high-profile cases discussed here have also highlighted the emerging influence of social media on the decision-making process. The importance of understanding the impact of the internet and social media on healthcare decision-making cannot be overstated. Expansion of research in these areas will assist understanding of how the law, policymakers and the broader public can harness the immense power of the internet and

¹¹³ Bryn Nelson, ‘A trip to remember, with strings attached: Researchers begin sorting through the tangled ethical and legal implications of medical tourism’ (2014) 122 *Cancer Cytopathol* 787.

¹¹⁴ Katie Forster, ‘Charlie Gard granted permanent residence in the US by Congress ‘to fly to America for treatment’ (*The Independent* 19 July 2017) <<https://www.independent.co.uk/News/health/charlie-gard-us-citizenship-congress-american-treatment-uk-high-court-appeal-life-support-turn-off-a7848391.html>> accessed 16 September 2018.

¹¹⁵ ‘Alfie Evans granted Italian citizenship in life support legal row’ (*BBC News* 23 April 2018) <<https://www.bbc.com/news/uk-england-merseyside-43872678>> accessed 15 September 2018.

¹¹⁶ This was the case in *Haastrup*, where international expert opinion was provided by medical practitioners based in Germany and Poland. In *Gard*, in the first instance the expert neurologist who advised of the possibility of the nucleoside therapy providing some improvement to the child’s quality of life had neither examined Charlie Gard in person, nor, according to the counsel for the hospital, scrutinised his medical records see, Katie Gollup, ‘GOSH’s position statement hearing on 24 July 2017’ (24 July 2017) <<https://www.gosh.nhs.uk/file/23731/download?token=TWJkSxZu>> accessed 15 September 2018.

the social support that can extend from social media. It will also allow the formulation of strategies to mitigate the potential these technologies have to harm those most closely involved in treatment disagreements.

- 53 It is currently unclear if disputes arise due to a sporadic approach to access to innovative treatments, or if there is an underlying problem with the current healthcare system and types of treatments being offered. Further research needs to be undertaken to gain more specific insight into why, how and what types of innovative treatments parents of critically ill children are seeking. Additionally, research is needed to develop existing guidance into ethically robust national – and international – processes for appraising parental requests for treatments.¹¹⁷ In tandem, a more consistent approach to judging the safety, efficacy, and impact of innovative treatment needs to be developed.
- 54 There is very little literature or empirical data on child medical tourism. There is a need to develop a research base on the nature, ethics, impacts, and effects of child medical tourism on the child, the family and healthcare providers both in the home country and overseas.¹¹⁸ Such research would highlight the most prominent forms of child medical tourism sought, the grounds for seeking it, and how it is accessed, and could inform the development of systems that ensure children are adequately protected, parental choices are informed, and that the benefits of access to second-country healthcare are properly integrated into existing healthcare provision.

Conclusion

- 55 Disagreements between parents and healthcare professionals about the treatment of critically ill children continue to be ethically, legally and socially fraught. Reaching a consensus can be difficult and traumatic for all parties, and the risk is that the focus on the child can be lost.
- 56 A new era in medical science, technology and communication has changed the way parents access and share healthcare information, creating numerous challenges. Recent high-profile cases involving the use of the internet and social media, access to innovative treatments, and child medical tourism demonstrate that parents are showing a greater readiness to scrutinise and challenge medical opinion and seek alternatives. These challenges are reshaping the social landscape in which the care and treatment of critically ill children are taking place.
- 57 The three issues discussed in this report raise important legal, ethical and social questions impacting on, influencing and affecting children, parents, medical teams and society at large. This affects the process of making decisions that are, ultimately, of paramount human importance. It is, therefore, essential that these new challenges receive serious consideration by those involved in developing law, policy, research and appropriate governance in this area.

¹¹⁷ Larcher V, Turnham H and Brierley J, 'Medical Innovation in a Children's Hospital: Diseases desperate grown by desperate appliance are relieved, or not at all' (2018) 32 Bioeth 36.

¹¹⁸ Lorraine Culley and others, 'Children travelling for treatment: what we don't know' (2013) 96 Arch Dis Child 442.

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Appendix 1: Recent high-profile cases in the UK

Child Name	Case Name and Citation	Outcome
Ashya King	Portsmouth City Council v Naghmeh King & Ors [2014] EWHC 2964 (Fam)	FACTS: Parents of child suffering cerebellar mutism syndrome and bulbar palsy (medulloblastoma) sought innovative treatment in the Czech Republic (Prague). DECISION: King allowed to travel to Prague for treatment.
Charlie Gard	Great Ormond Street Hospital v Constance Yates & Ors [2017] EWHC 972 (Fam)	FACTS: whether to allow lifesaving treatment be withdrawn & whether child can have innovative treatment in the U.S.A. DECISION: Lifesaving treatment can be withdrawn, treatment in U.S.A. not in best interests.
	Constance Yates & Ors v Great Ormond Street Hospital [2017] EWCA Civ 410	FACTS: Appeal with parents seeking declarations to allow child to be transferred to U.S.A. for nucleoside therapy. DECISION: Appeal dismissed.
	Great Ormond Street Hospital v Constance Yates & Ors [2017] EWHC 1909 (Fam)	FACTS: Appeal alleging new evidence in form of Children's Hospital in Rome willing to accept Charlie Gard. DECISION: Not fresh evidence, appeal disallowed.
	Gard v United Kingdom (2017) 65 E.H.R.R. SE9	FACTS: Allegation that U.K. had contravened art 2 & 5 of European Convention of Human Rights. DECISION: Case dismissed.
Isaiah Haastrup	Kings College Hospital NHS Foundation Trust v Takesha Thomas & Ors [2018] EWHC 127 (Fam)	FACTS: Whether to order lifesaving treatment be withdrawn. DECISION: Lifesaving can be treatment withdrawn.
	Kings College Hospital NHS Foundation Trust v Takesha Thomas & Ors (No 2) [2018] EWHC 147 (Fam)	FACTS: Permission sought to appeal. DECISION: Stay of orders to allow father to seek leave to appeal to Court of Appeal.
Alfie Evans	Alder Hey Children's NHS Foundation Trust v Thomas Evans & Ors [2018] EWHC 308 (Fam)	FACTS: Hospital sought declaration that continued ventilation support not in child's best interests. Further, parents sought to take child to Italy for treatment.

		DECISION: Withdrawal of life sustaining treatment allowed.
	E (A Child) [2018] EWCA Civ 550	FACTS: Appeal from [2018] EWHC 308 (Fam). DECISION: Appeal dismissed.
	Thomas Evans & Anor v Alder Hey Children's; Hospital NHS Foundation Trust & Anor (leave to appeal to Supreme Court)	FACTS: Appeal from [2018] EWCA Civ 550. DECISION: Appeal dismissed.
	Alder Hey Children's NHS Foundation v Thomas Evans & Ors [2018] EWHC 818 (Fam)	FACTS: Case returned to Trial Judge for directions as to how withdrawal of life sustaining treatment should take place. DECISION: Edorsement of NHS Trust care plan.
	Thomas Evans & Anor v Alder Hey Children's NHS Foundation Trust & Anor [2018] EWCA Civ 805	FACTS: Parents appeal seeking writ of Habeas Corpus. DECISION: Parents merely seeking to re-litigate issues. Appeal dismissed.
	Thomas Evans & Anor v Alder Hey Children's NHS Foundation & Anor (leave to appeal to Supreme Court)	FACTS: Parents appeal from [2018] EWCA Civ 805 seeking Habeas Corpus. DECISION: Leave to appeal denied.
	Alder Hey Children's NHS Foundation v Thomas Evans & Ors [2018] EWHC 953 (Fam)	FACTS: Italian Ministry of Foreign Affairs sought return of child. DECISION: Child had no connection to Italy. Case dismissed.
	Thomas Evans & Anor v Alder Hey Children's NHS Foundation Trust & Anor [2018] EWCA 984 (Civ)	FACTS: Application for permission to appeal from [2018] EWHC 953. DECISION: Appeal dismissed.