

# Introduction

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This collection was inspired by the decision of the Court of Appeal in *Great Ormond Street Hospital v Gard* [2017] (the ‘Charlie Gard case’). In *Gard*, and in the cases that followed, both the Court of Appeal (and later the Supreme Court in rejecting permission to appeal) affirmed the orthodox position that the threshold for judicial intervention in disputes about medical care of children is the welfare of the child, often referred to as the ‘best-interests’ approach. ‘Best interests’ is generally used to refer both to the threshold for intervention and as the test applied to determine what should be done once the court is involved. In this volume, we focus solely on the threshold question: when should the court be permitted to make decisions on behalf of very ill children when parents and the medical treating team cannot agree?

In *Gard*, the appellants’ case rested in part on the argument that in situations where there is a choice of treatments (the so-called ‘Category 2’ cases) it should fall to parents, rather than the courts or doctors, to make this choice. Inherent to this view was that there must be some degree of protection of parental discretion in relation to their children. The boundary proposed was that of a ‘risk of significant harm’, adapted from section 31 of the Children Act 1989 (the so-called threshold criteria that must be satisfied before the court can make a care or supervision order in child protection proceedings). One point made by counsel on behalf of Connie Yates and Chris Gard was that in the absence of such a boundary, the state would otherwise have unfettered power to intervene in parental decisions. Both the Court of Appeal and the Supreme Court rejected this argument. While the position in England and Wales is legally clear, there has been substantial debate in the literature about the appropriate boundaries for judicial power in this context, particularly in the ethics literature. The public debate around the Gard case also revealed that many in the community consider that parents should have the final say about a child’s medical care.

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*Gard* was neither the first case of its kind, nor the last (followed as it was by the Alfie Evans litigation (*Alder Hey NHS Foundation Trust v Evans* [2018] EWHC 308 (Fam)), which raised similar questions, as did the case of Isaiah Haastrup<sup>2</sup>), but it stands out as the case in which a serious challenge was made to the current threshold for judicial intervention in decisions about children's medical care. The case also drew substantial public attention, in part due to the issues around parental authority it raised. Concerns about the erosion of what some regarded as the territory of parental authority, as well as concern for Charlie himself, fuelled an extraordinary public campaign in support of Charlie's parents. At many points in this campaign, it was argued by supporters of the Gard family that it should be for parents, rather than the medical profession or the courts, to have final decision-making authority about a child's health.

It was the combination of this legal challenge and the considerable support for a shift in the law's position that inspired this collection. Both raised the question of whether the law currently draws the threshold for judicial intervention in the right place. It drew attention to the fact that while much of the case-law has focused on applying the test to determine what should be done, there has been comparatively little focus on *when* the court should legitimately intervene. This requires fresh consideration of whether there should be any threshold for court intervention in parental decision-making, and whether the medical context requires a different approach? Where should the line be drawn, and what would be the normative basis of this line? In particular, this collection will look at whether it is appropriate to adopt the 'serious risk of significant harm' approach proposed in *Gard*; the respective roles of parents, doctors and the courts; and the possible risks of inappropriate state intrusion in parental decision-making, and how we might address them.

An important dimension to such analysis must be consideration of what the law should do when public opinion and the law's position seemingly diverge. This is not, in and of itself, a sufficient reason for the law to change. But the substantial levels of concern expressed in some quarters should at least cause us to consider why these objections were raised and whether they are legitimate. We should take these concerns seriously because they go further than disagreement with the law. Rather, they go to a central

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<sup>2</sup> *Kings College Hospital NHS Foundation Trust v Ms Thomas, Haastrup and Haastrup* [2018] EWHC 127 (Fam), [2018] 2 FLR 1028.

concern – the appropriate boundary between private, familial decisions and the authority of the state. This goes beyond questions of the limits of parental authority into issues around the right role of the state in relation to the most vulnerable members of society and the extent to which its responsibility to them should trump considerations of familial privacy and parental authority.

It is not only some groups within the public whose views diverge from those of the law. Philosophers and ethicists have weighed in on the debate around parental decision-making, many doing so publicly at the time these cases were in the news.<sup>3</sup> Some criticised taking a court-based approach at all, but some argued for a move to a harm-threshold approach to judicial intervention. These very public statements, plus the popular concern and the direct challenge to orthodoxy brought in *Gard*, therefore make this very much a live question. Further, much of what was written at the time picked up on a debate about moving to a harm threshold that was already live in the ethics and medical law literature. For example, Douglas Diekema, Professor of Pediatrics at the University of Washington School of Medicine, has written extensively on the harm threshold.<sup>4</sup> Lynn Gillam has also offered many sensible insights into the issue via her work on the concept of a ‘zone of parental discretion’.<sup>5</sup> The *Gard* case, therefore, brought a question that has been a matter of academic interest into the spotlight and demonstrated precisely why it is a question with which we should actively engage.

This collection addresses this central question of *when* the court should have authority to intervene in medical decision-making on behalf of children. It focuses specifically on non-Gillick-competent children, and the withdrawal of treatment. Therefore, it does

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<sup>3</sup> S Boseley, ‘US Doctor’s Intervention in Charlie Gard Case “Raises Ethical Questions”’ *The Guardian* (25 July 2017) [www.theguardian.com/uk-news/2017/jul/25/michio-hirano-us-doctor-intervention-charlie-gard-case-raises-ethical-questions](http://www.theguardian.com/uk-news/2017/jul/25/michio-hirano-us-doctor-intervention-charlie-gard-case-raises-ethical-questions) (accessed 11 June 2019); J Savulescu and P Singer, ‘Charlie Gard: Why Donald Trump and the Pope Are Right’ *ABC News* (13 July 2017) [www.abc.net.au/news/2017-07-13/charlie-gard-donald-trump-and-the-pope-are-right/8706390](http://www.abc.net.au/news/2017-07-13/charlie-gard-donald-trump-and-the-pope-are-right/8706390); J Savulescu and D Wilkinson, ‘Agreement and Disagreement About Experimental Treatment. The Charlie Gard Appeal’, [blog.practicaethics.ox.ac.uk/2017/05/agreement-and-disagreement-about-experimental-treatment-the-charlie-gard-appeal/](http://blog.practicaethics.ox.ac.uk/2017/05/agreement-and-disagreement-about-experimental-treatment-the-charlie-gard-appeal/) (accessed 11 June 2019).

<sup>4</sup> D Diekema, ‘Parental Refusals of Medical Treatment: The Harm Principle as Threshold for State Intervention’ (2004) 25 *Philosophy of Medical Research and Practice* 243.

<sup>5</sup> L Gillam, ‘The Zone of Parental Discretion: An Ethical Tool for Dealing with Disagreement between Parents and Doctors about Medical Treatment for a Child’ (2016) 11 *Clinical Ethics* 1.

not concern itself with the issues around children who are competent to consent to treatment (if not to refuse it). It centres on those situations where a court is called upon to intervene in decisions about a child's medical care. This will generally be those situations where the medical team and parents are at loggerheads over what is to be done. But, as evidenced in *Gard*, this may also encompass situations where parents seek to opt for one medical professional's approach over another's. Both the Court of Appeal and the Supreme Court, in *Gard*, took the view that it held the ultimate authority to intervene in such situations once the child's welfare was engaged.<sup>6</sup>

This question is not one that can be easily answered. The court has the authority to intervene via its inherent jurisdiction as well as in situations covered by the Children Act 1989 (the 'Children Act'). Rob George and Rachel Taylor outline the exact position on that jurisdiction from a family law perspective in their chapters, teasing out some of the complexities that arise from the interaction between the common law, the Children Act and the Human Rights Act 1998 (HRA). Imogen Goold offers a detailed explanation of the common law foundations for the orthodox position on medical decision-making in her chapter.

Clarity about the legal position is not, however, a sufficient basis on which to determine what the law *should* be in this context. With this in mind, this collection was developed with the explicit intention of drawing on a wide range of relevant perspectives. Hence, the collection includes not only family and medical law academics, but also chapters written by medical professionals directly involved in the clinical care of children. Emily Harrop, Giles Birchley and Dominic Wilkinson all bring insights from their roles as clinicians to their chapters. Harrop presents a deeply moving account of the parental experience in such situations, while Wilkinson and Birchley blend clinical and philosophical analysis in their work. Jonathan Herring's chapter on vulnerability (of parents, children, medics and the judiciary) complements and augments these chapters by offering a unique lens through which to consider the issues (legal and ethical) raised in such cases.

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<sup>6</sup> *Great Ormond Street Hospital v Yates and Gard* [2017] EWHC 972 (Fam); Lady Hale's explanation of the Supreme Court's decision, as delivered in Court (8 June 2017) [www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html](http://www.supremecourt.uk/news/permission-to-appeal-hearing-in-the-matter-of-charlie-gard.html) (accessed 11 June 2019).

Having such chapters sit neatly and separately beside academic analyses of the issues would be a legitimate but rather unsatisfying approach to the central question considered by this collection. Mindful of this, the editors brought the contributors together early on in the process for a one-day workshop held in Oxford in 2018. Over the course of that day, the clinicians shared perspectives with the legal and philosophical academics, informing and shaping one another's perspectives. We were particularly fortunate to have Victoria Butler-Cole, who acted as Guardian to Charlie Gard in *Gard*, join us for that day to offer a perspective from practice, which proved invaluable, as did the practice experience of Rob George.

In this collection, then, we bring together a variety of backgrounds and a variety of views on where the threshold for judicial intervention is to be drawn. Some, such as Wilkinson and Goold, make the case for moving to some form of harm threshold. Others, such as Taylor, defend the law's current stance.

Other chapters offer additional perspectives. Louise Austin and Richard Huxtable, for example, call for further research into how disputes are being resolved (or not resolved) day-to-day between medical teams and parents, and consequently whether, if at all, we should amend out current mechanisms for addressing these disputes. Cressida Auckland, by contrast, drills down into the difficult and nuanced question of what constitutes 'futility' in the context of withdrawal-of-treatment decisions. Such an analysis is important given the weighty impact the determination that further treatment being deemed 'futile' has in these cases (as seen starkly in *Gard*). Sara Forvague offers an exploration of a particular aspect of these cases – parental requests for experimental treatments. *Gard* is a prime example of the direction of travel in these cases, where the Internet and social media enable parents to research treatments in a manner previously impossible, and also to contact (and be contacted by) those who offer treatments that the medical team has not offered. Jo Bridgman's chapter argues that in such complex cases, medical professionals are not merely applying to court because they consider a particular treatment will not be in the child's 'best interests'. Rather, in cases such as *Gard*, further treatment, in the professional judgement of the medical team involved, was *inimical* to Charlie's interests. Cases of this kind should, she argues, be understood as ones in which the provision of continued treatment is contrary to professional conscience. It is on this basis that the courts should approach the requests of medical professionals to cease treatment.

In determining whether the law should change, we should take account of the spectrum of perspectives on such situations. The law's approach should be both principled and practical. It should account for clinical realities and pay due respect to the professional opinion of those best placed to understand the medical aspects of a child's healthcare situation. But it must also be sensitive to the parents' needs as well as those of the child. We have little doubt that the courts are very much mindful of this, as it is the court that deals with these situations close-in on a daily basis. It is difficult for any regulatory system to balance all the competing needs and demands of those it covers, and the complexity of doing so and walking the line between respecting parental responsibility and protecting those most vulnerable among us is necessarily a difficult question that prompts strong feelings. We hope that the chapters in this collection may offer some valuable assistance in our efforts to answer this question.