Making decisions for children: Accommodating parental choice in best interests determinations. *Barts Health NHS Trust v Raqeeb* [2019] EWHC 2530 (Fam); *Raqeeb and Barts Health NHS Trust* [2019] EWHC 2531 (Admin).

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ABSTRACT

Four-year-old Tafida Raqeeb suffered a sudden and catastrophic brain injury resulting from a rare condition. UK doctors would not agree to a transfer of Tafida to a hospital in Italy in circumstances that they considered to be contrary to her best interests. Her parents applied for judicial review of the hospital decision and the hospital Trust applied for a determination of Tafida's best interests. The cases were heard together. The High Court ruled that Tafida could be taken to Italy for treatment. Applying the best interests test, Mr Justice MacDonald found that Tafida was not in pain and ongoing treatment would not be a burden to her. Further treatment would comply with the religious beliefs of her parents. The case is specific to its facts, but MacDonald J's interpretation of the best interests test is likely to have implications. In particular, we explore the separation of medical and overall best interests; the recognition of the relevance of international laws and frameworks to best interests determinations; and reliance not on what Tafida could understand and express but on what she might in future have come to believe had she followed her parents' religious beliefs.

KEYWORDS

Best interests, conscience, children, life-sustaining treatment, free movement, parental rights.

THE FACTS AND JUDGMENT

Tafida Raqeeb was born in 2014 and is now five years old. In February 2019 she had a sudden and catastrophic rupture of an arteriovenous malformation that caused substantially irreversible damage to her brain. When the team at Royal London Hospital, which is part of Barts Health NHS Trust, recommended that further treatment was contrary to Tafida's best interests, the

parents contacted other hospitals around the world. Gaslini Paediatric Hospital in Genoa reviewed the case and accepted a transfer request, but the team at Barts would not agree to the transfer in circumstances where they believed it to be contrary to Tafida's best interests. The hospital issued proceedings in the High Court under the Children Act 1989 and inherent jurisdiction. Concurrently, the parents sought judicial review of the Trust's decision to block Tafida's medical treatment in another EU Member State, claiming that it breached Article 56 of the Treaty for the Functioning of the European Union on provision and receipt of services.

Mr Justice MacDonald dealt first with the matter of the judicial review. He held that the decision to deny transfer to Italy was amenable to judicial review, notwithstanding that the Trust had sought a determination of Tafida's best interests from the court. Furthermore the Trust's decision was *prima facie* unlawful, as it failed to follow the procedure set down in *R v Human Fertilisation and Embryology Authority ex parte Blood*.[1] However, because the interference with free movement rights would have been a justified and proportionate interference (had this been duly considered by the Trust) given the established national procedure for settling best interests disputes,[2] MacDonald J declined to quash the unlawful decision: a remedy that would serve no practical purpose in this case.[3] The decision has implications in relation to the availability of judicial review more generally. It also raises complex issues around compliance with free movement rights in future cases, including around how and when UK hospitals should share information and otherwise cooperate with hospitals across the EU. We do not deal with them here.

This casenote focuses on the second aspect of the judgment: the determination under the Children Act 1989 and inherent jurisdiction of the court. MacDonald J confirmed that disputes of this nature must come before the court.[4] In his 'very finely balanced' decision,[5] he held that it was not appropriate on the facts to give the declaration sought by the Trust that treatment should be discontinued. The Trust declined to appeal.[6] This is not the first time a court has declined to give such a declaration,[7] and each case is decided on its particular facts. Our focus is not on the outcome of the case: it has been reported that, to the great relief of her family, Tafida has been successfully moved to Italy for the next stage of her treatment.[8] Rather, we comment on the articulation of the best interests test in this case, which is likely to have implications in both clinical practice and court.

THE REASONING

[1] [1999] Fam 151. [2019] EWHC 2530 (Fam), [155].
[2] *Barts Health NHS Trust v Raqeeb* [2019] EWHC 2530 (Fam); *Raqeeb and Barts Health NHS Trust* [2019] EWHC 2531 (Admin), [146]-[154]. (*Raqeeb*).
[3] *ibid* [156]-[158].
[4] *ibid* [105]-[109].
[5] *ibid* [185].
[6] Barts Health NHS Trust, *Media statement regarding our care of Tafida Raqeeb,* 4 October 2019 https://www.bartshealth.nhs.uk/news/media-statement-regarding-our-care-of-tafida-raqeeb-6626
[7] See *An NHS Trust v MB* [2006] EWHC 507 (Fam).
[8] BBC News, 'Tafida Raqeeb: Brain-damaged girl arrives in Italy' 16 October 2019 https://www.bbc.co.uk/news/uk-england-london-50068246

MacDonald J also presided over the case of *Kings College Hospital NHS Foundation Trust v Haastrup* in 2018. In that case, he granted the order sought by the Trust that it was in the best interests of 11-month-old Isaiah Haastrup that treatment be withdrawn. In cases of this nature, as MacDonald J made clear in *Haastrup*:

> The paramount consideration is the best interests of the child. The role of the court when exercising its jurisdiction is to take over the parents' duty to give or withhold consent in the best interests of the child. It is the role and duty of the court to do so and to exercise its own independent and objective judgment.[9]

The first consideration was Tafida's current medical condition and prognosis. Tafida has a prolonged disorder of consciousness. Evidence was presented that in the paediatric context, the distinction between vegetative state and minimally conscious state is 'somewhat artificial' and MacDonald J accepted that 'there is a consensus of medical opinion is (sic) that it is not possible to exclude in Tafida some level of conscious awareness'.[10] It was found that she is unlikely to feel pain 'at least in her resting state or standard condition'.[11] Transfer to Italy would be of minimal risk and the team at Gaslini Hospital were fully appraised of the situation and of excellent repute.

As for prognosis, there was a possibility that Tafida might be given a tracheostomy in Italy and returned to the UK to be cared for at home. The Italian team said that there was potential for her to be weaned from mechanical ventilation. Provided life-sustaining treatment was continued, she would be likely to live between 10-20 years. It was recognised that her physical condition would likely deteriorate in this time, to include problems such as drug resistant epilepsy, scoliosis, hip dislocation, pneumonia, bone disease, renal stones and pressure sores.[12] It was also considered possible that she might regain a (greater) level of awareness. MacDonald J accepted the view of the Trust that her medical condition and prognosis comprised:

> a bare situation of continued life likely, but not certainly, pain free but in a situation of minimal or no awareness, with no hope of recovery and the certain prospect of developing further debilitating conditions, which with any improvement in awareness will further burden Tafida.[13]

MacDonald J concluded that: 'On the evidence, this is an accurate but as I will come to, incomplete formulation'.[14] Turning to consideration of her overall best interests, MacDonald J noted that other children are treated in the UK with long term ventilation and the treatment offered by the Gaslini hospital would continue the care given by the Trust rather than depart radically from it. Tafida was being raised within the Islamic religious tradition and had begun

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[9] *Kings College Hospital NHS Foundation Trust v Haastrup* [2018] 2 FLR 1028, [69]. (*Haastrup*).
[10] *Raqeeb* (n 2) [161].
[11] *ibid* [162].
[12] *ibid* [34], [163].
[13] *ibid* [167].
[14] *ibid* [167].

to understand and adhere to the faith.[15] Article 9 of the European Convention on Human Rights (ECHR) applies even to young children, and this right is to be given weight, though it was not determinative, given derogations under Article 9(2).[16] MacDonald J concluded that, taking into consideration the care Tafida would receive from her family, signs of her religious commitment and open and caring attitude to those with disabilities, the benefits to her of continued treatment outweighed the burdens.[17]

The views of her parents - Shelina Begum and Mohammed Abdul Raqeeb - were highly relevant to the best interests determination. They had obtained a *fatwa* restating the principle of sanctity of life. Though Article 8 of the ECHR was not relied upon to a great extent in submissions and is trumped by the best interests of the child, MacDonald J considered that overriding the parental choice might interfere with Article 8 ECHR protecting private and family life in light of his best interest determination.[18]

In both *Raqeeb* and the earlier case of *Haastrup*, MacDonald J confirmed that:

> There will be cases where it is not in the best interests of the child to subject him or her to treatment that will cause increased suffering and produce no commensurate benefit, giving the fullest possible weight to the child's and mankind's desire to survive.[19]

On the facts, the judge found that *Haastrup* fell within this bracket and *Raqeeb* did not. The *Raqeeb* judgment restates the best interest test but applies it in a novel way which has potentially far reaching implications. In the following two sections we argue that the application of the test in *Raqeeb* protects parental choice in an unprecedented manner. We then explore the implications of the decision for the medical profession.

THE CHILD'S BEST INTERESTS OR PARENTAL RIGHTS?

I. JUDICIAL ASSESSMENT OF MEDICAL BEST INTERESTS

The judge held that the Trust had framed best interests too narrowly. As we shall argue, the wider framing focused predominantly on Tafida's interests in upholding her and (controversially, we will argue) her parents' religious preferences as to the sanctity of life. There was also a wider *medical* consideration that the court found persuasive: the potential for Tafida to be cared for at hospital or home on long term ventilation (LTV) in common with others in a similar position.[20] This was decided notwithstanding counsel for the NHS Trust, Ms Gollop's, argument that there is insufficient evidence regarding the position of other children on LTV or as to whether or not Tafida's situation is comparable.[21] Cases of LTV are growing in number and there is recognition of the need for clear guidance for HCPs as to when LTV is

[15] *ibid* [76].
[16] *ibid* [184].
[17] *ibid* [168].
[18] *ibid* [182].
[19] *ibid* [186]; *Haastrup* (n 9) [69].
[20] *Raqeeb* (n 2) [168].
[21] *ibid* [73].

in a child's best interests.[22] In the absence of such guidance, inconsistencies in its use may have arisen, and reliance on the mere fact that LTV occurs is ethically dubious if some of those cases might contravene the best interests of children.

As for the clinical factors set out by the Trust, it is notable that little weight was placed on the potential for current and future burden to Tafida. The Children's Guardian, who argued that treatment was not in Tafida's best interests,[23] was concerned that the possibility that Tafida feels pain cannot be excluded. MacDonald J was sceptical given that the standard of proof is the balance of probabilities.[24] As to future burdens, which are relevant according to section 1(3)(e) of the Children Act 1989, the Trust argued they could be significant based on Tafida's inevitable physical deterioration and potential for heightened awareness. Tafida was thought to react to intense painful stimulation, though no changes to the EEG were visible.[25] Cases are fact-specific and medical considerations are but one of a number, but for parents and HCPs trying to work out how much weight to give to a child's *potential* pain, comparison with dicta in *Haastrup* might cause puzzlement. In that case the potential for pain was given greater weight, though there was no external or objective evidence that Isaiah felt pain.[26] MacDonald J stated there that:

> Isaiah's likely attitude to treatment must also be evaluated against the fact that the prospect facing him is one of continued life sustaining treatment that will do not more than sustain him in, at best, a state of profoundly depressed consciousness in which, if he is aware, he is more likely than not only to be minimally so, with no prospect of improvement or recovery and the prospect of repeated chest infections, deformity scoliosis and hip dislocation. Within this context, … I am satisfied that Isaiah's point of view would be that treatment … would be very unlikely to be acceptable to him, particularly if he is feeling pain.[27]

Returning to *Raqeeb*, the court offset potential future burdens against medical (as well as social and religious) benefits: in particular Tafida's potential to breathe without mechanical support. But the court acknowledges that there is no evidence that this will be achieved:

> Whilst there is consensus that Tafida is currently unable to breath without mechanical support, and the doctors in this jurisdiction are sceptical that this position will ever change, the Italian doctors consider that the question of whether Tafida could be weaned off a ventilator following a tracheostomy requires further, detailed evaluation.[28]

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[22] S Ray, J Brierley, A Bush, et al 'Towards developing an ethical framework for decision making in long-term ventilation in children' (2018) 103 *Archives of Disease in Childhood* 1080.
[23] *Raqeeb* (n 2) [82].
[24] *ibid* [175].
[25] *ibid* [23].
[26] *Haastrup* (n 9) [37].
[27] *ibid* [100].
[28] *Raqeeb* (n 2) [26].

The Italian team were not expressing a view that weaning Tafida from mechanical ventilation is likely, but that it is a matter that requires 'detailed evaluation'. As such, on the same balance of probabilities argument that mitigated against consideration of potential current and future pain, the potential to wean Tafida from mechanical ventilation was of questionable value as a perceived benefit.

II PARENTAL RIGHTS BY THE BACK DOOR?

If we accept evidence that Tafida does not and will not suffer pain and is of insufficient consciousness to suffer burden from her existence, another issue is raised by the assumption that Tafida's interests are defined by her parents' cultural and religious beliefs.

In his assertions that life was worthwhile from Tafida's point of view, MacDonald J acknowledged that Tafida was unlikely to have had any concept of her current situation before her catastrophic injury. What was significant was that:

> It is plain on that evidence that Tafida had a growing understanding of the practices of Islam, had developed a concept of the importance of life and an accepting and non-judgmental approach to those with disability.[29]

The significance of religion to four-year-old Tafida is exaggerated. She lacked a deep understanding or adherence to religion and could not have understood the implications of living on with limited or no awareness as her body deteriorated. MacDonald J is thus clear that:

> as fairly conceded by the mother, given Tafida's age and understanding, I am also satisfied that she would have had in February 2019 no concept or contemplation of her current situation, or of the complex and grave legal, moral and ethical issues it raises.[30]

He adds that 'it would be unsafe to infer from the available evidence an acceptance by Tafida of, or wish to live' 'a life of minimal awareness with no prospect of substantive recovery'.[31] Yet he draws from these clear statements of Tafida's very limited understanding of her situation and what her wishes might be for treatment the following summary:

> if Tafida was asked she would not reject out of hand a situation in which she continued to live, albeit in a moribund and at best minimally conscious state, without pain and in the loving care of her dedicated family, consistent with her formative appreciation that life is precious, a wish to follow a parent's religious practice and a non-judgmental attitude to disability.[32]

What would not be rejected 'out of hand' is not the situation that it is admitted she barely if at all grasped, but a continued existence whose significance lies in an 'appreciation that life is precious'. Such an appreciation is essentially that of her parents, and is only 'formative' on her

[29] *ibid* [166].
[30] *ibid* [166].
[31] *ibid* [167].
[32] *ibid* [168].

part. But what can it mean to say that it is 'formative?' It seems to be ambiguous between 'already partially formed,' 'being formed,' and 'would have been formed'. From the evidence it can only mean that she would have grown up to share her parents' religious views and culture. She might indeed have formed such an outlook, but it was barely if at all formed as matters stood when her understanding of her situation was appraised.

It would seem then that what was judged to be best for Tafida was what cohered with the deeply held religious beliefs of her parents. MacDonald J stated that life sustaining treatment was a benefit for Tafida and thus an important element of what was in her interests because:

> it permits Tafida to remain alive in accordance with the tenets of the religion in which she was being raised.[33]

That such treatment 'is consistent with the religious and cultural tenets by which Tafida was being raised' was what, in MacDonald J's view, clearly tipped the balance towards seeing her best interests as served by according 'in the final analysis' the choice of what shall be done to her parents.[34]

The importance given to 'religious and cultural tenets' in the assessment of Tafida's best interests sits oddly with the final statement of MacDonald J:

> Absent the fact of pain or the awareness of suffering, the answer to the objective best interests tests must be looked for in subjective or highly value laden ethical, moral or religious factors extrinsic to the child, such as futility (in its non-technical sense), dignity, the meaning of life and the principle of the sanctity of life, which factors mean different things to different people in a diverse, multicultural, multifaith society.[35]

The claim made here appears to be that there is no right or objective answer to what is in a child's interests, only 'subjective' judgments that derive from the diverse outlooks of different communities in our society. If this is the claim being made it conflates a factual and true assertion concerning the existence of moral disagreement in society from a philosophical claim about the plurality or relativity of moral value. This latter claim is deeply contentious and would indeed be disputed by most philosophers. Moreover, the fact that citizens do disagree morally about important matters – such as the value of dignity or the sanctity of life – does not discharge the court from its fundamental obligation to determine what in its view is objectively in the child's best interests.[36] Making such a determination, where it disagrees with the deeply and sincerely held views of parents, is not to show disrespect to those views nor the culture and religion from which they derive.

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[33] *ibid* [173].
[34] *ibid* [182].
[35] *ibid* [191].
[36] On which see *Haastrup* (n 9) [69], per MacDonald J.

The centrality to the judgment of religious views about the sanctity of life is not acknowledged in the rapid responses by two commentators on the case, Dominic Wilkinson and Julian Savulescu, published by the Science Media Centre soon after the judgment was released.[37] Indeed, Savulescu states that the issue is not about religion but justice, and that decisions about continued treatment should be best made on grounds of distributive justice, not on grounds of a human being better off dead. This is curious given the published views of both authors in their recent book.[38] There they state:

> For example, a person might request that mechanical ventilation be continued because he believes that we should not intervene in God's will. Such beliefs are arguably irrational.[39]

Later they state that 'a reasonable view about treatment cannot be justified on the basis of reasons that are judged to be unacceptable by wider society'[40] and make that applicable to the current context by adding:

> In the UK (and in other countries, such as France), societies have come to the stronger conclusion that there are situations where life should not be prolonged even if the patient would have wanted treatment to continue, or the family are requesting that treatment. In those societies, it would not make any sense to count in favour of the reasonableness of providing treatment a view based on a strong sanctity of life ethic.[41]

It would seem that on their published view at least, the beliefs of Tafida's parents are 'arguably irrational' and anyway should not be counted as reasonable in the UK.

As Emily Jackson stated in her own rapid response published by the Science Media Centre, because the judge found that Tafida was not in pain and ongoing treatment would not be a burden to her, '[he] ruled the decision could be taken by her parents, in the light of their religious beliefs about the sanctity of human life'.[42] The legal basis for this position is not explored in the judgment, which is reconcilable with the view that parental choice should be protected provided it does not cause the patient significant harm. Indeed, Tafida's parents have since called for a change in the law so that hospitals should be unable to block requests to transfer children to reputable hospitals.[43] This builds on related arguments following the

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[37] Science Media Centre, *Expert reaction to Tafida Raqeeb ruling from High Court* (3 October 2019) https://www.sciencemediacentre.org/expert-reaction-to-tafida-raqeeb-ruling-from-high-court/.
[38] D Wilkinson and J Savulescu, *Ethics, Conflict and Medical Treatment for Children* (London: Elsevier, 2019).
[39] *ibid* 88-89.
[40] *ibid* 112.
[41] *ibid* 113.
[42] Science Media Centre (n 37). And see Raqeeb (n 2) [182].
[43] BBC News, 'Tafida Raqeeb: 'Law should be revisited', say parents' 5 October 2019 https://www.bbc.co.uk/news/uk-england-london-49944602 .

Evans[44] and *Gard*[45] cases. But the significant harm test was firmly rejected in *Gard*,[46] and the position on parental preferences set out by Holman J in *An NHS Trust v MB* remains good law:

> Their own wishes, however understandable in human terms, are wholly irrelevant to consideration of the objective best interests of the child save to the extent in any given case that they may illuminate the quality and value to the child of the child/parent relationship.[47]

A more likely possibility is that MacDonald J sought to align the decision with McFarlane LJ's interpretation of *Re King*[48] in *Gard*. There, McFarlane LJ said:

> [I]n the end it is the judge who has to choose the best course for a child. Where, as in the case of *Re King* before Mr Justice Baker, there really was nothing to choose as between the benefits and detriments of the two forms of radiotherapy, the court readily stood back and allowed the parents to make their choice.[49]

What made the *Raqeeb* case so finely balanced for MacDonald J was the close alignment of Tafida's and her parents' interests, which we have argued is problematic in this case. Some will celebrate the fact that, notwithstanding recent decisions in *Haastrup*,[50] *Gard*[51] and *Evans*[52] to grant the declarations sought by the relevant Trusts to withdraw life-sustaining treatment from children, MacDonald J makes clear in *Raqeeb* that medical considerations can be trumped by weightier factors. This has long been thus, but the *Raqeeb* case gives a consideration to parental preferences that blurs the distinction between the child's point of view and that of her parents.

THE ROLE OF HEALTHCARE PROFESSIONALS IN BEST INTERESTS DECISION-MAKING POST *RAQEEB*

HCPs have scope to accommodate parental choice in their consideration of a child's best interests when making an assessment of overall best interests.[53] The impact of factors such as disagreement, non-compliance, or a parent moving their child to another provider on the well-being of the child legitimately factors into their overall assessment of what plan is best for the child. As a result, an agreed course of action may not be clinically optimal. However, HCPs

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[44] ITV News, 'MEP Launching Campaign for 'Alfie's Law' to Give Parents More Say' 26 April 2018 http://www.itv.com/news/granada/2018-04-26/mep-launching-campaign-for-alfies-law-togive-parents-more-say/.

[45] Charlie Gard Foundation, Charlie's Law: https://www.thecharliegardfoundation. org/charlies-law/.

[46] *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates and others* [2017] EWCA Civ 410, [105].

[47] *An NHS Trust v MB* (n 7) and see endorsement in *Re A (A Child)* [2016] EWCA Civ 759.

[48] *Re King* [2014] EWHC 2964 (Fam).

[49] *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates and others* (n 46) [96].

[50] *Haastrup* (n 9).

[51] *Great Ormond Street Hospital for Children NHS Foundation Trust v Yates and others* (n 46).

[52] *Evans v Alder Hey Children's NHS Foundation Trust* [2018] 2 FLR 1269.

[53] See discussion in E Cave, E Nottingham, 'Who knows best (interests)? The case of Charlie Gard (2018) 26(3) Med LR 500.

can only accommodate parental preferences to the extent that this would not conflict with their professional obligations to protect the best interests of the child. As Jo Bridgman argues, most decisions about continuation of life-sustaining treatment are 'only referred to court where the clinicians, supported by second opinions and in accordance with professional guidance have reached the limits of what is professionally conscionable'.[54] Bridgman explains that the predominance of cases in which judges agree with HCPs rather than parents reflects their respect for professional obligations rather than deference to the medical profession.[55]

I. MEDICAL OR OVERALL BEST INTERESTS?

Professional obligations should guide HCPs as to the extent to which they are prepared to accommodate parental preferences in the interests of the child. *Raqeeb* raises questions as to what approach was taken by the treating HCPs. It is not clear whether they took an entirely medical conception of best interests or made an assessment of overall interests but concluded that the clinical factors were of such magnitude that treatment would conflict with professional obligations. In either scenario, the HCPs' best interests assessment is subject to independent review by the court, but in the former case the court would be correcting a misapplication of the best interests test and in the latter case the court would be overruling the Trust's conception of professional obligations. Whilst either approach is open to the court, opacity could lead to misinterpretation.

The judgment refers several times to 'medical best interests'[56] in contrast to overall best interests. It is possible that the 'entirely medical perspective'[57] of the Trust flowed from their application of a 'medical best interests' test and either this was in error because they should have applied a wider best interests test (which we consider below) or this approach was understandable given their expertise, but is not the approach that is to be taken by the court. The latter would be troublesome on two levels. Firstly, it does not accord with the Supreme Court judgment in *Aintree v James* (in the context of an adult patient lacking capacity), that the role of *decision makers* is to consider best interests widely from the position of the patient.[58] Where the decision-maker is a doctor, professional guidance from the General Medical Council urges them to look beyond clinical factors when assessing best interests.[59]

Secondly, it would be problematic because perpetuation of a *medical* best interests test would lead to decisions from HCPs that do not fully reflect the wishes and preferences of the

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[54] J Bridgeman, 'Beyond best interests: A question of professional conscience?', 138 in I Goold, J Herring, C Auckland (eds) *Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post Great Ormand Street Hospital v Gard* (Hart, 2019).

[55] *ibid* 151.

[56] *Raqeeb* (n 2) [1], [18], [35], [178].

[57] *ibid* [75].

[58] *Aintree University Hospital NHS Foundation Trust v James* [2013] UKSC 67, [39] per Lady Hale.

[59] GMC, 0-*18: Guidance for all doctors* (2007, updated 2018), paras 12 and 13 https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/0-18-years/assessing-best-interests; GMC, *Treatment and care towards the end of life: good practice in decision making* (2010), para 13 ('Overall benefit'), para 92 https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life.

individual patient, or at least to perceptions from patients that this is the case. It could lead to a significant increase in applications to the court. Anecdotal but immediate evidence that this risk is tangible flows from the Barts Health NHS Trust media statement following the case which states that:

> Unfortunately there are sometimes rare situations where an agreement cannot be reached, and where the treating team believe that continued treatment is not in the *best medical interests* of a child.
>
> In such situations we are expected to follow the national guidance of the General Medical Council, and seek an independent legal view about *the overall best interests* of the child.[60]

With respect, this position is not an accurate reflection of the law. The treating team should not apply a different test (best medical interests) to that applied by the judge (overall best interests). Rather, the medical team must accept that their application of the overall best interests test is subject to independent oversight by the court. They may be found to have erred in their assessment, and they may have more limited ability to reflect on evidence of the wider aspects than a court, but neither factor implies that it is acceptable that they apply a wholly different test.

Is this what happened in Tafida's case? Did the Trust make a purely medical best interests assessment? If the Trust limited itself to a consideration of clinical factors when assessing best interests, then they applied the wrong test and breached professional guidance. As MacDonald J asserts, 'Tafida is more than simply a patient who is the subject of medical treatment'.[61] MacDonald J lamented the overly narrow 'entirely medical perspective'[62] of the Trust, which suggests that the wrong test was applied. However, an alternative explanation is that 'medical best interests' was merely a label for the conclusion reached by the Trust after consideration of *overall* best interests. Clarification would be helpful in light of our suggestion above that it is already leading to confusion as to what is the appropriate test.

II. THE LIMITS OF WHAT IS PROFESSIONALLY CONSCIONABLE

Assuming that the HCPs considered Tafida's overall interests and concluded that the medical factors were such that continued treatment would not be professionally conscionable, the effect of the judgment is either to correct that view of what is professionally conscionable, or to render professional conscience secondary to other considerations.

The opinion of the treating team was considered by the court to be responsible, but evidence that an *alternative* responsible medical opinion exists was central to the refusal of the Trust's

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[60] Barts Health NHS Trust, *Media statement regarding our care of Tafida Raqeeb*, 4 October 2019 https://www.bartshealth.nhs.uk/news/media-statement-regarding-our-care-of-tafida-raqeeb-6626 (italics added).

[61] *Raqeeb* (n 2) [172].

[62] *ibid* [75].

application. The alternative view was reached in the context of the Italian framework on best interests which was relevant because 'this jurisdiction does not hold the monopoly on legal and ethical matters'.[63] The grounds for this proposition are not clear. Presumably the absence of a monopoly flows from free movement rights within the EU, but EU law does not necessarily prevent Member States from adopting a particular ethical position that impacts on free movement. For example, Germany did not restrict free movement of goods when it banned laser-tagging games: Germany's 'monopoly' on the principle of human dignity was protected.[64] Furthermore, the statement raises the issue which MacDonald J himself warned against in *Haastrup*:

> It would be extremely unfortunate if the standard response to applications of this nature was to become one of scouring the world for medical experts who simply take the view that the medical, moral or ethical approach to these issues in their jurisdiction, or in their own practice is preferable to the medical, moral or ethical approach in this jurisdiction. This is particularly so where parents in the situation these parents find themselves in are understandably desperate to grasp any apparent life raft in the storm that is engulfing them.[65]

MacDonald J contrasted the *Raqeeb* case with 'the clandestine involvement of inappropriately qualified foreign medical practitioners'[66] in certain recent cases such as *Haastrup*. Furthermore, as referred to above, much was made of the fact that the course of action advocated by the Gaslini hospital is often adopted in the UK. But if these factors were central to the decision, then the rejection of a 'monopoly on legal and ethical matters' seems unnecessary, because continuation of life-sustaining treatment was arguably compliant with both UK law and ethics. The implication for future cases is that practices that are acceptable in reputable institutions abroad (be they to do with maintenance of life, innovative treatment, or other issues) should not be rejected merely because they are unlawful or unethical here, provided the body of opinion is 'responsible'. Insofar as the limits of what HCPs consider acceptable are controlled by what is professionally conscionable according to UK law and professional guidance, *Raqeeb* suggests that this is too narrow a conception.

Turning now to the implications of the decision in the immediate case, MacDonald J set them out clearly: 'The effect of these decisions is that either the NHS Trust or the Gaslini Hospital in Italy (or another hospital) will have to continue to provide Tafida with life-sustaining treatment.' A duty has been established to keep Tafida alive. If Tafida's parents had decided at this point that they no longer wanted to travel to Italy, it seems that the Trust would have needed to continue life-sustaining treatment if no alternative provider could be found and provided there were no significant changes in Tafida's condition. This is so notwithstanding the

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[63] *ibid* [178].

[64] *Omega Spielhallen- und Automatenaufstellungs-GmbH v Oberbürgermeisterin der Bundesstadt Bonn*, C-36/02. We are grateful to Dr Barend van Leeuwen, Durham University for alerting us to this point when commenting on a previous draft.

[65] *Haastrup* (n 9) [83].

[66] *Raqeeb* (n 2) [178].

pronunciation early in the judgment that: 'The court has no power to require doctors to carry out a medical procedure against their own professional judgment.'[67]

The two statements can be reconciled if the former is considered to represent a collective duty on the part of the Trust and the latter to refer to individual doctors: no individual doctor will be required by the court to treat against their professional view, but the position of the Trust as to Tafida's best interests has been shown by the court to be erroneous. In these circumstances, this leads to a duty to maintain life-sustaining treatment.[68] This has implications for moral distress for HCPs if it results in them treating contrary to widely held professional obligations.

In this sense, *Raqeeb* opens up the potential to bypass certain judicial protections designed to enhance professional control of the treatment options open to patients in the UK. The court will not hear cases that are hypothetical in nature.[69] MacDonald J's assertion that *all* disputes are brought before the court[70] can be contrasted with McFarlane LJ's statement in *Gard* that it is 'conventional' to do so.[71] The argument that this should include hypothetical cases where no responsible HCP has been located who is willing to treat is dubious but not impossible. Given that 'responsibility' is not to be judged according to British standards and laws alone, we are likely to see an increasing number of disputes that would once have been considered hypothetical because no UK doctor would consider the proposed course of action to be in the child's best interests based on domestic professional guidance and standards.

Another issue is that consideration that ongoing or new treatment is in a child's best interests in another country may lead to pressure to offer or continue it in the UK. An individual cannot require a Clinical Commissioning Group to fund treatment,[72] but if a best interest determination is triggered then the paramount consideration will be the welfare of the child rather than resource implications. In circumstances where a duty to continue treatment is acknowledged by the court, there are cost implications for the NHS. The Science Media Centre records Julian Savulescu's rapid response to the case as being a decision that is justified on the basis of distributive justice:

> There are independent good reasons to stop treatment based on justice: there are not enough resources in the NHS to indefinitely continue treatment for so little expected benefit. But this should not stop parents taking her to Italy at their own expense for continued treatment.[73]

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[67] *ibid* [115].
[68] *University Hospitals Birmingham NHSFT v HB* [2018] EWCOP 39; *Royal Bournemouth and Christchurch Hospitals NHS Trust v TG & OG* [2019] EWCOP 21. See E Cave, 'Selecting Treatment Options and Choosing Between them: Delineating Patient and Professional Autonomy in Shared Decision-Making' *Health Care Anal* (2019) https://doi.org/10.1007/s10728-019-00384-8.
[69] *AVS v A NHS FT* [2011] EWCA Civ 7.
[70] *Raqeeb* (n 2) [107].
[71] *Ibid* [105].
[72] *R v Cambridge District Health Authority, ex p B* [1995] 1 WLR 898c.
[73] Science Media Centre (n 37).

But the judgment refers to a plan to return to the UK for long term ventilation at hospital or home and a likely future of increased physical deterioration will require further treatments.

CONCLUSION

The precedents of *Gard* and *Evans* demonstrate the limits of the court's consideration of parental choice in making best interests determinations for children. The *Raqeeb* case turned on an unusual set of facts: it was considered that Tafida could not feel pain and would not be burdened by continued life which, according to Tafida's religious and cultural upbringing in her first four years of life, was sacred. Compassion for the parents in this sad case will lead many to agree with the outcome. Our concern and focus have been on the articulation and application of the best interests test.

Giles Birchley's rapid response published by the Science Media Centre recognised the potential for this case to exacerbate the confrontational nature of debates around treatment where parents and HCPs cannot agree.[74] We echo this concern. Condemnation, abuse and lack of trust of HCPs who stand in the way of parental choices has seen a marked rise. Free movement rights and a novel interpretation of best interests bring new scope to parental claims. A more worrying implication of this case would be that fewer disputes might arise because the media and the law have elevated parental rights (at least for those with sufficient knowledge, support and funds) to the extent that HCP obligations to act in the best interests of children are undermined.

What concerns us in this case is not that a court can overrule the clinical view of overall best interests. That potential is the very purpose of the hearing. Rather, our fear is that the interpretation of the best interests test in *Raqeeb* raises the potential for Trusts to conclude that professional obligations to the child can be secondary to those to the parents. This flows from a novel approach to best interests in the judgment including: the separation of medical and overall best interests; the recognition of the relevance of international laws and frameworks to best interests determinations, notwithstanding their potential conflict with national judgments and professional guidelines; and reliance not on what Tafida could understand and express but on what she might in future have come to believe had she followed her parents' religious beliefs.

[74] *ibid*.