

Institution: University of Oxford		
Unit of Assessment: 30 - Philosophy		
Title of case study: Critical decisions: Ethical framework for resuscitation and treatment withdrawal decisions in children and infants		
Period when the underpinning research was undertaken: 2010-2019		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Dominic Wilkinson	Role(s) (e.g. job title): Director of Medical Ethics, Professor of Medical Ethics	Period(s) employed by submitting HEI: July-Dec 2010, Dec 2013-present
Period when the claimed impact occurred: 1 January 2015-31 December 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words)		
<p>Dominic Wilkinson's research on the ethical basis for life and death decisions in the care of seriously ill children and infants has been incorporated into professional guidance in the United Kingdom, Australia, and the Philippines. It has influenced over 13 court judgements in the UK alone where it has been quoted in the delineation of when withholding or withdrawal of treatment is in an infant's best interests, when treatment is considered futile. In these cases, content from the guidelines directly informed the judgements given. In over 30 media appearances, he has also changed public and professional understanding of the underlying ethical issues at stake in this controversial area.</p>		
2. Underpinning research (indicative maximum 500 words)		
<p>Over the last decade, the Critical Decisions research, led by Wilkinson, has provided systematic ethical analysis of life and death decisions for children and newborn infants. The aim of this work has been to use the tools of analytic medical ethics to clarify the basis of decisions, constructively revise and improve existing guidance for professionals, and to improve health professionals' and the public's understanding of these fraught and difficult decisions. The body of work resulted in a novel 'dissensus' framework which has been widely cited by peers and used to influence vital medical decisions.</p> <p>The first part of this research, was conducted between July and December 2010, in a postdoc following his PhD. During his postdoc time, Wilkinson built on his PhD research by elaborating and extending his account of the ethical boundaries for parental decision-making. He submitted for publication his "threshold framework" relating to brain damage and disability and its role on decisions for newborns (submitted July 2010, published 2011) [1], and wrote a book proposal and the first draft of his monograph (published by Oxford University Press in 2013) [2]. That work set out a conceptual analysis of decisions based on the child's quality of life – clarifying and distinguishing various ways in which disability might be relevant to a child's best interests. He examined the role of parents in decisions and proposed a 'Threshold framework' as a way of conceptualising the limits of parental discretion in decisions [1,2].</p> <p>Subsequently (from 2013-20) Wilkinson extended his earlier research to develop a parallel 'Threshold' framework for decisions relating to the initial care of extremely premature infants (EPI) [3]. He argued that such decisions should move away from a focus on the specific degree of prematurity and focus instead on infants' prognosis [3,4].</p> <p>Recent work (2017-19) following a series of high-profile and controversial cases, has examined issues relating to disagreement over the treatment of children or infants. That culminated in a book, co-authored with Oxford colleague Julian Savulescu, which analyses the scope and place of reasonable disagreement in such decisions [5]. He proposed a novel 'dissensus' framework</p>		

for helping to resolve disagreements, and published in leading medical journals on the ethical approach to resolving disagreement with parents [6].

3. References to the research (indicative maximum of six references)

1. [Journal Article] Wilkinson D. A life worth giving: the threshold for permissible withdrawal of treatment from disabled newborn infants. *American Journal of Bioethics* 2011; 11(2): 20-32. DOI: [10.1080/15265161.2010.540060?scroll=top&needAccess=true](https://doi.org/10.1080/15265161.2010.540060?scroll=top&needAccess=true)
2. [Authored Book, available on request] Wilkinson D. *Death or Disability? The Carmentis machine and decision making for critically ill children.* Oxford University Press. 2013. ISBN: 9780199669431.
3. [Chapter, available on request] Wilkinson D. 'Who should decide for critically ill neonates and how? The grey zone in neonatal treatment decisions.' In *When doctors and parents disagree: Ethics, paediatrics and the zone of parental discretion* Ed McDougall R, Delany C, Gillam L. Federation Press. Melbourne, 2016. ISBN 9781760020590. Available at: <https://www.ncbi.nlm.nih.gov/books/NBK436918/>
4. [Journal Article] Hayden D, Mendoza, Uy, Wilkinson D. Resuscitation of preterm infants in the Philippines: a national survey of resources and practice. *Archives of Disease in Childhood - Fetal and Neonatal Edition.* 2019. DOI: [10.1136/archdischild-2019-316951](https://doi.org/10.1136/archdischild-2019-316951)
5. [Authored Book] Wilkinson D, Savulescu J. Ethics, conflict and medical treatment for children: from disagreement to dissensus. Elsevier. 2018. Available at: <https://www.ncbi.nlm.nih.gov/books/NBK537987/>
6. [Journal Article] Wilkinson D, Barclay S, Savulescu J. Disagreement, mediation, arbitration: resolving disputes about medical treatment. *The Lancet* 2018; 391(10137): 2302-2305. DOI: [https://doi.org/10.1016/S0140-6736\(18\)31220-0](https://doi.org/10.1016/S0140-6736(18)31220-0).

Grants

Dominic Wilkinson (PI). 'Rational decisions: the ethics of rationing in newborn intensive care' Wellcome Trust Society and Ethics Program, Health Professional Research fellowship WT106587/Z/14/Z: GBP240,000 (2015-19).

4. Details of the impact (indicative maximum 750 words)

Each year in the United Kingdom, approximately 40,000 seriously ill infants and children are admitted to intensive care units. Despite advances in medical science and treatment, a proportion of these children do not recover from their illness. The majority of deaths follow decisions to withdraw or withhold potentially life-prolonging treatment. In clarifying ethical questions surrounding these decisions, and in the development of novel ethical frameworks for clinical decision-making, Wilkinson's research has significantly impacted public understanding and debate, legal rulings, and professional guidance, each discussed below.

Development of a clear ethical framework used in courts for quality of life decisions for children

Wilkinson's research has examined pre-existing guidance for UK health professionals around decisions for children. There is no statutory law relating to withdrawal of life-sustaining treatment, but professional guidelines had been cited by judges in cases, and consequently incorporated into case law. Wilkinson was part of a working group that revised the ambiguous criteria that were being used, and published new guidelines in 2015 [A]. The guidelines the group developed have subsequently informed decisions on at least 13 cases related to such medical decisions in the UK, specifically quoting the revised criteria in the new guidance [B]. For example, in introducing an expert witness report on the case of *Re M (Declaration of Death of a Child)* [2020], Sir Andrew McFarlane noted directly that Professor Wilkinson's "high level of professional expertise" in his involvement in developing the 2015 guideline was of "direct relevance to the issue in these proceedings" [B, page 6]. In another example (the court case of *Alder Hey v Evans*, 2018), Justice Hayden noted "It is necessary here to root my own

conclusions in the framework of the Law and within the available guidance. The Royal College of Paediatrics and Child Health has produced guidance, ..." He then quoted verbatim from the revised guidance [B], [C, page 17].

Influence on decisions relating to extremely premature newborn infants: development/revision of national and international guidelines

Wilkinson's research into the basis for decisions regarding extremely premature newborn infants has international reach, having influenced professional guidance outside the UK, in Australia and the Philippines. Wilkinson was the lead author on the first South Australian guidance relating to resuscitation decisions for extremely premature newborn infants [D]. This was the first published professional guidance to specifically incorporate prognosis into decisions, drawing on Wilkinson's novel framework (the PAGE framework – Prognosis Average Gestation Equivalent) [3, above]. He was consulted by a working group developing similar guidance in Queensland, and the PAGE framework was also included in that guideline [E].

In the Philippines, Wilkinson has collaborated with neonatologists and ethicists to address the extremely challenging treatment decisions they faced in a limited-resource setting. There was no existing ethical guidance for such decisions, and in January 2018 he conducted a national survey of specialist neonatologists in the Philippines to assess existing practice, attitudes and understanding [4, above]. In February 2019, he convened a consensus workshop at the Philippine Society of Newborn Medicine national conference [F]. The Vice President of the Philippine Society has noted that Wilkinson was "very effective" in coordinating a large group of professionals to develop consensus and that he completed the first draft the resulting guidelines, which are highly rated by local paediatricians and "very relevant in our practice" [G]. Another participant in the workshop who facilitated Wilkinson's work in the Philippines wrote, "Prof Dominic [Wilkinson] has been a catalyst of ethical change in the Philippines context of neonatal care." [H]

In 2018-9, Wilkinson was part of a working group that developed a new national framework for resuscitation of extremely preterm infants for the UK. That framework was published in October 2019 [I]. The ethical principles underpinning that framework were based on Wilkinson's published research, and he wrote key sections of the framework, particularly relating decision-making to prognosis. The president of the British Association of Perinatal Medicine has acknowledged Wilkinson's "enormous contribution" to the framework, his "very active role" in developing the guidance [J]. The new guidance endorsed the possibility of providing active stabilisation to a group of extremely preterm infants at 22 weeks gestation – where previous guidance had recommended against active treatment. An editorial in *The Lancet* noted that "the report provides a practical and thoughtful approach in this very complex area of perinatal medicine" [K].

Improvement of public understanding and contribution to public debate in relation to parent-doctor disagreement concerning medical treatment

Wilkinson's research into ethics around conflicts between doctors and parents led to wide national and international public attention at the time of high-profile cases (Charlie Gard March-July 2017, Alfie Evans Jan-April 2018, Tafida Raqeeb September-October 2019). Wilkinson's work with the media around these cases was cited positively by the UK Science Media Centre (who clarify poorly understood science headline stories):

"Without Dominic and a frustratingly small number of other medics, the media would have had no access to impartial, evidence-based expertise whatsoever, and the public would have been woefully misinformed about childhood disease and prognosis." [L]

These cases attracted a great deal of media attention [M], and Wilkinson gave interviews nationally and internationally, including on the BBC, CNN, Sky Television, *The Times*, [M]. Social media comments also highlight his role in helping to inform wider understanding about the role of

parents and of the courts, with Twitter users who had watched his interview with Good Morning Britain, which had an average daily audience of 640,000 in 2018 [N, page 3]. Comments on social media included a referral to Wilkinson's "incredibly important point[s]" [M, page 5], commending him as "the voice of reason" [M, page 2], and expressed gratitude to Wilkinson for "publicly giving a much needed, very balanced and empathic presentation" [M, page 6]. He has subsequently been consulted and been involved in working with families and professionals to develop practical ways to improve resolution of such disagreements. He was co-author of a Royal College of Paediatrics and Child Health guideline relating to reducing conflict [N].

Around this time, Wilkinson acted as a script consultant for a BBC television program – *Holby City* (audience 4,500,000), which ran a story over a recent season exploring conflict between parents and doctors around treatment [N]. Wilkinson provided input to a script workshop and direct feedback on scripts that was termed "invaluable" by the script writers in helping keep the story "grounded in reality" [O]

5. Sources to corroborate the impact (indicative maximum of 10 references)

A. Royal College of Paediatrics and Child Health (2015). National Guidelines: *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice*. Wilkinson was an author of the guidelines.

B. List of 13 court cases that cite the RCPCH 2015 National Guidelines [A] and classification of decisions. Taken from Westlaw Edge UK and BALII UK (2020). URLs provided in document.

C. Royal Courts of Justice (2018). Alder Hey Children's NHS Foundation Trust. Neutral Citation Number: [2018] EWHC 308 (Fam). Case No. FD17P00694. This case cites the new national guidelines which were developed by Wilkinson.

D. South Australia Health (2019). Perinatal Practice Guideline: Perinatal care at the threshold of viability. 2013, revised 2019. Available at: https://www.sahealth.sa.gov.au/wps/wcm/connect/8ddf798042ac004d9f11bfad100c470d/Perinatal+Care+at+the+Threshold+of+Viability_PPG_v2_0.pdf?MOD=AJPERES&CACHEID=ROOTW-ORKSPACE-8ddf798042ac004d9f11bfad100c470d-m.5uUHq

E. Queensland Health (2014). Clinical Guideline: *Perinatal care at the threshold of viability*. Available at: https://www.health.qld.gov.au/_data/assets/pdf_file/0023/142259/q-viability.pdf. Wilkinson is listed as a member of the working group on this guideline (page 33), and his work is cited (pages 28-29).

F. National guideline authored by a group including Wilkinson as lead author: Wilkinson D, Uy EM, McTavish J, Hayden D, (2019). National Guideline: Decision-making around resuscitation of extremely preterm infants in the Philippines: a consensus guideline. *Journal of Paediatrics and Child Health* 2019; 55(9): 1023-1028. Available at: <https://doi.org/10.1111/jpc.14552>

G. Statement from the President of the Institute of Child Health & Human Development at the National Institutes of Health in the Philippines about Wilkinson's impact on perinatal ethics in the Philippines, 11 February 2020.

H. Testimonial from Scottish Catholic missionary priest, surgeon and moral theologian with the Verbum Dei Missionaries (assigned in the Philippines for over 16 years and currently the Provincial Superior) about Wilkinson's impact on perinatal ethics in the Philippines, 5 February 2020.

I. A national (UK) guideline on managing preterm babies; Wilkinson was part of the working group that developed the guideline: British Association of Perinatal Medicine (2019). National Guideline: *Perinatal management of extremely preterm birth before 27 weeks gestation*.

Available at: <https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019>

J. Testimonial Letter from the President of British Association of Perinatal Medicine noting Wilkinson's Contribution to UK Guidelines (see [I] above), 30 November 2020.

K. Editorial mentioning the UK guideline published in *The Lancet* (2019). *A new framework for managing extremely preterm births*. *Lancet*, 394(10209):1592. Available at: [https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736\(19\)32670-4.pdf](https://www.thelancet.com/pdfs/journals/lancet/PIIS0140-6736(19)32670-4.pdf) (written by Lancet Staff)

L. Letter from the Senior Press Manager of the Science Media Centre, 30 November 2020, praising Wilkinson for helping improve the science-base of the stories in the media about Charlie Gard and Alfie Evans.

M. Report by REF Impact Facilitators January 2020 of Impact from Media Appearances, Viewership and Social Media Comments Concerning Wilkinson's Contributions Regarding Controversial Treatment Cases.

i) URLs from reports in The Guardian, BBC, ITV, The New York Times, and others

ii) URLs and descriptions of social media reactions to Wilkinson's appearances

N. A document that Wilkinson helped author to provide practical guidance to paediatricians regarding managing conflict in difficult cases. Royal College of Paediatrics and Child Health. (2019). National Guideline: *Achieving Consensus: Advice for Paediatricians and other Health Professionals : On prevention, recognition and management of conflict in paediatric practice*. <http://dx.doi.org/10.1136/archdischild-2018-316485>

O. Letter from Producer of *Holby City*, 7 December 2020, noting Wilkinson's role in the production of the popular television show.