

# THE RIGHTS OF CHILDREN IN BIOMEDICINE (VOL. 1): REGULATING RISK AND UNCERTAINTY TO PROTECT CHILDREN AND THEIR RIGHTS

In the 21<sup>st</sup> century, the rights of children in biomedicine have increasingly become regulated by both international and national legal orders through complex, intersecting norms and regulations. Since the promulgation of the Convention on Human Rights and Biomedicine, human rights authorities have exponentially sharpened their focus on the rights of children in health care, especially due the scientific risks and uncertainty inherent in many biomedical interventions. Many of these interventions have posed significant dangers to children’s lives, health, and physical integrity, as well as their rights to autonomy, privacy, and identity.

This first volume of *The Rights of Children in Biomedicine* is aimed at establishing a model for examining how national legal orders address standards of care, informed consent, and the protection of children’s human rights. It frames multiple juridical questions in light of overarching international law norms. It further examines how seven European jurisdictions regulate biomedical interventions, particularly in healthcare. It explores how these jurisdictions – the five Nordic countries, England & Wales and Latvia – align and diverge in their regulatory approaches to biomedicine and its relationship to human rights. The book’s final section sets forth comparative assessments of how these seven jurisdictions conceive and enforce rules regarding scientific risk and uncertainty in several contexts, with recommendations regarding what reforms need to be made to future regulatory approaches to promote the best interests of children and to protect their rights.

*Participating authors:* Cressida Auckland, Hrefna Friðriksdóttir, Jameson Garland, Hrefna Gunnarsdóttir, Imogen Gould, Mette Hartlev, Tom Liefgaard, Liisa Nieminen, Karina Palkova, Elisabeth Rynning, Kirsten Sandberg, Henriette Sinding Aasen, Anna Singer, Santa Slokenberga, Karl Harald Sjøvig, Olita Stanislavska.

.....

# THE RIGHTS OF CHILDREN IN BIOMEDICINE (VOL. 2): BIOMEDICAL INTERVENTIONS AND THE RIGHTS OF CHILDREN TO THE HIGHEST ATTAINABLE STANDARD OF HEALTH

The second volume of *The Rights of Children in Biomedicine* examines in detail how different biomedical interventions negatively impact children’s rights. The thematic focus of the book is the importance of ensuring that scientific advances in biomedicine actually improves the lives and health of children. Indeed, the Convention on the Rights of the Child requires medical interventions to be science-based, evidence-based and child-specific to ensure that children actually benefit from scientific progress. The individual chapters address either specific biomedical interventions or a class of such interventions to determine whether they pose risks and uncertainties to children’s health in ways that threaten their rights. This remains a concern even when these interventions are considered true innovations from a biomedical viewpoint.

This volume critically examines a wide array of biomedical interventions to scrutinize whether they meet the highest attainable standards of healthcare. The book covers interventions at the earliest stages of human development that can have a lifelong impact on children’s lives, including preventive

care, genetics, and clinical practices for children classified as minorities based on their gender, sexuality, and physical sex characteristics. It also specifically examines children diagnosed with serious physiological and psychological health needs, as well as a wide variety of interventions, including sexual and reproductive care, clinical research, and transplantation. Examining a full array of interventions from prenatal life to end-of-life decisions in childhood, the book concludes with recommendations regarding how these different interventions may be better regulated in the future.

***Participating authors:*** Caroline Adophsen, Kristof Van Assche, Katharina Ó Cathaoir, Jo Dorscheidt, Claire Fenton-Glynn, Jameson Garland, Aart Hendricks, Pin Lean Lau, Audrey Lebret, Stevie Martin, Signe Mežinska, Tanya Ni Mhuirthile. Clayton O'Neil, Annika Frida Petersen, Janne Rothmar Herrmann, Kirsten Sandberg, Anna Singer, Mirjam Sombroek, Ralph Sandland, Judit Sandor, Reidar Schei Jessen, Santa Slokenberga, Anniken Sørli, Jakob Wested.