Universiteit Leiden
The Netherlands

Voices of experience in periviable decision-making and artificial placenta technology

Boer, A.H.A. de

Citation

Boer, A. H. A. de. (2025, July 1). *Voices of experience in periviable decision-making and artificial placenta technology*. Retrieved from https://hdl.handle.net/1887/4252056

Version:	Publisher's Version
License:	Licence agreement concerning inclusion of doctoral thesis in the Institutional Repository of the University of Leiden
Downloaded from:	https://hdl.handle.net/1887/4252056

Note: To cite this publication please use the final published version (if applicable).

Voices of experience

in
periviable decision-making
and artificial placenta technology

A.H.A. de Boer

Voices of experience
in periviable decision-making and artificial placenta technology

© 2025 – A.H.A. de Boer
All rights reserved. No part of this publication may be reproduced or transmitted in any form or by any means without the written permission of the author.

The research presented in this thesis was carried out within the departments of Obstetrics and Ethics and Law of the Leiden University Medical Center and the department of Neonatology of the Radboudumc Amalia Children's Hospital

ISBN
978-94-6522-377-3

Cover design
Kunstwerk en design door Nicoline Frederique, Atelier Ink Amsterdam
www.ink-amsterdam.nl

Design/lay-out and print
Provided by thesis specialist Ridderprint, ridderprint.nl
Printing: Ridderprint
Layout and design: Anna Bleeker, persoonlijkproefschrift.nl

Financial support for printing of this thesis was kindly provided by
the Universitaire Bibliotheken Leiden

Voices of experience

in

periviable decision-making and artificial placenta technology

Proefschrift

ter verkrijging van

de graad van doctor aan de Universiteit Leiden,

op gezag van rector magnificus prof.dr.ir. H. Bijl,

volgens besluit van het college voor promoties

te verdedigen op dinsdag 1 juli 2025

klokke 11.30 uur

door

Angret Hinke Alies de Boer

geboren te Groningen

Promotor en promotiecommissie

Promotor:	Prof. Dr. M.C. de Vries
Co-promotores:	Dr. E.J.T. Verweij
	Dr. R. Geurtzen (Radboud Universitair Medisch Centrum)
Promotiecommissie:	Prof. dr. A.M. Stiggelbout
	Dr. N. de Graeff
	Prof. dr. W.P. de Boode (Radboud Universitair Medisch Centrum
	Dr. N. Crombag (Universitair Medisch Centrum Utrecht)

Table of contents

Chapter 1	General introduction	8
Part I: Values in decision-making at the limit of viability		
Chapter 2	A scoping review of parental values during prenatal decisions about treatment options after extremely premature birth	28
Intermezzo A	How we handled our son's birth at the limits of viability after an unexpected pregnancy – Dirk-Jan Berken & Hiske van Dam	50
Chapter 3	Perspectives of extremely prematurely born adults on what to consider in prenatal decision-making: a qualitative focus group study	56
Intermezzo B	'Vroeggeborenen willen zorg op maat: 'levenslange gevolgen' (in Dutch)	76
Chapter 4	Voices of experience: what parents teach us about values and intuition in periviable decision-making	82
Part II: The artificial amnion and placenta technology as potential treatment for extremely premature infants		
Chapter 5	Navigating the Ethical Landscape of the Artificial Placenta: A Systematic Review	104
Chapter 6	Capabilities and Stakeholders – Two Ways of Enriching the Ethical Debate on Artificial Womb Technology	124
Intermezzo C	Rapport Workshop 'Begeleidingsethiek' (in Dutch)	132
Chapter 7	Stakeholder Perspectives on the Design of First-In-Human Trials for Artificial Amnion and Placenta Technology: A Qualitative Study	162
Chapter 8	Healthcare professionals' and parental perspectives on human artificial placenta technology-trials: counselling and informed consent	178
Chapter 9	The ethical concerns of Dutch perinatal healthcare professionals and parents regarding artificial amnion and placenta technology	194
Chapter 10	English summary and general discussion	218
Chapter 11	**Appendices**	
	Nederlandse samenvatting	240
	List of abbreviations	244
	List of publications	245
	Curriculum vitae	247
	Dankwoord	248