



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  
perivable 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](http://www.ink-amsterdam.nl)

### **Design/lay-out and print**

Provided by thesis specialist Ridderprint, [ridderprint.nl](http://ridderprint.nl)

Printing: Ridderprint

Layout and design: Anna Bleeker, [persoonlijkproefschrift.nl](http://persoonlijkproefschrift.nl)



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

**Voices of experience**  
**in**  
**perivable 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

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