



UvA-DARE (Digital Academic Repository)

Children's competence to consent to medical treatment or research

Hein, Irma

[Link to publication](#)

Citation for published version (APA):

Hein, I. M. (2015). Children's competence to consent to medical treatment or research. Amsterdam: Amsterdam University Press.

General rights

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

Disclaimer/Complaints regulations

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <http://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

Children's competence to consent to medical treatment or research



Irma Hein

Children's competence to consent to medical treatment or research

The studies described in this thesis were performed at the Department of Child and Adolescent Psychiatry of the Academic Medical Center, University of Amsterdam, the Netherlands. The research project was financially supported by the Netherlands Organization for Health Research and Development.

Lay-out: Crius Group, Hulshout

© Irma Hein / Amsterdam University Press B.V., Amsterdam 2015

All rights reserved. Without limiting the rights under copyright reserved above, no part of this book may be reproduced, stored or introduced into a retrieval system, or transmitted, in any form or by any means (electronic, mechanical, photocopying, recording or otherwise) without the written permission of both the copyright owner and the author of the book.

Children's competence to consent to medical treatment or research

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad van doctor
aan de Universiteit van Amsterdam
op gezag van de Rector Magnificus
prof. dr. D.C. van den Boom
ten overstaan van een door het College voor Promoties ingestelde
commissie, in het openbaar te verdedigen in de Aula der Universiteit
op vrijdag 17 april 2015, te 13.00 uur

door Irma Marijke Hein
geboren te Vries

Promotiecommissie:

Promotor:	Prof. Dr. J.B. van Goudoever	Universiteit van Amsterdam
Copromotores:	Dr. R.J.L. Lindauer	Universiteit van Amsterdam
	Dr. P.W. Troost	Universiteit van Amsterdam
Overige leden:	Prof. Dr. T. Grisso	University of Massachusetts
	Prof. Dr. M.A. Grootenhuis	Universiteit van Amsterdam
	Prof. Dr. P.J. Hoekstra	Rijksuniversiteit Groningen
	Prof. Dr. J. Legemaate	Universiteit van Amsterdam
	Prof. Dr. A. Popma Prof. Dr. D.L. Willems	VU / Universiteit Leiden Universiteit van Amsterdam
Faculteit:	Geneeskunde	

Contents

1	Introduction	7
2	Why is it hard to make progress in assessing children's decision-making competence?	9
3	Accuracy of assessment instruments for patients' competence to consent to medical treatment or research.	19
4	Assessing children's competence to consent to research by a standardized tool: a validity study	49
5	Accuracy of the MacArthur Competence Assessment Tool for Clinical Research (MacCAT-CR) for measuring children's competence to consent to clinical research	65
6	Key factors in children's competence to consent to clinical research	79
7	Assessing children's competence to consent to treatment	91
8	Why do children decide not to participate in clinical research: a quantitative and qualitative study	103
9	Informed consent instead of assent is appropriate in children from the age of twelve	117
10	Summary and future perspectives in research on children's decision-making competence	129
	Nederlandse Samenvatting	139
	Reference List	145
	Dankwoord	155
	Curriculum Vitae	159