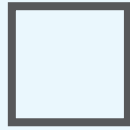


Increasingly, pleas are made for extending the involvement of minors in decision-making about participation in pediatric research. However, a number of issues arise from this desired participation of minors. First, involvement in decision-making requires children and adolescents to be adequately informed about what participation in research entails. Second, the plea for increased involvement in decision-making requires further investigation whether children indeed **can, should** and **want** to play a role in the decision about research participation.

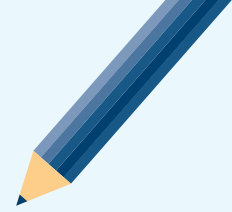
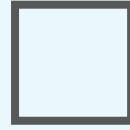
This thesis *Targeted Informed Consent - Empowering young participants in medical-scientific research* addresses these issues and thereby contributes to insights in how to empower minors in the context of informed consent for research participation.

We present new informed consent material, that was developed in close cooperation with children and other end-users, the process of which is described and evaluated. In addition, insights in the role that minors can, should and want to play in the informed consent procedure are described. These insights were obtained by reviewing multidisciplinary scientific evidence on the competence of minors, by an ethical reflection on the view on children that we should adopt, and by consulting minors themselves about the perspectives on their role in decision-making about clinical research participation.

Finally, the insights from all different aspects of this research project are combined and recommendations are provided on how to empower minors in decision-making about research participation.



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Targeted Informed Consent

Empowering young participants in medical-scientific research

Petronella Grootens-Wiegers

