Maastricht University

From lab to fertility clinic

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Valorization addendum

In this thesis, I investigated how to responsibly deal with medical risks of new reproductive technologies for children born as a result of their clinical application. The results of this study can contribute to improve the innovation and practice of medically assisted reproduction (MAR). In this addendum, I first explain how this research benefits relevant stakeholders. Secondly, I discuss which valorization activities have been undertaken.

Contributing to responsible innovation in medically assisted reproduction

The insights generated from this research are relevant to four groups of stakeholders. First, to MAR families. Responsible innovation in MAR is aimed to improve the quality and safety of the techniques for those dependent on them and for those born after them. This thesis provides insights into how to innovate MAR in an ethically responsible way, thereby contributing to safer reproductive treatment, both in the short and long term.

Second, this research provides handhold for researchers, as it illustrates how different research steps (preclinical research, clinical study, follow-up) can be conducted in practice responsibly. Additionally, it may answer some ethical questions that researchers themselves struggle with, such as questions surrounding the justification of research with animals and/or human embryos.

Third, this thesis provides insights on how healthcare professionals in the field of MAR should deal with offspring safety risks. This counts for both professional organizations, such as the European Society of Human Reproduction and Embryology (ESHRE) or the American Society for Reproductive Medicine (ASRM), and for individual professionals. For example, this thesis proposes to make several amendments to the normative framework of responsible innovation that ESHRE proposes. These amendments are discussed more extensively in the Discussion chapter. As to individual professionals, for example, a justification for motivating patients to participate in follow-up in specific contexts is given.

Last, this thesis hopes to inspire policy makers to adjust legislation and gives practical advice on how to do so. Firstly, legislation that is not ethically sound and hampers responsible innovation in MAR should be changed or abandoned. For example, as argued in the

Discussion, the ban on creating human embryos for research as contained in the relevant legislation of several European countries including the Netherlands, should be lifted on conditions. With this specific recommendation, this thesis contributes to a current national debate about this issue for which the initiative was taken by the Dutch government in the fall of 2019. And secondly, this thesis insists on the need for a legal framework to make sure self-regulation is followed and treatments are efficient and safe.

Undertaken valorization activities

I have undertaken multiple valorization activities to generate attention for the findings of this study. First, the results of my work have been published in international journals focusing on technical and normative aspects of reproductive and genetic medicine. This way, the outcomes of this research were available for both clinicians and the scientific community.

Second, I published two brief Dutch-language articles. One considered the Dutch Embryos Act and was published in a Dutch newspaper[1]. In this article, I argued that there is no moral justification for upholding the current categorical ban on creating human embryos for research and that this ban should be lifted, because it hampers responsible innovation. The aim was to bring this topic to the attention of the general public and policy makers. The second article was published in the journal of the Dutch Society for Obstetrics & Gynaecology (NTOG).[2] This gave me the opportunity to address a broad range of possibly interested professionals with the main findings of my paper on innovation and precaution (Chapter 4 of this thesis). The NTOG-article was written on invitation for a special section of the journal devoted to the presentations by Dutch professionals given at the 2019 ESHRE conference in Vienna.

Third, I presented my work at three annual ESHRE conferences (2017, 2018 and 2019). This way, the results of my research were made available to a large, international, group of clinicians, scientists and ethicists in the field of reproductive medicine. I was invited

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[1] Verna Jans en Wybo Dondorp. Sta weken voor onderzoek toe. *Trouw* 14 juni 2017; https://www.trouw.nl/nieuws/sta-kweken-embryo-voor-onderzoek-toe~ba2f7d74/

[2] V Jans, WJ Dondorp, GMWR de Wert. Verantwoorde introductie van nieuwe voortplantingstechnieken. Tussen innovatie en voorzorg. *Ned Tijdschr Obstet Gynaecol* 2020; 133 (4): 205-206. http://www.ntog.nl/dynamic/media/3/documents/NTOG_2020_4_web.pdf

as a speaker at a precongress-course on the safety of MAR preceding ESHRE's 2020 conference in Copenhagen. This would have been a further occasion to bring my work under the attention of the most relevant group of professionals. Unfortunately, due to the corona-pandemic, this conference was cancelled.

Last, this thesis is part of the Science and Ethics of stem cell derived Gametes (SEGa) project. I presented during public events organized by the project's team. For example, in 2020, a science meeting discussing the outcomes of the project was organized in Ghent, for which people could register. This way, my research outcomes were also brought to the attention of societal partners of the project, such as representatives of patient organizations, and to a lay audience.