Maastricht University

Mind the gap

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VALORISATION

“The more extensive a man’s knowledge of what has been done, the greater will be his power of knowing what to do.”

Benjamin Disraeli (1804-1881)

This part of the thesis focus on strategies to valorise the results of the conducted research. Valorisation of knowledge is the actual process of making research results suitable and available for the general public and society [1]. The outcome of the evaluation performed has led to new insight and knowledge about online e-research. This chapter will therefore focus on the value of valorisation of these new insights and the possible valorisation strategies.

Relevance for valorisation of knowledge ***Minding the gap***

The relevance and importance of valorisation of research results should not be underestimated. Even the result of clinical trials with small effect sizes could be disseminated and valorised. This chapter elaborates on the valorisation strategies for the results of the research performed for this thesis. This thesis explores the potential, and also the effectiveness of Kopstoring, an online preventative course for adolescent offspring of parents who are dealing with mental illness or addiction. Surprisingly, for the research executed within this thesis, it is not the result of the clinical effectiveness study that is most important to valorise, but the knowledge gained about the obstacles encountered when performing this online randomised controlled trial. From the obstacles and problems met during the study, researchers, policy makers, legislators and patients can learn a great deal.

Valorisation strategies ***Bridging the gap***

In this part of the valorisation chapter, we propose several strategies to optimize valorisation of the knowledge obtained and in addition the information gathered concerning the problems encountered during the execution of the online randomised clinical trial. A general strategy to valorise results of this thesis could be disseminating results among the scientific community and the community of health care professionals. This process has already started by publishing the results of the studies in International peer reviewed journals. In addition, the results are sent out to the National platform Kopstoring and mental health institutions. Secondly, the results are partly disseminated at National (Amsterdam and Maastricht) and International conferences (Italy, Germany, Canada and the United States of America). In answer to the early dissemination of various studies, Kopstoring attracted a lot of attention and the Karolinska Institute in Sweden has bought the rights to be able to provide Kopstoring in Sweden. At the other side of the world, in Portland, Oregon (USA) experts also see the potential of Kopstoring and are trying to find a platform for negotiations with the developers (Trimbos Instituut and four mental health institutions) to see if there is a potential for the provision of the course in Oregon.

A second valorisation strategy focuses on valorisation of the knowledge obtained about problems with obtaining both written and online informed consent and the concerns about the age differences for legal decision making for medical treatment and (medical) research. The goal of this strategy is to create optimum awareness about the knowledge gathered because the inclined answer to solve this problem is specifically for National Parliament; the National legislator and policy maker. The first strategy to create awareness and valorise the results of our study on legal issues is one that needs investment. As described in chapter 6 of this thesis, the legal obligation to obtain 'written' informed consent creates serious problems for online research in some cases making it virtually impossible. This claim has been supported by medical and health researchers for some years now, and it has even been noticed and acknowledged by the medical research ethical committee (MReC) and the National Central Committee on Research Involving Humans (CCMO) [2]. Amending an act or legislation is a task that can be performed only by National Parliament [3]. However, since the messages has not been picked up yet it might be time to use more convincing strategies. A first step could be to write a petition which can be served to members of Parliament. Writing a petition is a good strategy to create awareness and build a large community to support this initiative to allow online consent in medical research (in cases where it is deemed absolutely necessary and under strict regulation). If the petition is constructed the correct way it will be understandable, clear and demanding only minimal effort from the supporting party. In accordance to writing a petition a citizens initiative is a second tool which can be used to create awareness and with enough support (online signatures) has a direct impact on the political agenda [4].

In addition to the scientific community and Dutch policy makers and Parliament, the target population would benefit from transparent valorisation and dissemination of the results of this thesis. After all, they are the ones suffering from the situation they are in. The course participants have already indicated how valuable Kopstoring can be. Communicating the results of this evaluation, will hopefully lead to more effective adoption of Kopstoring. As laid out in this thesis, future provision of Kopstoring might be threatened by future re-organisations of the youth mental health care sector and its financial consequences. Valorisation is even more important in that regard, therefore we will disseminate the study results by sending the thesis to health care providers, participants, municipalities and health care insurers.

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