

Organ donation education

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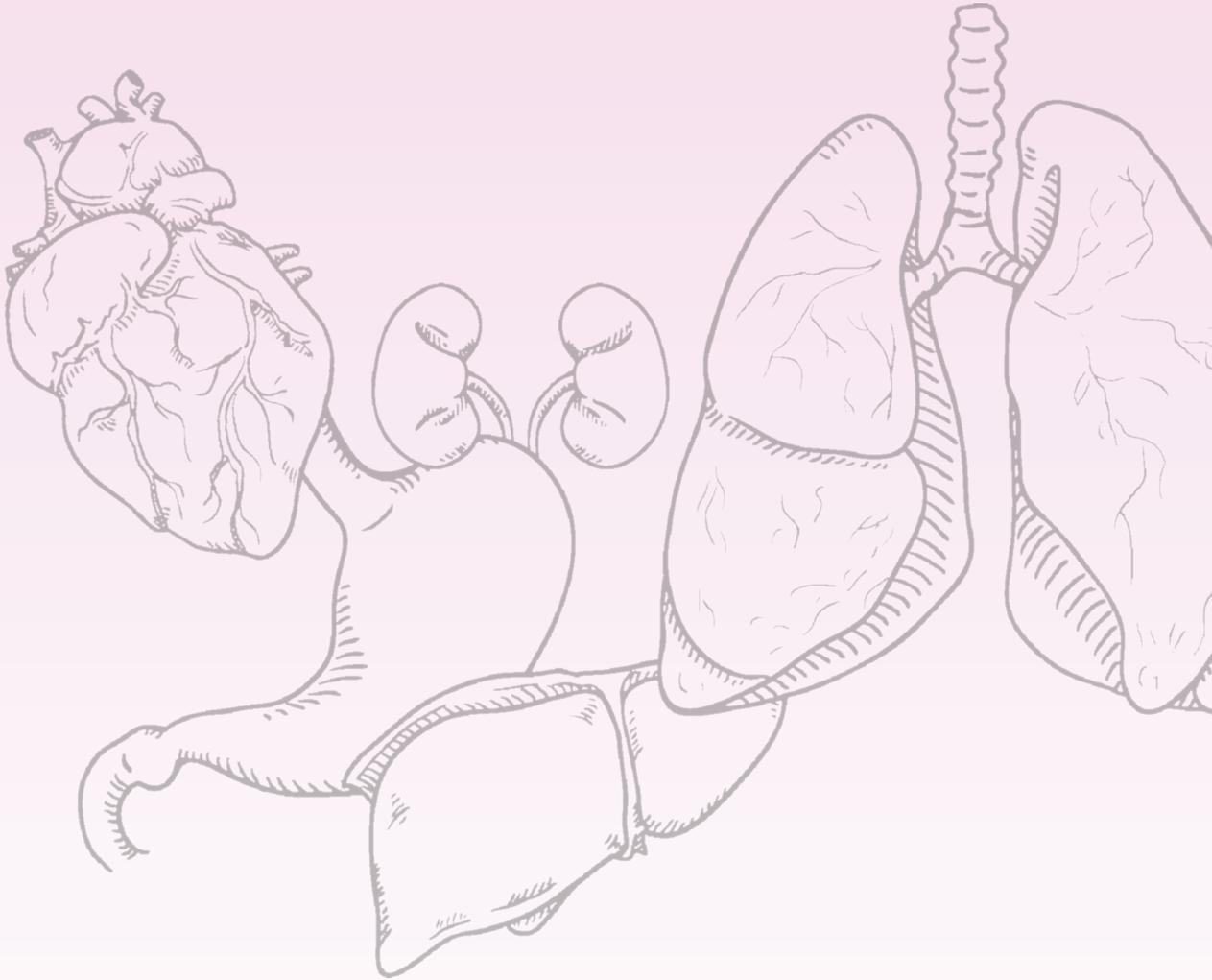
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Valorisation addendum



Obtaining a PhD was never a goal in itself for me. I had the ambition to improve society through my day-to-day activities at work. This project gave me the opportunity to do so. While research might have a scientific value first, in the long run, the societal value of doing research in the field of health promotion is large. Research can be put to use in several ways. This chapter will elaborate on the relevance of the research presented in this thesis.

The societal value of this thesis is to contribute to increasing organ donation registration rates among lower-educated adolescents in the Netherlands. This was done through the adaptation and implementation of a web-based educational program in schools for vocational education. Adolescents were encouraged to actively make a decision about organ donation and to register this decision.

Encouraging adolescents to register a decision does not necessarily benefit their own health. Increasing registration rates is however essential to lower the burden on many others in society, including their own family members, patients on the waiting list and medical professionals. If people register an active decision, it takes away the insecurities about organ donation when someone dies. Further, if more people register as a donor, it has the potential to help more patients. At this moment, many families reject the idea of organ donation when they are confronted with a proposal when a loved one dies, while actually, the majority of the Dutch population is willing to donate their organs.

The societal value of this topic is undeniable. This chapter will explain how this value was further increased during the project and what could be done in the future for the program to reach its full potential.

Sharing of findings, data and products

The results of and materials used in the studies in this thesis could/should be of interest to several target groups. Throughout the project, we therefore actively invested in sharing the findings of our research and the data and products that we used with others. This further increases the relevance of the research in this thesis.

First of all, other researchers could benefit from the studies that were done. Our research was conducted in a very specific setting: a Dutch lower-educated school setting. As a very large group of people attends this type of education, insights could be useful for other (health promotion) programs in this school setting. Further, even if the topic or target group of this research is outside of researchers' own expertise or interest, general lessons can be learned about e.g. implementation in a school setting, working with a heterogeneous target group or adapting interventions. The results of our studies could then be applied to new contexts, also in other countries.

The findings of all studies were published in international peer-reviewed scientific journals, preferably open-access, or are available at a pre-print server. Further, the results were presented at several (inter)national conferences. All publications include a link to Open Science Framework, where other researchers could find the questionnaires, interview guides, syntaxes, datasets (without personal data) and other materials of that particular study. Doing this maximizes scrutiny of the research that was done, allows for a replication of the research and facilitates the use of the data in meta-analyses(132).

With a project that has a high direct relevance for society, it is important to not only share with the scientific community, but also with others that can benefit from the results. The results of the studies were therefore shared with different target groups in different ways. First, the results and the program were shared with other parties in the field, including policy makers, that are working on organ donation education. This can help us to learn from each other and improve the quality of organ donation education. Also, policies could eventually assist in embedding organ donation education in the curricula at schools.

Efforts were also made to reach other (health) professionals in the field. This was done by publishing a Dutch opinion piece in a journal directed at health professionals. Further, the results of the studies were used in education at Maastricht University and University College Venlo. By doing this, the results do not only reach current health

professionals in the field, but also health promoters in training – these are the health professionals of the future.

Finally, actions were taken to inform the general public about the results of the studies. This was done by informing participants in the studies of the results. After the determinant study (Chapter 2) and evaluation study (Chapter 3 to 5) participating schools were informed about the results of the study in layman's terms. The results of the study in Chapter 7 were shared with the Flycatcher community and in the form of a press release. This helps to involve the general public more in the research that we do, which is especially important with a topic like this.

Dissemination of the program

The program has been developed with care and has been proven to be effective in both a high school and vocational school setting. The program goes beyond the provision of information and is unique in its focus on behaviour (i.e., registration). It further has a specific focus on a vulnerable group in our society when it comes to organ donation decision-making. This makes the program a valuable addition to existing organ donation registration initiatives in the Netherlands.

Based on the effect evaluation, suggestions were given to further improve the program, which could increase the effectiveness. These suggestions were taken into consideration and possibilities are explored to add these to the program. However, having an effective, high-quality program is not enough to have an impact on the society. With limited resources, the question is whether these are spent best on optimizing the program even more. Spending resources on reaching a large number of schools and students therefore seems more valuable.

The positive results of the evaluation study encourage a national dissemination of the program. Currently, half a million people attend Intermediate Vocational Education in the Netherlands(298). Sustained implementation of the program in this type of education could be an efficient way to reach a large group of people with accessible informa-

tion. As it prepares people for actually filling out the registration form, participants in the program are more likely to register a decision afterwards. The potential impact of a national dissemination of this program on organ donation registration rates in the Netherlands is therefore large.

For the evaluation study, teachers (or their department heads) were contacted individually and seemed to have a lot of freedom to decide whether or not to implement the program. As the curriculum of Citizenship is not strictly decided, this leaves room for teachers to give their own interpretation to the course. This could be an advantage for a dissemination of the program. Teachers play an important role in the implementation of the program. They are not just study objects, but actively contribute to the success of the program. All participating teachers were interested in using the program again and many are still contacting me today to ask whether they could use the program again in their class. The teachers' enthusiasm shows promise for the dissemination.

However, targeting all teachers individually is very time consuming and keeping up with the staff turnover is difficult. The challenge for the dissemination of this program might therefore not lie in finding teachers that are willing to participate, but to mobilize entire schools or departments to disseminate it within their schools or departments. This is not an easy task considering the liberal nature of the curriculum of Citizenship. However, if the program can be integrated within the curriculum of a school or department, chances are higher that the implementation of the program can be sustained.

There are many facilitating factors for the dissemination of the program. The program is not too long and can therefore easily fit in an existing schedule. Further, the program is very easy to use, and teachers can start with the implementation without further requirements or materials. The website is self-explanatory, and teachers can download a manual for further information. The relevance of organ donation registration for this age group further facilitates the dissemination as well as the fact that the program is free of charge for everyone. However, all these facilitating factors do not guarantee

that the program is automatically picked up by the target group. An active strategy is needed to reach school boards, departments or individual teachers.

The program is currently owned by a small, local foundation called SIDVO. It is unlikely that this organization has the resources to disseminate the program nationally and to sustain implementation over time. It is therefore recommended to find a larger, national organization to become responsible for the dissemination of the program and keeping it up to date. Ideally, the program would become part of the national organ donation campaign from the Ministry of Health, Welfare and Sports and the Dutch Transplantation Society. The program could then be part of a uniform message and all campaign components could reinforce each other. Communication with both organizations has been initiated during the project and opportunities were explored for a collaboration or takeover.