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Impact paragraph
Worldwide, young people with a chronic condition are increasingly involved in research and innovation projects in health and social care that concern them. Great expectations are raised about the impact of this so-called Patient and Public Involvement (PPI). Consequently, more and more young people with a chronic condition and professionals are investing their time in PPI. However, it is unclear how different forms of impact can be achieved. In addition, there is limited high quality data available on the actual achievement of this impact. These issues were addressed in this thesis. This chapter reflects on the scientific and societal impact of this thesis and the dissemination of its findings.

**Scientific impact**

This thesis has scientific relevance, as it adds knowledge to an important field that made limited progress in the past decades. First, it demonstrates how the quality of research on PPI of young people with a chronic condition can be improved. The current scientific evidence base would benefit from improved reporting, the application of more systematic and objective measures, the inclusion of both young people’s and professionals’ perspectives and the application of innovative methods to build on previous work. Second, this thesis monitored over thirty projects that involved young people with a chronic condition to learn about factors that can hinder or facilitate PPI. The current evidence base is predominantly based on reports about PPI in a single project. The overarching analysis of PPI processes in many different projects led to solid evidence regarding the best ways to work together with young people with a chronic condition. Third, this thesis adds insights that are valuable to the continuous scientific debate about the impact of PPI. Many questions exist about whether impact should be measured and, if so, how it should be measured. This thesis demonstrates that impact measurements are always of value, regardless of the reasons for doing PPI. In addition, it provides extensive insight in the definition of impact and how it can be operationalized and measured. Researchers can use these insights to improve PPI evaluations and enhance the evidence base about the difference PPI can make and the approaches that work best to achieve different forms of impact.

Although the findings of this thesis primarily apply to PPI of young people with a chronic condition, they also have merit for PPI of other health service users. For example, the findings regarding impact can create awareness among scientific researchers that impact means something different to different stakeholders. They also contain the general message that measuring impact is very suitable to learn about the achievement of the desired impact and what works. In addition, the evaluation methods used in this thesis can serve as an example for the evaluation of PPI in general.
**Societal impact**

This thesis can facilitate the wider implementation of PPI of young people with a chronic condition. It addresses different ways of involving young people with a chronic condition in projects. In chapter 4, lessons learned and practical tips are provided on how to organize PPI and how to deal with some common issues, such as sharing power, reimbursing the young people involved and making time for PPI. These lessons can aid inexperienced young people with a chronic condition and professionals, such as researchers, health care providers and policy makers, to shape their collaboration and achieve their aims. They are also valuable to those who already do PPI, but struggle with specific challenges or wish to improve their collaboration.

Further implementation of PPI of young people with a chronic condition can also lead to wider societal impact. First, it helps to improve the quality of research and innovation, as these are more in line with the needs and wishes of young people with a chronic condition. This can lead to improvements in the care services they use and eventually enhance their quality of life and participation in society. Second, it does justice to the right of young people to be heard in matters that concern them. It facilitates the use of their talents and encourages them to take part in society as an active and democratic citizen. Third, it improves the way professionals are doing their job and increases their commitment, as they obtain a better understanding of young people with a chronic condition and their lives.

**Dissemination of findings**

Various channels were used to disseminate the findings of this thesis to young people with a chronic condition, researchers, policy makers, health care providers and other stakeholders. All the articles in this thesis were published (or accepted for publication) in international, peer-reviewed journals. Three of these articles are accessible free of charge, since they are published open access. All articles are available through the Nivel repository. The articles were generally quickly accepted for publication, suggesting a general need for research on this topic. The findings of this thesis were presented at national and international conferences, such as the International Conference on Integrated Care 2020 and the 2019 CareDays ‘Science for citizens – Citizens for science’ in the Netherlands.

The above mentioned channels predominantly reach researchers. Other channels were used to disseminate the findings to a broader group of stakeholders, such as young people with a chronic condition, policy makers and health care providers. Workshops were organized for them, for example at the Dutch conference ‘Krachtpatsers’ by FNO. In addition, the findings of the studies reporting on data retrieved from the Care and Future Prospects program are also available in Dutch, in the report ‘Overkoepelend Evaluatieonderzoek: Programma Zorg én Perspectief’. Together with young people with a chronic condition, this
report was also translated into a youth friendly booklet. The practical tips described in chapter 4 of this thesis were disseminated among young people with a chronic condition and professionals in the Netherlands through an accessible and appealing infographic.