

# Optimizing implementation of patient-centered innovations

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## Impact

In this chapter I explain about current and possible implications of the research reported in this thesis on science and on society. Traditionally health care was characterized by paternalism, but already more than 20 years ago a change towards a partnership between patients and physicians was recognized.<sup>1</sup> Acknowledging this partnership, the delivery of healthcare became more 'patient-centered'. Patient-centeredness is a biopsychosocial approach and attitude that aims to deliver care that is respectful, individualized and empowering. It implies the individual participation of the patient and is built on a relationship of mutual trust, sensitivity, empathy and shared knowledge.<sup>2</sup> Probably resulting from the change to a more patient-centered healthcare delivery, but also building on the 'digital revolution' from the last decades, many patient-centered (digital) healthcare innovations take place. Usually, many stakeholders are involved in these innovations, besides the patients: Academic researchers, policymakers, healthcare professionals and commercial company representatives are amongst them. In this quickly moving field, influenced by the many stakeholders, a scientific evaluation may not be part of all patient-centered innovation projects, possibly leading to new standards of care without robust scientific evidence. Cancer care is one of the medical fields where many of these innovations take place. We aimed to contribute to sustainable implementation of patient-centered innovations in cancer care, by means of a critical assessment of several patient-centered innovation projects from a practice driven viewpoint. The projects were chosen based on relevance and actuality and regarded cancer care treatment decision-making and patient empowerment by electronic health applications. The impact of the results is described on the patients, healthcare professionals, policymakers and academia.

## Patients

The burden of cancer is heavy for patients and their relatives and cancer treatment decisions may have significant impact on their lives. Understandably, patients often wish to (be empowered to) participate in decision-making about cancer treatment. However an important moment in decision-making occurs in cancer multidisciplinary team meetings (MDTs), without the patients' presence. We explored strategies to make these meetings more patient-centered. We communicated the results to cancer patient representatives at a symposium, empowering them as a group to use this information in their activities. Implementation of the recommended strategies resulting from the study in practice may contribute to more patient participation in cancer treatment decision-making. We also contributed to a better understanding of shared decision-making (SDM) perception in patients suffering from hematological cancer. SDM is a model to engage patients in the process of health care decisions. Importantly, our results pointed out that

the decision-making step 'preference talk', where the professional takes an explorative stance and tries to learn about the patient's preferences, requires more attention. In the future, patients may profit from the next steps that could be taken to implement SDM in the hematology practice, for example by using tools that support this model and specifically by focusing on preference talk. Finally, two projects addressed electronic health (e-health) innovations. Currently, numerous e-health applications are being implemented in cancer care. However often development and/or implementation of these applications limitedly occurs with participation of patients. This may result in low adoption of these applications by patients and most importantly, they will therefore not contribute to patients' wellbeing. Serving as a best practice example, our study may contribute to a sustainable implementation and therefore societal impact of e-health innovations. Furthermore, following further development of the multimodality application that this thesis reported on, patients may profit from its application in multiple myeloma care practice.

### **Healthcare professionals**

Healthcare professionals have participated throughout all research projects in this thesis. In general their participation raised awareness for the investigated patient-centered innovations and concepts. This has lead to several discussions about current and future care delivery amongst them. Similar to the patients, the healthcare professionals are key stakeholders in the studied patient-centered innovations and their participation matters when successful implementation is desired.<sup>3</sup>

During the writing of this thesis I have performed several activities, enabling me to share the expertise gained from conducting the studies in this thesis: First, by participation in a professional association committee about SDM (*Werkgroep Samen Beslissen*, FMS), which amongst others helps with SDM implementation in clinical practice and medical education. Second, being co-author of an informative manuscript about SDM legislation in the Dutch setting. Third, supporting a SDM training study for oncologists and participation in guideline development for redesigning the MDT in the Isala hospital. Finally participating in the Innovation committee (*Commissie Zorgvernieuwing en Innovatie*) of the Dutch Hematology Association.

### **Policymakers**

Policymakers create the frameworks in which healthcare acts in practice, thereby also setting the stage for patient-centered innovations. This requires considering the trade-off between costs and benefits of healthcare. In the Netherlands, about 6-7% of the total healthcare expenses are for cancer care, mostly due to hospital care.<sup>4</sup> Furthermore, the relative expenses of healthcare compared to the gross domestic product have

doubled over the past 20 years and healthcare expenses nowadays exceed 25% of the total government expenses.<sup>5</sup> Therefore, policymakers need to consider the added value and costs of patient-centered innovations. Although we can learn from unsuccessful projects, patient-centered innovations are ideally developed in a way that health impact is high and implementation is successful. This would optimize the effort and money put into it. The studies in this thesis may inform policymakers about possible determinants of successful implementation of patient-centered healthcare innovations and may serve as best practice example. Furthermore, as the policy for patient-centered care is still in its infancy, currently being limited to one law and reimbursement regulation about shared decision-making,<sup>6,7</sup> the findings in this thesis may inform engaged professionals and policymakers to optimize the regulations.

## Academia

The results from this thesis contribute to a deeper understanding of the studied patient-centered innovations or models. Results are available through publication in peer-reviewed journals and at (inter) national conferences. The insights that have been obtained in this thesis have been or are currently being used in various research projects: One project aims to refine and implement an 'Integrated Oncology Decision-making Model' (IODM) to further improve personalized treatment decision-making for cancer patients, partially building upon our findings. Informed by the findings in this thesis, I have contributed to a grant award for a decision aid for chronic lymphocytic leukemia and a grant application for a decision aid for multiple myeloma. Following the pilot study of the e-health application for patients with multiple myeloma, the application is currently being evaluated in a randomized clinical trial.

Traditional academic driven research implicates 'top-down' knowledge transition. A collaborative knowledge generation by academics working alongside other stakeholders is believed to result in significant societal impact, as opposed to traditional knowledge translation research.<sup>8</sup> The participatory methods used in this thesis may inform other researchers about collaborative research approaches, serving as a best practice example. The increased use of collaborative approaches may result in more effective application of research.

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