

# Facilitating shared decision making with a patient decision aid for choosing a treatment for multiple sclerosis

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# Valorisation

This chapter discusses the societal value of the results found in this thesis for three groups of stakeholders: patients and healthcare professionals, policy makers, and the scientific community. Moreover, the efforts made to disseminate the knowledge gained from this thesis and the additional actions to be taken are described.

## **Societal value of this dissertation**

### **Patients and healthcare professionals**

The number of treatment options for reducing the number of relapses and/or delay disease progression for patients with multiple sclerosis (MS) has been increasing rapidly. Patients with the relapsing-remitting type of MS (RRMS) or clinically isolated syndrome (CIS) often have often two or more options of treatment with disease-modifying drugs (DMDs). Therefore, an adequate treatment decision needs to be made; no single treatment option is the dominant choice, as the most suitable option can differ according to the patient's situation and preferences. Consequently, international recommendations for MS treatment have highlighted the importance of involving patient preferences in the treatment decision [1, 2]. Accordingly, the different characteristics of treatment options need to be considered and weighed. This can be a difficult process for patients and healthcare professionals. The patient needs to capture all of the information, develop preferences and communicate these preferences with the healthcare professional. The healthcare professional needs to educate the patient about the treatment options, balance the information provided and elicit the patient's preferences.

This dissertation aims to develop a patient decision aid to facilitate shared decision making for DMDs for MS. Patient decision aids help patients to feel informed, to have more confidence in the decision, and, importantly, to achieve more congruence between the treatment chosen and the patient's preferences [3]. The online patient decision aid proposed in this dissertation is based on the principles of multi-criteria decision analysis (MCDA). This patient decision aid enables the filtering of treatment options based on the patient's personal and medical characteristics, elicitation of the patient's preferences for specific characteristics of treatments, and ranking of the treatments for which the patient is eligible from most to least fitting with the patient's individual preferences. The ranking can be used to focus the deliberation process of studying and discussing the treatment options, i.e., based on the ranking, the patient can identify a small number of treatment options to read more about. Accordingly, in contrast with other approaches for patient decision aids, such as schematic summaries of treatment options according to frequently asked questions, in which the patient needs to grasp the characteristics of all available treatment options, an MCDA-based approach for patient decision aids may relieve the cognitive burden of considering the treatments in situations with many options and many varying characteristics. The proposed patient decision aid is one of the first MCDA-based patient decision aids for MS, and the first patient decision aid for MS in the Netherlands.

During the development of our tool, alpha pilot testing of the developed patient decision aid enabled the identification and resolution of problems regarding patients' comprehension and the usability of the decision aid for patients and healthcare professionals. Further development and evaluation of our patient decision aid for optimizing the content and implementation strategy and assessing whether the patient decision aid results in the effects on the quality of the decision and of the decision making process as reported for patient decision aids for other decisions [3]. Both patients and healthcare professionals expressed a positive attitude towards the potential use of our patient decision aid for supporting shared decision making about DMDs.

The implementation of shared decision making supported with the patient decision aid in clinical practice could improve the quality of care for patients, and could also result in improved persistence and adherence levels in taking prescribed medication, and consequently in improved health outcomes and quality of life, as our early economic evaluation of the cost effectiveness of shared decision making for MS suggested.

### **Policy makers**

Healthcare policy makers and healthcare insurance companies decide on the allocation of funds for the implementation and reimbursement of new interventions based on a number of factors, including cost effectiveness [4]. Like all assessments of consequences in terms of the costs of an intervention and benefits gained, policy makers need to make decisions in the face of uncertainties [4]. This dissertation informs policy makers about the potential cost-effectiveness of implementing a shared decision aid in clinical practice in order to determine whether shared decision making should be implemented and reimbursed. The early economic evaluation demonstrated a favourable incremental cost-effectiveness ratio in different scenarios, which supports arguments for implementation and reimbursement. This study suggests that if shared decision making improves persistence and adherence to treatment with DMD, shared decision making could potentially be cost-effective in achieving improved health outcomes.

### **Scientific community**

Both parts of this dissertation, i.e. the chapters focusing on the development of the patient decision aid and the chapters exploring how web-based health services and research for MS can be optimized, are of added value for researchers in the field of patient decision aid development, and in the assessment of shared decision making and MS. First, methodologies which have been increasingly applied in health technology assessment, i.e. best-worst scaling surveys and MCDA, have been applied successfully in the development of patient decision aids. Researchers could therefore consider using stated preference research to prioritize which information should be included in a patient decision aid. Moreover, MCDA can be considered as an approach for the development of a decision aid

in situations with many different options and/or many characteristics which must be considered or for patients with impaired cognitive abilities.

In part two of this dissertation, the adherence of patients to assessment schedules in web-based research was examined. Long assessments at low frequency are more often completed within a set time frame in comparison with highly frequent short assessments. In addition, personal contact with a researcher shortly after commencing participation in the study could positively affect patient adherence to assessment schedules. Researchers considering web-based measurement schedules could consider these findings in the design of protocols for direct-to-patient research.

## Dissemination of knowledge

Several efforts have been undertaken to disseminate the findings from this dissertation to the various stakeholders [Table 1]. Dissemination among researchers and policy makers has been stimulated through publication of the study results in scientific journals and by publication of this dissertation. Three articles have already been published in open access peer-reviewed journals, and the two remaining articles have been submitted to open access journals. In addition, the results of the studies described in this dissertation have been presented at several international conferences, such as the conferences of the Society for Medical Decision Making, the International Shared Decision Making Society, the European Committee for Treatment and Research in Multiple Sclerosis, and ISPOR- the Professional Society for Health Economics and Outcomes Research.

Moreover, patients and healthcare professionals have been involved in a number of phases of the developmental process. An advisory committee was formed consisting of patient representatives from two patient organizations (Nationaal MS Fonds, MS Vereniging Nederland) as well as neurologists and nurses from several hospitals in the Netherlands. This collaboration brought about continuous contact with patient organizations regarding the progress of the development of the patient decision aid, and led to interest in the patient decision aid from patient and professional magazines. Two articles about the patient decision aid for MS were published in these magazines (i.e. *Nieuwslijn*, 2017 and *Medidact Neurologie*, 2019), creating awareness among patients and healthcare professionals about the future availability of the patient decision aid, and stimulating both patients and healthcare professionals to participate in the decision aid's development.

The attention paid to the patient decision aid by these magazines also highlights for policy makers the need for its implementation in clinical practice. The implementation of patient decision aids in hospitals is not straightforward, due to the initial investments needed by hospitals to acquire licenses, train staff and adjust structures to facilitate the use of patient decision aids [5]. Moreover, shared decision making could result in longer consultation time and in more expensive or cheaper treatments being chosen [6]. The successfulness of securing sustainable implementation of patient decision aids in clinical practice is reported to be, in part, dependent on available financing [5], i.e. who is paying for it. We are currently

examining the feasibility of different financial structures and incentives to achieve organizational and financial sustainability for the implementation in clinical practice and to optimize the uptake of implementation across hospitals in the Netherlands, in collaboration with a partner experienced in the implementation of patient decision aids. We have been working on acquiring research and implementation grants from consortiums formed by the pharmaceutical industry and government grants to overcome the initial financial barriers for hospitals, such as training staff and acquiring licenses. Other structures, such as healthcare insurers' reimbursement of shared decision making, could also be considered, aiming at achieving sustainable implementation of shared decision making supported with patient decision aids on a large scale for all treatment and screening decisions. For example, the National Healthcare Authority's policy "Experiments" allows conditional reimbursement by a healthcare insurer if both healthcare insurer and healthcare provider want an innovation to be embedded for limited time [7]. After the experiment is terminated, a decision could be made about structural reimbursement for the innovation [7].

Before the initiation of such structures, further information about the consequences for patients and healthcare budgets is needed. This information enables determining the cost-effectiveness of shared decision making supported with a patient decision aid for MS and its budgetary impact for budget holders, i.e. policy makers from healthcare providers and/or healthcare insurers. Moreover, a business case should be developed, which summarizes the costs and benefits in monetary and non-monetary terms for each stakeholder, including the effects on the quality of healthcare and the benefits for patients. A business case and budget impact analysis could provide grounds that support implementation of the new intervention, and convince budget holders that these investments are worthwhile in improving quality of care.

Additional research concerning the patient decision aid is planned. Before implementation in hospitals, we will optimize and update the patient decision aid in terms of content, user-friendliness and health literacy, and test the feasibility of implementing the patient decision aid in a before-and-after pilot study. Moreover, a controlled trial is planned to research the effects of the patient decision aid on the quality of the decision, the decision making process, on adherence, persistence and treatment choice, health outcomes, quality of life and costs.

Other research areas of value are optimization of risk communication for patients with MS, setting up an international network of patient decision aid developers for MS to possibly develop an international tool, and to embed the patient decision aid in a multicomponent intervention to support patients in the management of their MS. Pending the update of the Dutch clinical guidelines for MS, we will also strive to connect the patient decision aid to these guidelines to keep the content of the patient decision aid up-to-date.

Table 1. Completed and intended activities for dissemination of knowledge

<p>Patients and healthcare professionals</p> <ul style="list-style-type: none"> <li>✓ Involvement during the developmental process, involvement in advisory group</li> <li>✓ Continuous contact with patient organizations</li> <li>✓ Article in patient and professional magazines (<i>Nieuwslijn, 2017; Medidact Neurologie, 2019</i>)</li> <li>○ Optimize and update content, user-friendliness (e.g. risk communication) and health literacy of patient decision aid</li> <li>○ Increase commitment of intended users to implementation</li> <li>○ Connect patient decision aid with guidelines for clinical practice</li> <li>○ Embed patient decision aid in a multicomponent intervention for MS management</li> </ul>
<p>Policy makers</p> <ul style="list-style-type: none"> <li>✓ Publications of papers in scientific journals and of dissertation</li> <li>✓ Presentation of studies during (inter)national conferences</li> <li>○ Mapping structures to ensure financial sustainability of implementation</li> <li>○ Conduct a controlled trial to determine the (cost-)effectiveness, perform budget impact analysis and develop a business case</li> </ul>
<p>Scientific community</p> <ul style="list-style-type: none"> <li>✓ Publications of papers in scientific journals and of dissertation</li> <li>✓ Presentation of studies during (inter)national conferences</li> <li>○ Investigate opportunities for international collaboration for MS patient decision aids</li> </ul>

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