

# Shared decision-making in oncology

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# Impact statement

As patient participation in healthcare decisions continues to grow, there is a greater need for decision support tools and processes, such as patient decision aids (PDAs) and shared decision-making (SDM) respectively, that help patients and clinicians collaborate. These innovations often fail at the implementation stage because of a lack of attention to user perspectives and workflows. Therefore, in this thesis we investigated what matters to patients, how they experience the decision-making process, and how patient-clinician communication can be enhanced. In this section, we present the scientific and societal impact of our findings.

## Scientific impact

### Development of a prostate cancer PDA

The outcome of the first three studies described in **Chapters 2-4** of this thesis was a web-based PDA for prostate cancer patients that is publicly available on <http://beslissamen.nl>. Since patients considered the consequences of treatment side-effects on their daily lives important, it was later decided to augment the PDA with prediction models that present the probability of an individual patient experiencing a certain side-effect, such as incontinence or erectile dysfunction, based on his clinical characteristics. The implementation of the augmented PDA is underway. As of July 2021, initial work has been conducted to understand how prostate cancer patients evaluate risk information. This work will form the basis for fine-tuning the PDA to display risk predictions in a format that is preferable to patients. Once implemented, we hypothesize that the PDA will increase the level of SDM in the consultation and patient knowledge about prostate cancer and the relevant treatments, and decrease the level of decisional conflict. These variables will be measured by means of the validated SDM-Q-9 and SDM-

Q-Doc questionnaires (for patients and clinicians respectively), a 20-item knowledge test with true/false questions, and the validated Decisional Conflict Scale questionnaire. In addition, patients' preferred level of participation in decision-making will be measured by means of the Control Preferences Scale. An impact study will be performed that compares these values directly after the decision-making consultation and three months after the consultation with an intervention group that receives the PDA and a control group that undergoes usual care (without the PDA). At a broader level, our current findings illustrate the principles of user-centered design, namely the process of involving end-users early, understanding their needs and requirements, incorporating user feedback and evaluating design prototypes in an iterative and dynamic manner. This process enhances user-friendliness and increases ownership, particularly among clinicians, which make successful PDA uptake more likely.

### Implementing SDM in lung cancer

Within oncology, the interest in promoting SDM has generally been centered around preference-sensitive conditions such as prostate cancer and breast cancer. In these disease areas there are multiple treatment options with different benefits and harms, and there is room for the patient's preferences to be taken into account. In contrast, conditions such as lung cancer have received little attention in the SDM literature. Lung cancer is characterized by rapid progression, severe complications, and serious side-effects from treatment, resulting in a decision-making process that is more dominated by clinical guidelines than other cancer types. These guidelines tend to prioritize progression-free survival and do not sufficiently incorporate the patient perspective, even though lung cancer is considered a terminal illness, and palliative/end-of-life care decisions are preference-sensitive. In **Chapters 5** and **6** of this thesis we conducted exploratory work on incorporating SDM into lung cancer decision-making through clinical decision support systems

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(CDSSs) and SDM training. Our findings have been published in a peer-reviewed journal and add to the small but growing literature on SDM in lung cancer. Our results provide insights for researchers and CDSS developers on specific lung cancer use cases where prediction models could provide added benefit, and emphasize the importance of clinician involvement in the development process. Encouragingly, we observed a growing awareness among lung cancer specialists regarding the potential benefits of artificial intelligence (AI) to assist decision-making as well as implementation barriers such as lack of trust. Researchers may further explore the notion of clinician trust, such as how clinicians define trust and how AI-based predictions can be made interpretable so that these predictions form a reliable component of data-driven SDM.

### Adapting PDA format

PDA's come in a variety of formats (digital, print, information booklets), but by and large the most common ones are digital. These are easier to update and offer the benefit of having multimedia content. This thesis lays out the challenges and benefits of both types of PDA's. We established that digital PDA's offer a multitude of possibilities to help patients understand their disease and treatment options, clarify their values, and test their knowledge. In-consultation paper PDA's, on the other hand, bring this process into the clinical interaction and provide a structure for the SDM conversation, as shown in **Chapter 7**. By interviewing clinicians who have used paper PDA's in their consultations, we were able to establish that this format was instrumental in structuring the SDM conversation and helped clinicians put the main steps of the SDM process into action. On the basis of our findings, researchers can further explore ways to integrate digital and paper PDA's so that clinicians and patients can benefit from decision support that is adapted both for consultations as well as home use by patients. An example would be a hybrid PDA with an interactive digital version containing multimedia content for the patient to use at home and a

corresponding printed version in the form of decision cards, structured according to the SDM steps, that the patient and clinician can use during the consultation.

## Societal impact

### Patient-clinician collaboration

Throughout the course of this thesis, we observed that the majority of patients we enlisted in the PDA development phase as well as those who participated in the PCI decision were enthusiastic about SDM. However, most patients still expect the paternalistic model of decision-making and thus taking an equal role in decision-making with the clinician is not yet the norm. The creation of the publicly available PDA on <http://beslissamen.nl> can spread awareness among newly-diagnosed patients about the fact that multiple treatment options exist with different harms and benefits. With greater knowledge about their options, patients can more readily ask questions and participate in a dialogue with their clinician, even in contexts where SDM has not yet been formally implemented. Furthermore, patient organizations can play a role in bringing SDM to the fore, disseminating PDAs, and helping prepare patients for a SDM consultation in terms of being informed and the type of questions to ask.

By involving clinicians in the development process of the prostate PDA and in SDM training for lung cancer, our work increased clinicians' awareness of the patients' perspectives and desire for participation. Our findings from the Danish context (Vejle Hospital), where SDM/PDA implementation was well underway, showed that empowering clinicians with practical tools like structured in-consultation PDAs to put knowledge into practice is a key success factor. This approach is complementary to Maastricht's digital PDAs, and our results provide a first step to developing a hybrid PDA that combines the strengths of both digital and paper PDA formats. This has become particularly relevant in light of the COVID-19 pandemic,

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in which many consultations had to be conducted virtually. Digital PDAs are ideal in such circumstances, and Vejle Hospital is currently exploring ways to digitize the existing paper PDAs so that patients have access to decision support regardless of location. This thesis is the first step in mutual learning between the two institutes and offers new possibilities in promoting patient-clinician collaboration.

### Redesigning patient pathways

Our findings shed light on the current clinical workflow in prostate cancer and lung cancer in the Netherlands and the possible barriers it can introduce to SDM/PDA implementation. Although considerable efforts are expended to support patients in SDM, much progress can be made by studying and modifying the treatment trajectory so that patient preferences are not only considered in the consultation but are honored throughout the patient pathway. On the basis of our findings, the role of GPs in the treatment trajectory can be formalized and their possible involvement in PDA implementation can be increased. The role of nurses can also be expanded as patients perceive them to be more approachable.

### Aligning incentives

A key finding in our work was that the current treatment trajectory can incentivize certain treatments over others due to factors such as volume quotas. An implication of our work is that stakeholders in the current healthcare system, such as health insurers, can play a significant role in aligning these incentives. The lung cancer study described in this thesis was a collaboration between Maastricht and the Dutch healthcare insurer CZ. Through this collaboration, named My Best Treatment, SDM was implemented and evaluated in the extensive-stage small-cell lung cancer trajectory. Such collaborations give health insurers insight into the decision-making process and effects of SDM so that reimbursement structures can be redefined to stimulate SDM.