Measuring shared decision making in oncology: an informed approach
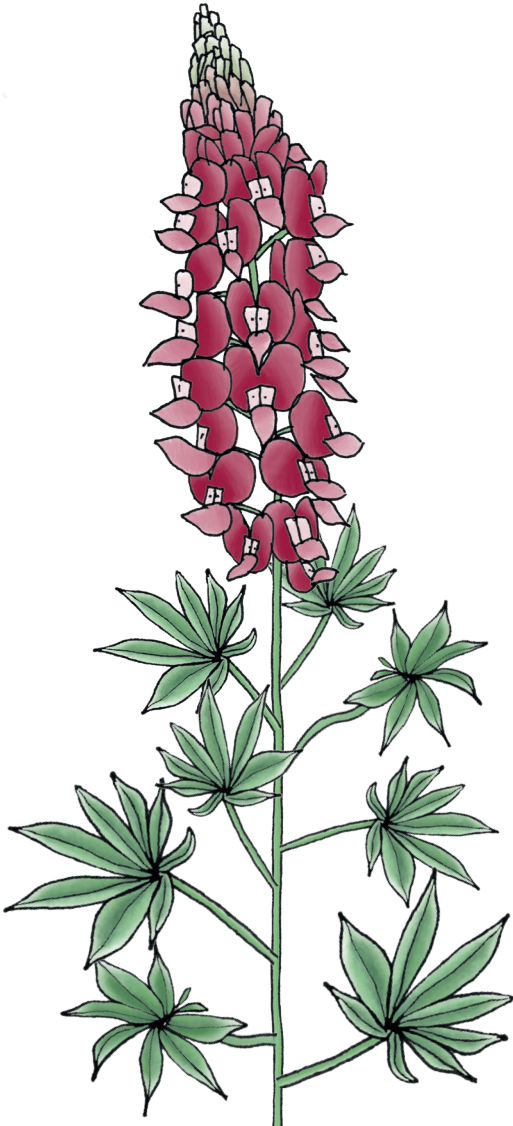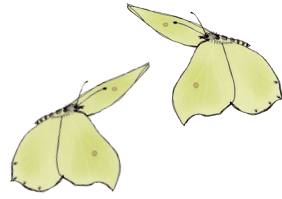
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Citation

Bomhof-Roordink, H. (2022, June 7). *Measuring shared decision making in oncology: an informed approach*. Retrieved from https://hdl.handle.net/1887/3307663
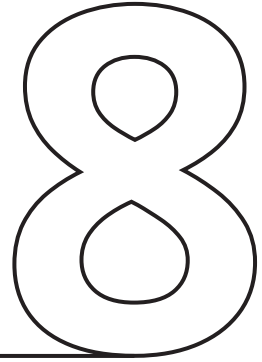
Note: To cite this publication please use the final published version (if applicable).

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SUMMARY
SAMENVATTING
DE iSHARE VRAGENLIJSTEN
LIST OF PUBLICATIONS
CURRICULUM VITAE
DANKWOORD

Summary

Chapter 1

In this thesis, we aimed to develop and validate a patient and physician questionnaire to measure the shared decision making (SDM) process in oncology. In Chapter 1, we described the history of SDM models and provided an overview of implementation activities in The Netherlands. We identified SDM measurement challenges: there is limited evidence on measurement properties, patients' role is not assessed while it is present in SDM models, patients and healthcare professionals have been involved only to a limited extent in the development of SDM measurement instruments, and a reflective measurement model is often assumed, while a formative might be more appropriate. The aim of this thesis was therefore to develop and validate questionnaires to assess the SDM process in oncology from both the patient and the physician viewpoints. We chose the oncology setting because it is a setting in which patients often face preference-sensitive decisions, and in which most patients prefer an active or collaborative role in treatment decision making. To inform the development and validation process of our questionnaires, we used the original COnsensus-based Standards for the selection of health Measurement INstruments (COSMIN) checklist and we wrote two reviews: one on existing SDM measurement instruments and one on existing SDM models.

Chapter 2

In Chapter 2, we systematically inventoried instruments assessing the SDM process and appraised their measurement quality, taking into account the quality of the methods used. To this end, we searched seven bibliographic databases for studies investigating instruments measuring the SDM process. Per instrument identified, we assessed the level of evidence separately for 10 measurement properties following a three-step procedure: 1) appraisal of the quality of the methods used using the COSMIN checklist, 2) appraisal of the psychometric quality of the measurement property using three possible quality scores, and 3) best-evidence synthesis based on the number of studies, the methodological and psychometric quality, and the direction and consistency of the results. In total, we included 51 articles describing the development and/or evaluation of 40 SDM process instruments: 16 patient questionnaires, four provider questionnaires, 18 coding schemes and two instruments measuring multiple perspectives. Our analysis showed an overall lack of evidence for their measurement quality, because either validation was missing or methods were poor. The best-evidence synthesis indicated positive results for a major part of instruments regarding content validity (50%) and structural validity (53%) if these had been evaluated, but negative results for a major part of instruments when inter-rater reliability (47%) and hypotheses testing (59%) had been evaluated. We therefore concluded that the choice of the most appropriate instrument can best be based on the instrument's content and characteristics such as the perspective from which the SDM process is assessed.

Chapter 3

In Chapter 3, we provided a systematic overview of SDM models, gave insight in the prominence of components present in SDM models, described who was identified as responsible within the components (patient, healthcare professional, both, none), showed the occurrence of

SDM components over time, and, finally, presented an SDM map, by healthcare setting, to identify SDM components seen as key. We searched the same seven databases for articles. We included peer-reviewed articles in English presenting a new or adapted model of SDM. In total, we included 40 articles, and each described a unique SDM model. Twelve models were generic, the others were specific to a healthcare setting. Fourteen were based on empirical data, and 26 primarily on analytical thinking. We identified 53 different elements and clustered them into 24 components. Overall, *'Describe treatment options'* was the most prominent component across models. Components present in >50% of models were: *'Make the decision'* (75%), *'Patient preferences'* (65%), *'Tailor information'* (65%), *'Deliberate'* (58%), *'Create choice awareness'* (55%), and '*Learn about the patient'* (53%). In the majority of the models (27/40), both the healthcare professional and the patient were identified as actors. *'Describe treatment options'* and '*Make the decision'* were the two components which were present in most models in any time period. *'Create choice awareness'* stood out for being present in a markedly larger proportion of models over time. In conclusion, our review showed that SDM models quite consistently share some components but that there is no unified view on what SDM *is*.

Chapter 4

In Chapter 4, we constructed a model of SDM about cancer treatment by conducting an extensive consultation of stakeholders, informed by the literature. We interviewed 76 stakeholders: cancer patients, potential future patients, oncologists, nurses, and SDM researchers. We asked, "If I say 'Doctors and patients making decisions together about cancer treatment,' what does this make you think about?" Ideas were further solicited by presenting 19 cards each describing a possible SDM element. Interviews were inductively coded and analysed, and the emerging themes were integrated into a model. The resulting model assigns specific roles in SDM to both oncologists and patients. Oncologists determine possible treatments, emphasise the importance of patients' opinion, explain treatment options, get to know patients, guide patients, and provide treatment recommendations. Patients ask questions, express thoughts and feelings, consider options, offer opinions, and decide or delegate decisions to oncologists. Outside consultations, patients search for information, prepare questions, and consider options. In short, next to oncologists' role, cancer patients also have a clear role in SDM about cancer treatment, during and outside consultations.

Chapter 5

In Chapter 5, we developed a patient and a physician questionnaire to measure SDM in oncology and determined their content validity and comprehensibility. The domains of the SDM construct were informed by our systematic review of SDM models and our oncology-specific SDM model. We formulated items for each SDM domain. Cancer patients and physicians rated content validity in an online questionnaire. We assumed a formative measurement model and performed online field-testing in cancer patients to inform further item reduction. We tested item comprehension in cognitive interviews with cancer patients and physicians. First, we identified 17 domains and formulated 132 items. Then, twelve cancer patients rated content validity at the item level, and 11 physicians rated content validity at the domain level. Finally, we field-tested the items among 131 cancer patients

and conducted cognitive interviews with eight cancer patients and five physicians. These phases resulted in the 15-item iSHAREpatient and 15-item iSHAREphysician questionnaires, covering 13 domains, clustered in six dimensions. The iSHARE questionnaires both assess patient and physician behaviours and cover the entire SDM process rather than a single consultation.

Chapter 6

In Chapter 6, we determined: scores, construct validity, test-retest agreement of the iSHAREpatient, and inter-rater agreement between the iSHAREpatient and the iSHAREphysician. Physicians from seven Dutch hospitals recruited cancer patients, and completed the iSHAREphysician and SDM-Questionnaire-physician version. Their patients completed the: iSHAREpatient, nine-item SDM-Questionnaire, Decisional Conflict Scale, Combined Outcome Measure for Risk communication And treatment Decision-making Effectiveness, and five-item Perceived Efficacy in Patient-Physician Interactions. We formulated, respectively, one (iSHAREphysician) and 10 (iSHAREpatient) a priori hypotheses regarding correlations between the iSHARE questionnaires and questionnaires assessing related constructs. To assess test-retest agreement, patients completed the iSHAREpatient again 1-2 weeks later. In total, 151 treatment decision-making processes with unique patients were rated. Dimension and total iSHARE scores were high both in patients and physicians. The hypothesis on the iSHAREphysician and nine out of ten hypotheses on the iSHAREpatient were confirmed. Test-retest and inter-rater agreement were >.60 for most items. We concluded that the iSHARE questionnaires show high scores, have good construct validity, substantial test-retest agreement, and moderate inter-rater agreement.

Chapter 7

In Chapter 7, we discussed the findings, including strengths and limitations and recommendations for clinical practice and future research. Patients have their own roles in SDM, and healthcare professionals should support them in their roles. Appropriate interventions may further assist patients. Both SDM models and SDM measurement instruments need a comprehensive description to inform future users. Further validation of existing SDM measurement instruments is needed and we recommend the use of the COSMIN tools. Both during the development and the validation of SDM measurement instruments, researchers need to consider the formative nature of the SDM construct, and should involve the end-users. Adapting existing SDM measurement instruments or building items banks might reduce study burden for patients, healthcare professionals and researchers. We recommend the use of the iSHARE questionnaires in an oncology setting, as they assess both patient and physician behaviours, cover the entire SDM process, are based on a thorough development process, and have adequate measurement properties.