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### Shifting from “What is the matter?” to “What matters to you?”

*Shared decision making for older adults with multiple chronic conditions and their informal caregivers*

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#### Publication date

2020

#### Document Version

Other version

#### License

Other

[Link to publication](#)

#### Citation for published version (APA):

Pel-Littel, R. E. (2020). *Shifting from “What is the matter?” to “What matters to you?”: Shared decision making for older adults with multiple chronic conditions and their informal caregivers.*

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# 9

## General discussion





## Introduction

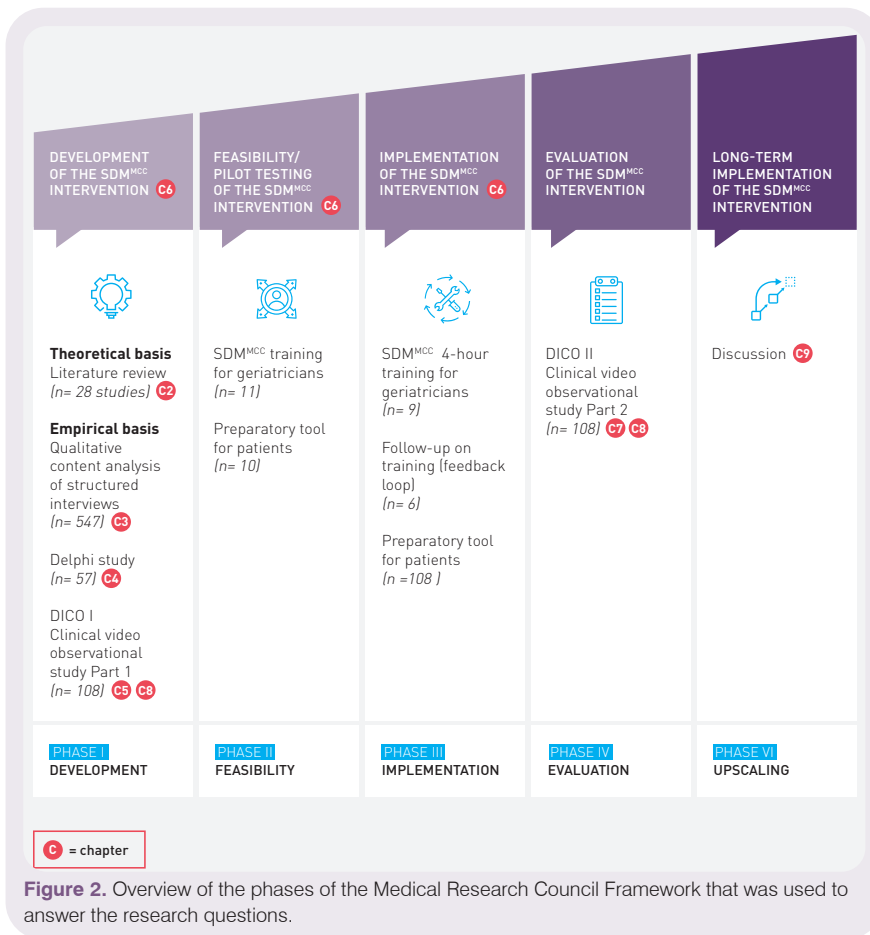
Shared decision making (SDM) is seen as a promising concept for making decisions that contribute to the desired personal health outcomes of older adults with multiple chronic conditions (MCCs). Personal health outcomes are considered from a broad definition of health, encompassing not only the bodily functions, but also daily functioning, mental functions, social participation, spirituality and quality of life<sup>1</sup>. Although the benefits of SDM for older adults have been described in the literature<sup>2,3</sup>, the implementation of SDM for older adults with MCCs and their informal caregivers faces several challenges.

In this dissertation we aimed to improve the implementation of SDM in geriatric outpatient clinics for older adults with MCCs and their caregivers and contribute to the scientific body of knowledge about this topic. For this purpose we developed and implemented the SDM<sup>MCC</sup> intervention, based on the 'Dynamic model of SDM with frail older patients'<sup>4</sup>. Using the framework of the Medical Research Council (MRC) for the development of complex interventions, the SDM<sup>MCC</sup> intervention was developed and evaluated step by step: (1) development phase, (2) feasibility phase, (3) implementation phase and (4) evaluation phase<sup>5</sup>. By following the steps of this MRC framework, we were able to explore a wide range of methods to answer the research questions as formulated in the introduction. Both qualitative and quantitative methods were used, such as a stratified content analysis, a Delphi design, a systematic literature review, a video observational study, a pragmatic trial and a mediation analysis. This resulted in novel insights about SDM with older adults with MCCs and their informal caregivers.

## Research overview

A schematic overview of the research is presented in Figure 1. In the *development phase* a theoretical basis for the SDM<sup>MCC</sup> intervention was identified, through a systematic literature review of barriers to and facilitators of SDM as experienced by older adults with MCCs, informal caregivers and health professionals (chapter 2). This was expanded with empirical research in three studies. First, we investigated the personal health priorities for older adults with and without MCCs by analyzing the data from a study on older adults living at home by means of a qualitative content analysis of structured interviews (chapter 3). Secondly, through focus group discussions and surveys, we gained insight into the views of older adults on which and how personal health outcomes should be discussed in health care consultations and we reached consensus on this through a Delphi study (chapter 4). Thirdly, a video observation study among 108 geriatric patients and their informal caregivers at the geriatric outpatient clinic of two hospitals gave us an unique insight into how SDM is operationalized in daily practice. In addition, a measurement instrument, the OPTION<sup>MCC</sup> was constructed (chapter 5). These studies guided the development of the SDM<sup>MCC</sup> intervention (chapter 6), which consists of an SDM<sup>MCC</sup> training for health care professionals and a preparatory tool for older adults and informal caregivers. In the *feasibility phase* the prototypes of the SDM<sup>MCC</sup> training for health care professionals and the preparatory tool for older adults and informal caregivers were pilot tested with end-users: health care professionals, older adults and their informal caregivers. The *implementation*

*phase* was conducted at the geriatric outpatient clinic of the two hospitals. The training was provided to geriatricians and the preparatory tool was sent to older adults with MCCs and their informal caregivers that were scheduled for a visit to the geriatrician in a selected period. The *evaluation phase* (chapter 7) consisted of a second clinical video observational study, in which SDM was measured by the newly constructed OPTION<sup>MCC</sup> and compared to the ‘care as usual’ as measured in the first video observational study. Finally, by analysing the data of the two video observational studies, the relationship between personal characteristics of older adults with MCCs on participation in SDM and outcomes of SDM was explored (chapter 8). In the following sections, each study is briefly introduced, the main findings are presented and placed in context and methodological considerations and implications for future research are discussed. This chapter ends with an update on *Phase V: Upscaling* in which the long term implementation of the SDM<sup>MCC</sup> intervention is described.



**Figure 2.** Overview of the phases of the Medical Research Council Framework that was used to answer the research questions.

## Presentation and discussion of main findings

### *Phase I: Identifying existing evidence*

#### **Research question 1: What are the experienced barriers to and facilitators of SDM with older adults with MCCs?**

SDM is not yet common practice, it is estimated that in only 10% of the situations in which health decisions are made SDM is used<sup>6</sup>. Both health professionals, older adults and informal caregivers experience barriers in making shared decisions. Although in previous reviews barriers to and facilitators of SDM in general are explored, we expected that for older adults with MCCs additional barriers and facilitators might be found. These insights could support the implementation of SDM for older adults with MCCs<sup>2,3</sup>.

#### **Research**

Therefore, we conducted a systematic literature review to identify the experienced facilitators of and barriers to SDM with older adults with MCCs, from the perspective of older adults, informal caregivers and health professionals (chapter 2).

We found in our review that personal characteristics, such as poor health and/or cognitive or physical impairments can form a barrier for older adults to participate in SDM. By contrast, when an older adult shares information about his/her personal priorities for health outcomes, this facilitates the SDM process. However, older adults need an explicit invitation to share personal information and preferences, since they often undervalue the importance of their own expertise. Also, many older adults state that living with MCCs gives them a lot of experience in how they cope with situations, what they prefer and what to expect from health care.

Most older adults with MCCs would like to have their informal caregiver involved in the SDM process and also informal caregivers themselves would like to participate in SDM<sup>7,8</sup>. Informal caregivers can facilitate SDM by helping older adults with decision support, although informal caregivers can also complicate the SDM process, for example when they have a different view on the treatment or the older adult's ability to be involved.

Health professionals can facilitate the SDM process when they tailor their information to the needs and capacities of the individual older adults and when they probe patient priorities. Also they can encourage informal caregivers to participate in SDM. Furthermore, in the case of care for older adults with MCCs there are often more professionals involved; a good coordination of care facilitates SDM. Barriers to SDM as experienced by health professionals are mostly about organizational constraints, such as time pressure or a high turnover of patients.

#### **Findings in context**

Some of the barriers and facilitators we found in our review are similar to other reviews not specifically focusing on older adults with MCCs, such as patients undervaluing their own expertise and thus the need to be explicitly invited to SDM<sup>9</sup>. Our review adds to the existing knowledge with the finding that the experience of older adults living with MCCs, in fact enables them better to express their priorities

compared to persons who are confronted with a disease for the first time. For example, an older adult who has been living with rheumatoid arthritis for over ten years, probably knows very well how to balance activity and rest compared to someone who has just been diagnosed with this disease.

Although the role of the informal caregiver was long underexposed in SDM literature, we were able to include some very recent studies which delineated a more detailed image of the participation of informal caregivers. We found that although informal caregivers are often the main caregivers for older adults with MCCs, they are often not seen as part of the team by health professionals. Yet, taking on the informal caregivers as 'part of the team' can be very challenging as there may be different views between informal caregivers and health professionals or conflicting views between informal caregivers and older adults<sup>10-12</sup>. Furthermore, it can be very complex for informal caregivers to on the one hand act as a representative of the older adult while they have on the other hand own views and priorities that may differ from that of the older adult. Health professionals must take into account this potential complexity and try to respect both parties.

Finally, the organization barriers as experienced by health professionals echo other research findings<sup>9, 13-16</sup>, even though we found that health professionals perceive that more time is needed to build a trustful relationship with older adults in complex situations.

### **Methodological considerations and implications for future research**

Although our review aimed to explore barriers to and facilitators of SDM among various type of health professionals, the majority of available literature described SDM for clinicians. However, in the care for older adults with MCCs there often are more than one health professional involved, such as nurses, physiotherapists, occupational therapists, dieticians, etc. Our findings may also be applicable to those health professionals. Yet, they often work in a different context (e.g. home care) and often have long standing relationships with their patients, which may affect the SDM process in various ways. 'Knowing your patient' is an important facilitator for SDM, but on the other hand, long-term relationships can cause health professionals to assume too much about the patient's preferences. Research is needed about how SDM can be facilitated for these health professionals and their patients. Furthermore, research is needed to gain more detailed knowledge on how to empower informal caregivers in SDM. Informal caregivers feel uncomfortable when, in the conversation with the geriatrician, for instance when the older adult does not recognize the cognitive decline and its impact on daily life. Informal caregivers are often torn between loyalty and support for their beloved one and the burden they experience<sup>10-12</sup>. Some geriatric clinics work with a hetero anamnesis, a separate conversation with the informal caregiver, in which they can speak freely. It is worthwhile to explore how a hetero anamnesis can facilitate the SDM process for informal caregivers.

### **Recommendations**

The recommendation based on this literature review is to explicitly invite older adults to participate in shared decision making, and to emphasize that their knowledge and experience of their personal situation is important to bring into the conversation. As a result, health professionals are better able to propose

treatment options that fit the personal situation and preferences of patients. Informal caregivers should be made aware that they can make a significant contribution to the decision making process. More attention should also be paid to the complexity of the role of informal caregivers.

### *Phase I: Gathering additional evidence*

## **Research question 2: What are views of older adults with MCCs on personal health outcomes?**

Although SDM has several steps, in this dissertation we highlighted an underexposed step in many models: the discussion of personal health outcomes (chapters 3 and 4). For health professionals this means a significant change, from a disease-oriented approach to a personal health outcome-oriented approach. Knowledge about a range of topics that older adults consider important regarding their situation facilitates health professionals in starting the discussion about personal health outcomes and priorities with their older patients.

### **Research**

To this aim we investigated the personal health priorities for older adults by performing a stratified content analysis on existing data from a study about older adults living at home (chapter 3). Our findings showed that regarding personal health priorities, older adults with MCCs often deal with the acceptance of aging and the associated deterioration. They are concerned about further limitations and social contacts, such as family. Regarding healthy aging, they feel it is important for them to have a healthy lifestyle, to keep busy, to maintain social contacts and to have a positive attitude. Older adults with and without multiple chronic conditions often mentioned the same issues when it came to ageing but an important difference was that older adults with multiple chronic conditions were more worried, looked more negatively to the future and were especially afraid of further physical decline and limitations.

### **Findings in context**

Our research gives meaning to the 'Action Steps for decision making for older adults with MCCs', that emphasizes to start with identifying and communicating patients priorities regarding personal health outcomes<sup>8</sup>. Although older adults vary in whether they want and are able to participate in SDM, discussing preferred health outcomes is relevant for all older adults, regardless of who makes the decision<sup>8, 17-19</sup>. Tinetti (2019) found that working according to patients priorities in personal health outcomes led to less treatment burden and less unwanted healthcare<sup>20</sup>. They also reported that initial fear among physicians that older adults would formulate unrealistic goals was unjustified; if older adults were guided through the SDM process, they formulated personal and realistic goals. This was confirmed by the study of Feder (2019) who also found that discussing personal goals led to a better relationship with physicians<sup>7</sup>. Our research facilitates the discussion of health outcomes goals by identifying a range of topics that many older adults find important in relation to their situation. Since we found that older adults with and without MCCs mostly share the same views on aging, our results



seem to apply to all older adults. However, health professionals should address the fact that older adults with MCCs have more concerns and more negative future expectations, in particular about further physical decline and limitations.

### **Methodological considerations and implications for future research**

Our stratified content analysis provided insight in the views on aging of more than 500 older adults. The questions that had been used to gather the data could have been more specific about preferred personal health outcomes. Following their previous research on goals setting for older adults with MCCs in SDM, Elwyn and Vermunt (2019) recently proposed an integrated, goal-based SDM model using a Goal Board to prioritize collaborative goals and align goals with interventional options. This model describes three goal levels: fundamental, functional and symptomatic. Fundamental goals are about what people hope for in life, or are afraid of. Functional goals address the activities one wants to be able to do or to carry on doing. Symptom or disease specific goals concern the symptoms of disease someone wants to change, for example less pain. For future research it is interesting to explore how this Goal Board could be used. For example, we are currently exploring whether the patient preparatory tool could be adapted to support older adults thinking about their goals on these different levels. Also, we are exploring if this goal-based SDM model could be integrated with the 'Dynamic model of SDM for frail older patients'.

### **Recommendations**

Based on this research, we recommend discussing with older adults what is important to them personally for their quality of life and what they are most concerned about. In this way health professionals can together with the older adults come to goals regarding personal health outcomes and discuss what (treatment or support) possibilities there are to achieve these goals.

### **Research question 3: Which patient reported health outcomes (PRO's) should be discussed in health care conversations according to older adults with MCCs?**

Patient Reported Outcome Measurements (PROMs) are questionnaires that provide information about a patients personal experience of his situation. Since PROMs could facilitate the discussion of personal health outcomes, we explored to which extent the TOPICS-MDS, a PROM used in Dutch geriatric care, covers the health domains which older adults value as important (chapter 3).

### **Research**

We conducted a Delphi study in combination with focus group discussions and gained insight into the views of older adults with different education levels and different cultural backgrounds on which and how personal health outcomes should be discussed in health care consultations. We found that older adults agreed with all the domains addressed in the TOPICS-MDS: 'functional limitations', 'emotional wellbeing', 'social functioning' and 'quality of life'. In addition, older adults also would like to discuss 'coping with stress' and 'dealing with health conditions and the effects on life'. Furthermore, they provided recommendations on how to

adjust the TOPICS-MDS questionnaire to improve the comprehensibility of the questions.

### Findings in context

The domains identified were in line with the findings of previous studies, including our study on views of older adults on personal health outcomes. For example, the importance of discussing functional limitations in health care communication has also been described in other studies on outcomes important for older adults<sup>21-24</sup>. Furthermore, older adults stressed the importance of a trustworthy relationship between the healthcare professional and the older adult when discussing emotional well-being. These findings support the results of the study by Ridd et al (2009), who found that a long-term relationship and continuity of care are important when discussing sensitive subjects<sup>25</sup>. As to the two additional domains recommended by older adults ('coping with stress' and 'coping with health problems and the effects on life') it is worth exploring whether the Brief Resilience Scale to assess a person's resilience, defined as 'the ability to bounce back and recover from stress', could be added to the TOPICS-MDS<sup>26</sup>. Our research provides evidence that the TOPICS-MDS is usable as a PROM to provide input for the discussion of personal health outcomes because it contains the health domains older people would like to discuss with the care professional. What is notable is that in addition to the domains already included in TOPICS-MDS, older people are particularly concerned about the impact of their health condition(s) on their daily lives.

### Methodological considerations and implications for future research

By involving older adults in assessing the domains, we added value to the use of the TOPICS-MDS as a PROM. Although using focus groups within a Delphi design is not common (because of prevention of response bias), it enabled older adults with a low level of education and a culturally diverse background to express their views. The older adults in our groups with a culturally diverse background or a low level of education emphasized more than the older adults with a high level of education the importance of discussing all health domains with health professionals. The results of previous studies support our idea that in the Netherlands these groups make more frequent use of health care resources, and generally have more chronic conditions than older adults with a high level of education<sup>27, 28</sup>. This could mean that through frequent contact with health care providers, people feel more confident when discussing different areas of health. Recently the TOPICS-MDS has been adapted to a short-form (TOPICS-SF) version whilst maintaining the domains as indicated by the older adults. The TOPICS-SF which is now increasingly used as a PROM in Dutch geriatric care. The next challenge is to connect the use of a PROM into the SDM process. We are currently exploring how this can be facilitated and in particular how the additional domains can be addressed in the preparation for the SDM conversation.

### Recommendations

The TOPICS-MDS, or preferably the short version (TOPICS-SF), when completed by older adults with MCCs, gives an overview of the current status of an older person regarding personal health outcomes that most older adults consider important.

The TOPICS-SF provides input for the ‘goal talk’, step 2 of the ‘Dynamic model of SDM in frail older patients’. However, it is important that health professionals ask older adults what the score on a personal health outcome means to them, for example: ‘I see in the TOPICS-SF that you have a few social contacts, how important are social contacts for you?’. This is a necessary step to come to goals on personal health outcomes. The Dutch Association of Clinical Geriatrists (NVKG) has recommended that an abbreviated version of the questionnaire, the TOPICS-Short Form (SF), be used in all Geriatric departments in the Netherlands. The NVKG particularly emphasizes the added value of the questionnaire if it is used for shared decision making with older adults in health care conversations. The questionnaire can be freely downloaded from [www.topics-mds.eu](http://www.topics-mds.eu).

#### **Research question 4: How can we measure observed SDM during consultations with older adults, their informal caregivers and health professionals, based on the steps of the ‘Dynamic model of SDM with frail older adults?’**

As a final step the development phase of the MRC framework, in which we gathered additional evidence, we explored whether, and if so, how SDM for older adults with MCCs is applied in daily practice. To this aim we conducted a video observational study: the Decision making In Complex Older populations (DICO I) study in two outpatient geriatric clinics of two Dutch hospitals.

Since we wanted in particular be able to observe the discussion of patient priorities regarding personal health outcomes as start of the SDM process, in other words: ‘goal setting’, we searched for an SDM model and measurement instrument that addressed these aspects. As explained before, the ‘Dynamic model of SDM in frail older patients’ explicitly describes goal setting in older adults with MCCs and thus proved to be a promising model to build our research on<sup>4</sup>. Furthermore, SDM for older adults is a process that involves not only health professionals and older adults, but often also their informal caregivers. Although there are several patient-reported measurement instruments, to our knowledge there were no instruments that measured observed SDM, as demonstrated by health professionals, older adults and their informal caregivers. To address these issues, we developed an observation instrument.

#### **Research**

To be able to measure the level of SDM in daily practice, we developed and tested the observed OPTION<sup>MCC</sup>, an observation instrument that builds on the existing Observer OPTION 5, but has been expanded to address issues in SDM that are specific to older adults with MCCs and incorporates the perspectives of geriatricians, older adults and informal caregivers (chapter 5). Based on our video observational study with 108 geriatric patients, 68 informal caregivers and 10 geriatricians we concluded that Observer OPTION<sup>MCC</sup> seems sufficiently reliable for the assessment of triadic SDM for older adults with MCCs, their informal caregivers and geriatricians. The scores on the Observer OPTION<sup>MCC</sup> showed that geriatricians apply SDM more compared to other specialists<sup>29</sup> (39.9 versus 23, range 0 – 100), but the relative low scores show that there is still room for improvement. Also, the geriatricians in our study had more time

for their consultations compared to other specialists<sup>29</sup> (average time 40.3 versus 13 minutes). Observer OPTION<sup>MCC</sup> scores regarding participation of patients and informal caregivers in SDM (resp. 1.05 and 1.04, range 0 - 2), indicated a responsive level of participation (passive- responsive- active).

### Findings in context

We built on the Observer OPTION 5 to develop the Observer OPTION<sup>MCC</sup>. Kunneman et al (2019) conclude in their review that although there are over 40 instruments to measure SDM, the 'discussion of patient priorities is underrepresented in SDM observer measurement instruments'<sup>30</sup>. With the Observer OPTION<sup>MCC</sup> we developed an instrument that clearly addresses the 'discussion of patient priorities' in SDM. The choice for the Observer OPTION 5 was supported by the review of Kunneman et al (2019) who stated that the four key elements of SDM: offering choice, discussing options and pros and cons, discussing views and priorities and making the decision, are best measured through the OPTION 5 and the DSAT 10<sup>30</sup>. However, a reflection is needed on the effect of introducing new SDM steps (goal talk, evaluation talk) on an observation instrument. The Observer OPTION<sup>MCC</sup> was constructed to measure a formative construct of SDM, while it is assumed that better performance on one item (e.g. goal talk) will automatically lead to better performance on other items (e.g. team talk). However, our findings show that a better performance on one item can go hand in hand with a worse performance on another item. In their reflection on the OPTION<sup>MCC</sup>, Pieterse et al (2019) already suggested that the underlying relationship between the items and the construction we are measuring should perhaps be reconsidered; should SDM be measured through a reflective model ((items are mutual interdependent) or a formative model (the items are independent from each other), in other words, how do the SDM items relate to each other<sup>31</sup>?

Although there exist measurement instruments that measure patient and informal participation, items to score this do not distinguish between patients and informal caregivers<sup>31</sup>. A strong advantage of the Observer OPTION<sup>MCC</sup> is that we developed items to measure the participation of each party separately.

### Methodological considerations and implications for future research

Although most health professionals favor SDM, many researchers warn that health professionals overestimate their own SDM skills<sup>32</sup>. Therefore, we chose to make video recordings of real life consultations between geriatricians and older adults and informal caregivers to get insight in SDM in daily practice. The video-images enabled us to differentiate more clearly who was talking (e.g. difference between an older female patient and her female informal caregiver) and also to see nonverbal communication (smiling, nodding, tearful).

We encountered three issues that complicated rating of SDM with the Observer OPTION<sup>MCC</sup>. First, we scored the patient and informal caregivers' participation on three levels: no participation, responsive participation and active participation (0-2). Although this was a feasible way to rate their participation, it prevented us from calculating a composite end score on the Observer OPTION<sup>MCC</sup>, since the scores of geriatricians have a different range (0-4). We suggest that future studies with the Observer OPTION<sup>MCC</sup> should considering recalculating the patient and informal caregiver item scores to a 0-4 range, so that a total triadic

Observer OPTION<sup>MCC</sup> score can be calculated. Second, the multitude of problems that were discussed in a consultation made it difficult to complete a measurement scale that is designed for taking one decision. We compensated for this by asking the geriatrician what in his/her opinion was the most important problem discussed and focused our observations on this problem, but this excluded SDM observations on other problems, which could also be important.

Third, the observer OPTION<sup>MCC</sup> is a verbal instrument, e.g. in line with the scoring manual of the Observer OPTION 5, we scored on spoken language, on phrases demonstrating SDM skills. However, watching the video recordings of consultations, we noticed that there are non-verbal communicative skills that contribute to the SDM, such as empathic nodding, humming, listening, smiling etc. Those skills could not be scored with the Observer OPTION<sup>MCC</sup>, but we think they do contribute to SDM, for example by encouraging older adults to share their views. Future research could explore how this behavior should be assessed in the context of SDM and whether the Observer OPTION<sup>MCC</sup> should be further developed for measuring non-verbal signals.

### Recommendations

The added value of the Observer OPTION<sup>MCC</sup> compared to existing measuring instruments for observing shared decision making is the measurement of discussing the personal goals of the older adult and the explicit measurement of the participation of the older adults and his or her informal caregivers in the shared decision making process. Therefore we recommend the Observer OPTION<sup>MCC</sup> for measuring SDM among older adults with MCCs. The Observer OPTION<sup>MCC</sup> can be freely downloaded via various websites ([www.healthcommunication.nl](http://www.healthcommunication.nl), [www.vilans.nl](http://www.vilans.nl)) and has been added to an international website where the various OPTION measuring instruments can be downloaded: [www.glynelwyn.com](http://www.glynelwyn.com).

### *Phase II: Feasibility and Phase III: Implementation*

### **Research question 5: Which theory- and evidence-based intervention can be developed, pilot-tested and implemented to improve the implementation of the ‘Dynamic model of SDM with frail older adults’**

The results of the previous chapters of this dissertation guided the development of the SDM<sup>MCC</sup> intervention (chapter 6) through the following recommendations:

Use the ‘Dynamic model of SDM with frail older patients’ to guide the SDM process, and within this model the intervention specifically focused on:

- an explicit invitation by the health professional to participate in SDM
- appraisal of personal experiences of patients
- discussion about personal goals that contribute to quality of life (‘what matters most to you’)
- a trustful relationship

- active involvement of informal caregivers and recognition of the potential burden of informal care
- forming a partnership between geriatrician, patient and informal caregiver
- reflecting on the decision making process, including making a treatment plan
- health professionals should tailor their information to a patients individual capacities and needs

### Research

The SDM<sup>MCC</sup> intervention was systematically designed based on both theoretical and empirical evidence and consists of an SDM<sup>MCC</sup> training for geriatricians and a preparatory tool for older adults and informal caregivers. Through the process of co-creating with the end users both products were tailored to the specific needs of older adults and geriatricians. The design of the training was presented in two consecutive rounds to 11 geriatricians working at various locations in the Netherlands (but not in AMC or MC Slotervaart). With the feedback of these geriatricians the final training was established. The training was given to four geriatricians in the AMC and five geriatricians in the MC Slotervaart. Key elements of the training for geriatricians in SDM<sup>MCC</sup> include the exploration of personal attitude, knowledge and current use of SDM. Furthermore the 6-step SDM<sup>MCC</sup> model was explained and practiced. The geriatricians gave the training an average grade of 8 (range 0-10). They indicated that they had learned to apply the steps of SDM and that they were particularly aware of the importance of discussing goals. The preparatory tool was submitted in three consecutive rounds to a total of ten elderly and informal caregivers and two geriatricians before it was finalized. The preparatory tool was sent to 108 geriatric patients who wanted to participate in the study and had an appointment at the geriatric outpatient clinic of the two participating hospitals. Key elements of the preparatory tool for older adults include an explicit invitation to participate in SDM, appreciation of older adults' own knowledge and exploring possible goals. Finally, the concerns of informal caregivers are addressed by recognizing partnership and inquiring about the potential burden of informal care. Two third of the older adults and informal caregivers who had filled in the leaflet thought it was a good and informative leaflet.

### Findings in context

With the development of the SDM<sup>MCC</sup> intervention we provide guidance to what is needed for the support of SDM according to the 'Dynamic model of SDM for frail older patients'. It connects to the increasing awareness of the need to explore personal goals in SDM in recent literature<sup>4, 33, 34</sup>. For example, Vermunt and Elwyn (2017, 2018) make a strong plea for setting personal goals in the context of SDM<sup>35, 36</sup>. The SDM<sup>MCC</sup> intervention focuses on triadic decision-making by including the role of informal carers and is in line with recent literature that emphasizes the role of informal carers of older adults in the SDM process<sup>37-41</sup>.

### **Methodological considerations and implications for future research**

Working according to the MRC framework for developing complex interventions led to a solid evidence base for what is needed to implement SDM for older adults with MCCs. Although we developed the intervention in co-creation with end users (older adults and geriatricians), the intervention was tailored to the *general* needs of geriatricians and older adults, and one size may not fit all. Further improvements on the SDM<sup>MCC</sup> intervention could focus on a better connection to a person's individual skills and needs, e.g. with regard to the skills needed to involve the older adult as a genuine partner in the SDM. For future research it would be interesting to study if the SDM<sup>MCC</sup> training for geriatricians could be aligned to build on the geriatrician's individual existing SDM skills and tailored to the specific skills that are lacking. Also, as shown by Nguyen et al (2018) the possibility to self-tailor the mode of the information presentation in patient tools (text, illustrations, video) may result in a patient preparation tool that is better in line with an individual person's needs<sup>42</sup>. As a result the patient preparatory tool might connect even better to older adults with a low level of education, cognitive decline or a culturally diverse background.

### **Recommendations**

Based on this research, we can conclude that the SDM<sup>MCC</sup> intervention, consisting of a training course for geriatric patients and a preparation instrument for patients, is feasible for use in daily practice.

### *Phase IV: Evaluation*

### **Research question 6: What are the effects of an evidence based intervention, based on the steps of the 'Dynamic model of SDM with frail older adults', to improve the implementation of SDM for older adults with MCCs?**

After implementing the SDM<sup>MCC</sup> intervention, we investigated how effective the intervention was in terms of observed and perceived SDM in the care of older adults with MCCs (chapter 8).

### **Research**

To this aim we conducted a second video observation study (DICO II) among 108 geriatric patients, 65 informal caregivers and 9 geriatricians (the same geriatricians as in the DICO I study). We studied if, compared to the first video observation study (DICO I) there were changes in observed SDM with OPTION<sup>MCC</sup> during video recorded consultations and in patient and informal caregivers reported outcomes regarding patient participation, perceived SDM and decisional conflict. We found significant improvements on four item scores on the Observer OPTION<sup>MCC</sup>, as well as significant decreases on two other item scores. On average, the combination of improvement on some items and deterioration on others did not lead to improvement, i.e. the total score on the OPTION<sup>MCC</sup> did not show a significant difference after the implementation of the SDM<sup>MCC</sup> intervention. On item level, 6 out of 7 items showed significant changes. The SDM items 'eliciting goals', 'discussing pros and cons of options' and 'eliciting priorities of options'



and 'deciding together', significantly improved after the intervention. Oppositely, the scores on SDM items 'forming a partnership' and 'evaluation of decision' decreased significantly. One geriatrician with a lower score had a strongly deviating score (-17.3) compared to the other eight geriatricians. When we considered this as an outlier, a subgroup analysis of the remaining 8 geriatricians revealed a significant positive effect on the overall OPTION<sup>MCC</sup> mean scores after the intervention. This indicates that a good implementation is important. The scores of the patients and informal caregivers on the observer OPTION<sup>MCC</sup> were mostly in the same line as the score of the geriatricians, indicating that if a geriatrician scored high on an item, patients and informal caregivers usually also scored high on that item. Furthermore, there was a great variety within the group of participating geriatricians in how much SDM was observed after the intervention, compared to usual care. There were no significant changes on patient reported SDM outcomes. Finally, although completed in 51.9% of the cases, the preparatory tool was rarely discussed during consultations (12%), which may have biased the effect of the SDM<sup>MCC</sup> intervention.

### Findings in context

The level of SDM as demonstrated by the geriatricians in our study was higher (39.7 <> 39.3, scale 0-100) both before and after the intervention compared to observer OPTION scores in other studies. Couet et al (2014) found an average OPTION-12 score of 23 (0-100) in a review of 33 studies (mainly among general practitioners) using OPTION-12<sup>29</sup>. However, it must be noted that the mean consultation time of the geriatricians in our study extended that of the studies in this review (39 <> 13 minutes), providing more opportunities to demonstrate SDM skills. This initial high SDM score might also explain why the improvement in our study is limited. There might be some explanations for our findings. First, our findings are echoed by other studies that urge to pay attention to scores on individual items, to discover SDM effects that are diluted by total mean scores<sup>30, 31</sup>. Furthermore, there was a wide range in individual geriatrician scores. Although the SDM<sup>MCC</sup> training was tailored to the general needs of a geriatrician, we conclude (as for many interventions) in SDM one size does not fit all, and this applies to both geriatricians as well as older adults and informal caregivers<sup>31, 43</sup>. Also, almost 30% of the participating older adults did not remember receiving the paper preparatory tool and subsequently had not used it. Since the Dutch mail is very reliable, the cognitive problems that were present in almost half of the participating older adults may have been the cause of this. In addition, it must be noted that the older adults received more information, e.g. an information letter about the study and informed consent form, this multitude of information may have distracted the attention for the preparatory tool. Second, the older adults did not initiate the discussion about the preparatory tool by themselves. When the preparatory tool was discussed, this was always at the initiative of the geriatrician. The preparatory tool was completed by 56 patient, but only with 11 patients the findings of the tool were discussed in the consultation. We might have overestimated that geriatricians would bring it up for discussion. The use of a preparatory tools may even cause reverse effects when this is not endorsed by the physician<sup>44</sup>. Finally, although in the training for geriatricians we focused on discussing personal goals, we underestimated that working according to this



SDM model, requires a behavioral shift from geriatricians in how to structure the consultation. Geriatricians that are used to start a consultation by inquiring about symptoms and problems, are expected to shift to start by discussing personal health outcomes, facilitated by the preparatory tool. Although SDM for older adults with MCCs meets many challenges due to the complexity of their situation, our study revealed a high level of observed SDM, demonstrated by geriatricians, older adults and informal caregivers in geriatric consultations. However, it also provides several issues that can be improved to facilitate further implementation of SDM.

### **Methodological considerations and implications for future research**

Although geriatricians seem to demonstrate higher SDM skills compared to other clinicians, it might be questioned why overall scores on the OPTION instruments are still very far from reaching a top score of 100. On the one hand one could argue that future training should focus more on the items that showed a low score, such as 'team talk' and 'evaluation'. On the other hand we might have to rethink if all items should bear the same weight, or that for example key items in the Dynamic Model such as 'goal talk' should gain more weight in relation to other items, such as evaluation of the SDM process.

Secondly, the issue must be addressed how the use of the preparatory tool can be improved, both in terms of patient preparation and in terms of bringing the tool up into the discussion. The patient preparatory tool could be made available in different versions, e.g. tailored to lower health literacy levels and both in a written as well as a digital version.

Finally, we conducted a pragmatic trial to study the effect of the SDM<sup>MCC</sup> intervention. The advantage of a pragmatic trial is that the usability of an intervention in real life is tested. This maximizes the applicability and generalizability of the results<sup>45</sup>. Previous studies show that combined interventions (e.g. provider training combined with patient preparatory tools) are more effective compared to studies with a single intervention<sup>46-48</sup>, the disadvantage of implementing a two-sided intervention in a non-blinded pragmatic trial, is that we have no information about which elements have which effect. Furthermore, since the intervention group was monitored almost a year after the usual care group, this might have caused bias due to external influences, such as an increased awareness of SDM in hospitals and in society. Also the non-blinded character of the study may have caused bias, as both the geriatricians and the patients were aware of the interventions (training and preparatory tool). Although the use of this design has given us several clues to a long term implementation, another research design, such as an RCT with a before-after design and a treatment and control arm, could have provided more information on the effectiveness of the different components of the intervention. Also, when using a multi-centre design, the condition of blinding could be met. Prevention of researcher bias was prevented by using a fourth, blinded, observer to assess a mixed sample of the video recorded consultations of both (DICO I and II) studies.

### **Recommendations**

Based on this research we recommend that the SDM<sup>MCC</sup> intervention can be used to facilitate the discussion of personal health outcomes through SDM in geriatric

consultations. However, the SDM<sup>MCC</sup> needs further development regarding several aspects of the SDM<sup>MCC</sup> training ('team talk' and 'evaluation') and regarding the implementation of the patient preparatory tool in the consultations.

### **Research question 7: Which personal characteristics of older adults with MCCs influence the participation in SDM and the outcomes of SDM?**

In our literature review we learned that personal characteristics of older adults with MCCs may hamper the participation in SDM. In order to facilitate health professionals in engaging older adults with MCCs in SDM, we need to gain a more detailed understanding of which characteristics influence participation of older adults in SDM, the experienced shared decision making afterwards and the experienced (un)certainly about a decision taken.

#### **Research**

To this aim, we analyzed the data from both the first and second video observation study (DICO I and DICO II study) to gain insight into the influence of personal characteristics of older adults, such as education, anxiety and health literacy, on the perceived level of SDM and decisional conflict (chapter 8). Perceived level of SDM refers to how the patients have experienced SDM. Decision conflict is defined as 'personal uncertainty about which course of action to take when choice among competing options involves risk, regret, or challenge to personal life values'<sup>49</sup>. We investigated whether SDM communication during the consultation could have a mediating effect for these characteristics on the perceived level of SDM and decisional conflict and built a model for this. Results showed that a lower education level and less anxiety are associated with higher perceived SDM. Higher education, lower health literacy and more anxiety were associated with more decisional conflict. Regarding the mediator, higher age and lower health literacy were related to less participation in SDM. For older adults with lower health literacy, increased participation in SDM process reduced decisional conflict. Thus, decisional conflict is mediated by participation in SDM in older adults with lower health literacy.

#### **Findings in context**

To our knowledge there are no similar studies that have analyzed the influence of education, anxiety and health literacy on the perceived level of SDM and decisional conflict. By observing how older adults participated in the actual SDM, we were able to reveal new insights for older adults with lower health literacy. We found that if more SDM communication takes place in the consultations, this has a positive effect on the level of decisional conflict for older adults with a lower level of health literacy. The review of Durand (2014) suggested that SDM interventions tailored to socially disadvantaged groups (e.g. poverty, ethnic minority status, lower health literacy, living in poorer areas) benefit participation in decision making and reduce decisional conflict<sup>50</sup>. Those interventions were characterized by the use of plain language and were concise, simple and tailored to these specific groups. However, most interventions consisted of training of patients, patient decision aids and the use of videos. Although very few interventions in this review focused on decision

participation during the consultation, the characteristics as describe above are also likely to apply well to enhancing decision participation during the consultation. An explanation for the lower levels of perceived SDM and more decisional conflict among higher educated older adults may be that higher educated older adults are more aware of the complexity of the decisions they face. When they are better involved as partners in the decision making, for example in the exploration of health outcomes, when the options are presented more clearly and benefits and harms of the options are explained, this SDM communication was expected to have a positive effect on the perceived level of SDM and decisional conflict.

In addition, current SDM communication does not seem to benefit older adults with high levels of anxiety in terms of perceived level of SDM. Further research should focus on what is needed to increase the perceived level of SDM and decrease decisional conflict for these groups.

### **Methodological considerations and implications for future research**

Due to the frail character of the population we were limited in the number of personal characteristics we could study in relation to the perceived level of SDM and decisional conflict. Future research might add other characteristics to this research question, for example emotional wellbeing. We were able to observe patient participation in the SDM communication with the observer OPTION<sup>MCC</sup>. Since we focused on patient communication, we choose to use the patient OPTION<sup>MCC</sup> score. However, for future research it could add value if an integrated OPTION<sup>MCC</sup> score could be used.

### **Recommendations**

The results of this study support the findings from the literature review (chapter 2) that it is important to adapt SDM communication to the personal characteristics of older adults, for example by using plain language, be concise and the use of teach-back methods<sup>51</sup>. This is especially true for older adults with lower health literacy. If it is possible to involve them better in the shared decision making process, this has a positive effect on the outcomes, especially decision conflict. Furthermore, we recommend to assess health literacy before SDM, to enable health professionals to adapt their communication. Although there exist numerous tools to assess health literacy, the challenge is to find short, usable assessment tools for daily clinical practice<sup>52</sup>. Although the Short Assessment of Health Literacy (SAHL) tool used in our study is a valid and reliable tool, it took the geriatric patients in our study quite some time to complete the 22 questions, which makes which makes it less usable for clinical practice. A single question tool to assess health literacy that could be further explored for this purpose is the Single Item Literacy Screener (SILS): "How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?"<sup>53</sup>. Although this instrument targets reading ability, which is only one the elements of health literacy, we could study the validity of the SILS for clinical purposes.

## General reflections

### A research focus on implementation of SDM in the care for older adults with MCCs

Although there is increasing attention on SDM as a facilitator for person centered care, the implementation of SDM stays behind<sup>54, 55</sup>. In 2016 ZonMw, the Netherlands Organization for Health Research and Development, plead for more focus on implementation of SDM in daily practice. This guided our choices for a pragmatic trial, for study designs focusing on the views and experiences of older adults, for developing implementation interventions and for a design with video observations in daily practice. We did not want to start from scratch but aimed to build on existing work, such as the 'Dynamic model for SDM in frail older patients', existing SDM trainings and existing patient preparatory tools. Although we gained knowledge about what is needed for the implementation, the actual implementation can be further improved. Changing daily practice requires also support on changing behavior of health professionals, for example how to change established routines in the structure of a consultation. Shifting from 'what are your problems' to 'what matters to you most' is a major change not to be underestimated, as geriatricians are trained to work in the first way. In addition, the strategies that enable older adults to prepare for a conversation with the geriatrician can be improved. Sending a preparatory instrument by post is just one of the ways we investigated in our study, but alternatives as a digital instrument or over the phone could also prove useful. However, our focus was mainly on the content of SDM. For future studies or implementation programs we recommend more focus on the impact of the changes that are required from health professionals when implementing SDM. Designing a patient journey with all healthcare professionals involved could provide insight into the changes needed in the regular workflow of a local hospital to facilitate SDM.

### Does SDM really lead to improved personal health outcomes for older adults with MCCs?

Although the societal changes as described advocate SDM and ethical principles (e.g. autonomy of patients)<sup>56</sup>, support the concept of SDM, the question is in which way SDM really contributes to better health outcomes for older adults with MCCs. In the field of SDM extensive research has been carried out to chart the benefits of SDM. Shay and Lafata (2015) distinguish three types of outcomes of SDM: (1) cognitive-affective, (2) behavioral and (3) health outcomes<sup>57</sup>. Most studies report on cognitive-affective outcomes of SDM, such as knowledge and decisional conflict and the evidence points towards positive effects of SDM in this perspective<sup>3, 31, 57</sup>. In particular the many studies about the effects of using patient decision aids provide evidence on these outcomes<sup>3, 58</sup>. Also in our studies we reported on cognitive-affective outcomes of SDM, such as perceived level of SDM, participation in SDM, preferred and perceived roles in SDM and decisional conflict. There are fewer studies about behavioural outcomes such as compliance to treatment or adoption of health behaviours and about health outcomes such as quality of life<sup>57</sup>. Also the positive effects of SDM were less evident in those studies<sup>59, 60</sup>. Furthermore, SDM may lead to an increased use of patient reported

outcomes and possibly, due to the increased involvement of patients, less complaints and less legal procedures<sup>61</sup>. A major challenge for future research on SDM for older adults with MCCs is to explore if the discussion of personal health outcomes as a starting point in SDM, really leads to attaining the goals that are set to reach those personal health outcomes. Although the PROM TOPICS-SF is intended to monitor health outcomes over a longer period, the connection must be improved between the use of this PROM and the SDM process, in particular regarding 'goal talk'. For example, by linking PROM questions to the question of how important this topic (for example social functioning) is to someone and what he or she would consider a personal health outcome with regard to this topic.

Furthermore, the process of SDM goes beyond that what happens in the consultation between the health professional and the patient. Elwyn (2016) raises awareness about possible long term effects of SDM that are still rarely studied<sup>61</sup>. For example, much is unknown about the effect of SDM on professionals; some may experience SDM as intrinsically rewarding but others may find SDM burdensome and impractical<sup>61</sup>. Also, SDM is closely connected to value based health care, and value-based health care has many implications for production-driven health organisations. The impact of SDM needs to be further studied in order to understand its contribution to value-based healthcare. To conclude, SDM seems to be a promising concept regarding cognitive-affective patient outcomes, but the implications of SDM should be studied in a broader, long term perspective and in relation to personal health outcomes.

### **Older adults with MCCs as target population**

We observed a lack of knowledge and a lack of tools to facilitate SDM in older adults with MCCs. This could be explained by the lack of evidence in guidelines on the benefits and harms of treatment options for older adults. Further challenges in SDM for older adults with MCCs lie in the variety of health problems, not merely in the physical domain, but also in the functional, psychological and social domain. Although, due to different barriers, older adults continue to be underrepresented in studies, we took up the challenge to involve older adults with MCCs in our research projects<sup>62-64</sup>. To involve as many older adults as possible, we carefully planned the recruitment, through a personal approach, offering optional assistance in completing questionnaires, involving informal caregivers in logistic arrangements and to minimize the study burden for participants. In our studies we sought for representative samples of older adults with MCCs. Since we know that older adults with a lower education or a different cultural background often are underrepresented in studies, we put extra effort in engaging those participants (chapter 4)<sup>64</sup>. For the main studies, the observational DICO I and DICO II study, we recruited a sample of geriatric patients. Although we found no significant differences between participants and non-participants on age and gender, the sample could be biased on other characteristics. Finally, a strength of this study is that we were able to involve many informal caregivers, who often have an important role in the SDM process.

## Reflections on the ‘Dynamic model of SDM with frail older patients’

This thesis builds on the model for SDM, the ‘Dynamic model of SDM with frail older patients’. We investigated how the model could best be implemented in the daily practice of geriatric patients and we gained the first experiences with working according to this model. For the future, we think that it might be of added value to make the item goal talk, in our opinion one of the most important strengths of this model, more explicit. For example, in the proposed line of Elwyn and Vermunt, by differentiating goals on the level of life goals, functional goals and symptom goals. Furthermore, we wondered whether discussing partnership should be further elaborated as a separate measurement item, or more integrated in the other items, such as goal talk. We learned in our study that this item is difficult to measure, but if the goal talk is conducted well, it also shows to the patient that his or her input with regard to personal health outcomes is just as important as the knowledge and experience of the health professional.

## Implications for policy

There is an increasing awareness in the care for older adults with MCCs that is important to discuss with each individual person what his or her desired personal health outcomes are. Although this research has focused on care in an outpatient geriatric clinic, we recommend that these discussions could start much earlier than the moment that an older adult (often in an acute situation and bad condition) is admitted to the hospital. For home dwelling older adults, the General practitioner, the General practice-based nurse specialist or the district nurse, often have a long-standing relationship with their older patients. Here, the conversation about preferred personal health outcomes should start and this information should be used throughout the ‘patient journey’ that older adults with MCCs make (encountering a variety of (health) professionals in a variety of care or social settings). And since priorities on personal health outcomes may change over time, regularly and in particular after life events, the conversation about preferred health outcomes should be updated and recorded in the medical file. Although in the last decade much progress has been made in the coordination of the care for older adults<sup>65</sup>, to our knowledge there are not yet person-following PROMs through the care chain. This requires further exploration and coordination between social, primary and secondary care which and how PROMs could contribute to discussing preferred personal health outcomes.

Secondly, there is an urging need in the Netherlands to better align care to the needs of persons with chronic conditions. The ‘Right Care in the Right Place’ movement (2018) and the integrated care movement ([www.integratedcarefoundation.org](http://www.integratedcarefoundation.org)) is a movement towards organizing care around the patients or clients and communities instead of organizing care from the perspective of healthcare providers, with a focus on daily functioning of people. In this movement it is stated that ‘SDM is in this the guiding principle’, but ‘a prerequisite to this is available information about (patient reported) health outcomes’<sup>66</sup>. Although this stresses the need for information about health outcomes for older adults, in the report ‘More attention towards older adults in the hospital’ (2019) researchers and clinicians addressed the issue of a lack of knowledge about

health outcomes for older adults, and the urge to develop patient decision aids tailored to older adults with MCCs<sup>67</sup>. This dissertation provides information about important personal health outcomes for older adults with MCCs and how these can be integrated in SDM resulting in decisions that contribute to the achievement of personal health goals. Moreover, SDM could even reinforce these movements, as SDM encourages older adults to express their preferences in care.

Thirdly, the development of the SDM<sup>MCC</sup> intervention is in line with the recommendations as formulated in the 'Vision on SDM'(2019) by the Federation of Medical Specialists. As the report states that 64 % of medical specialists expressed needs for an SDM training, more attention should be paid to SDM in continuing training of medical specialists. Positive signs are that SDM is now included in the curriculum of most medical studies and also in the curriculum of Bachelor Nursing 2020. However, the report 'Vision on SDM' points out that there are more barriers to be crossed in SDM implementation, mainly in the organizational and financial context<sup>68</sup>. As the studies from this dissertation provide guidance to improve the implementation of SDM in the primary process, further research should address these organizational and financial issues, also as a prelude to explore other, more long-term effects of SDM.

## Implications for practice

### *Phase V: Upscaling*

The results described in this dissertation can be used to reach out to a broader implementation of SDM for older adults with MCCs, in particular at geriatric wards. The Dutch Geriatric Society (NVKG) should be a key factor in this, together with the Dutch Nurses Society (V&VN Geriatrics & Gerontology). Also senior organisations and organisations for informal caregiver support should raise awareness among older adults and caregivers that it is important to prepare for and to participate in SDM. In cooperation with different stakeholders, I developed and applied several implementation strategies to reach this aim which I will describe below.

### **Health professionals**

Our first step in facilitating a larger group of health professionals, and in particular geriatricians, in SDM was to use an existing online platform to digitalize the SDM<sup>MCC</sup> training, by creating interactive online scenarios in which consultations with older adults are translated into conversations with virtual training actors. The online SDM<sup>MCC</sup> training has been piloted at the department of geriatrics in five other Dutch hospitals and is now free available for all health professionals (<https://samenbeslissen.dialoguetrainer.com/>). In addition to the original training, the online training includes 3 follow ups and contains a self-assessment for geriatricians. They are encouraged to assess their own audiotapes of real life consultations with an adapted practice version of the observer OPTION<sup>MCC</sup>. Furthermore, together with the Dutch Geriatric Society (NVKG) and the Dutch Nurses Society (V&VN Geriatrics & Gerontology) and the largest Dutch senior organisation KBO-PCOB, we initiated an implementation programme to facilitate both health professionals as well as older adults and their informal caregivers



in SDM with the TOPICS-SF (a short version of the TOPICS-MDS). Within the implementation programme geriatricians use the online training to train in SDM. Also, a toolbox has been created, containing change management information but also communication tools such as posters, postcards, reminders, patient information, infographics, etc. The toolbox is free available at [www.zorgvoorbeter.nl/samenbeslissen](http://www.zorgvoorbeter.nl/samenbeslissen).

### Older adults with MCCs

Our aim is to empower older adults to prepare for a consultation and to share their priorities on personal health outcomes with health professionals. To this aim we adapted the layout of the patient preparatory tool to align with the implementation of the TOPICS-SF and in coordination with the Dutch patient association we aligned the layout to the national 'Ask3questions' campaign to enhance the recognizability for the Dutch older population. Furthermore, we developed a short, animated information film, to inform and motivate older adults to prepare for SDM with help of the TOPICS-SF. Also, similar as the online training platform for health professionals, we developed, in co-creation with older adults, a scenario with conversations with a virtual trainings 'doctor' (De Oefendokter). 'De Oefendokter' is free available in the same portal: <https://samenbeslissen.dialoguetrainer.com/>

Within the implementation programme we work closely together with the Dutch senior organization KBO-PCOB and NOOM, the Dutch organization for older migrants. The KBO-PCOB has 800 local organisations. They provide both online and offline information sessions to inform older adults and informal caregivers about SDM and the importance to prepare for a conversation with the health professional. Finally, we published in May 2020 an information article about SDM for older adults in the KBO-PCOB magazine (250.000 circulations)<sup>69</sup>.

### Informal caregivers

This dissertation showed that informal caregivers should be empowered to participate in SDM. To this aim we want to raise awareness of their role and possible challenges in SDM. Together with the Dutch caregivers association MantelzorgNL we published in Oct 2019 an article in their magazine about how informal caregivers could participate in SDM and we developed a list of 'eight tips for caregivers in SDM' (50.000 circulations)<sup>70</sup>. Also MantelzorgNL provides support for overburdened informal caregivers. Furthermore, in the SDM<sup>MCC</sup> e-learning for geriatricians (that we developed based on the SDM<sup>MCC</sup> training) we addressed the role of informal caregivers in one special part of the e-learning (follow-up 3). Finally, as mentioned above, the Dutch senior organization KBO-PCOB organized information sessions throughout the Netherlands to empower both older adults as well as informal caregivers to prepare for and participate in SDM.

## Conclusion

The person-centred care that is needed for older adults with MCCs should be guided by personal health outcomes. When the SDM starts with the exploration of personal health outcomes, this directs the following SDM steps as presenting and discussing options to decisions that align with the older adult's desired personal



health outcomes. The findings of this dissertation emphasize that older adults with MCCs should be more explicitly invited to participate in SDM, and that their personal experiences and knowledge about their personal situation is important to share with the health professional. PROMs that provide insight into personal health outcomes of older adults provide input for the discussion of personal health outcomes goals. Such a PROM should include the health domains as the older adults stated in our studies: functional limitations, emotional well-being, social functioning, quality of life, coping with stress and coping with the effect of their health status on daily life. The added value of the observer OPTION<sup>MCC</sup> compared to other SDM measurements is that it measures triadic decision-making (including the participation of patients and informal caregivers) and that it measures items that are particularly relevant for older adults with MCCs, such as goal talk. The SDM<sup>MCC</sup> intervention proved feasible in daily clinical practice, although the effects could be enhanced by tailoring both geriatric training and the preparation tool for older adults to individual needs. Since we found that increased participation in SDM leads to less decisional conflict among older adults with lower health literacy, we recommend that a brief health literacy assessment is made prior to the consultation so that the geriatrician can tailor the communication for this patient. Based on this dissertation, we recommend adding to the current implementation strategy change management tools, such as designing patient journeys for the local situation. Finally, our findings also lead to new research questions, such as exploring the complex role of informal caregivers in SDM, how the scope of SDM can be broadened from clinician focused to other health professionals in the care for older adults, and how goal based SDM can be further developed.

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