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### Improving online health information provision for older cancer patients

*Online health information usage and its influence on patient outcomes*

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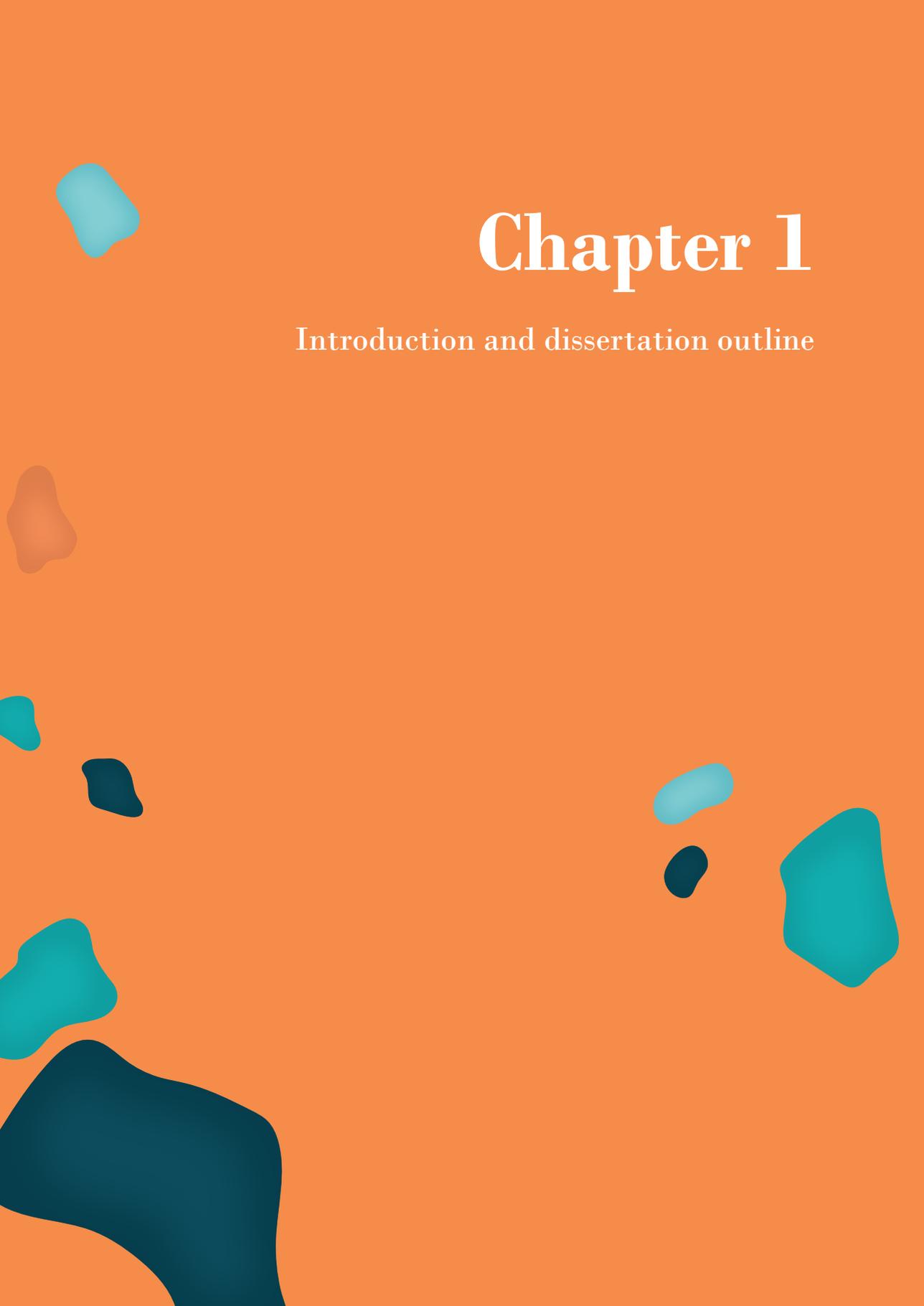
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# Chapter 1

Introduction and dissertation outline



## Introduction and dissertation outline

Cancer is a disease that is common in older individuals (American Cancer Society, 2020; IKNL, 2020). In the last decade, the cancer incidence rate increased in individuals over 65 years and older, and especially in individuals between 70 and 75 years old (IKNL, 2021). This trend is expected to continue the coming years, since the Dutch population will include an increasing number of older individuals (CBS, 2020). Effective health communication is key to good health outcomes (Richard et al., 2017; Street et al., 2009). Since effective communication during medical consultations with older cancer patients can be complicated (Sparks & Nussbaum, 2008), the increase in older patients with cancer means that healthcare providers will be faced more often with challenges regarding communication with these patients.

Communication with older patients during consultations involves difficulties because of several reasons. First, age-related decreased cognitive functions (Cohen et al., 2017; Noordman et al., 2017; Sparks & Turner, 2008; Sparks & Nussbaum, 2008) may impede older patients' adequate information processing during medical consultations (Sparks & Nussbaum, 2008) and subsequent recall of information provided to the patient during these consultations (Jansen et al., 2008; Nguyen et al., 2018). Second, older patients ask less questions during consultations, resulting in healthcare providers sharing less information with older patients than with younger patients (Goss et al., 2015), which could further hamper effective communication during consultations. On top of that, healthcare providers' stereotypes of older patients, especially the perception that older patients are incompetent and unfit to deal with their medical condition (Chodosh et al., 2000; Higashi et al., 2012), can also lead to healthcare providers sharing little information with older patients and using simple language to discuss medical information.

These age-related issues complicating communication between healthcare providers and older patients are problematic because it could inhibit informed decision making. Nowadays, older cancer patients are increasingly asked to participate in treatment decisions (Hawley & Jagsi, 2015). The ability to correctly recall information provided to patients is seen as an important prerequisite to make an informed treatment decision (Gaston & Mitchell, 2005). Therefore, age-related cognitive declines could also negatively affect informed treatment decision making. Aside from age-related issues complicating information processing during consultations, older patients are already more prone to make less informed treatment decisions (Meyer et al., 2007), since cognitive declines also complicate decision processes such as deliberate reasoning (Bruine de Bruin et al., 2012; Finucane & Gullion, 2010; Mata et al., 2007; Mata et al., 2010; Mata et al., 2012).

Acquiring relevant information could help patients to make informed treatment decisions both directly and indirectly via patient outcomes related to decision making such

as satisfaction and information recall (Gaston & Mitchell, 2005). Even though healthcare providers are still the most important information source for patients with cancer, the internet is often used as complementary information source to acquire additional information (Barnes et al., 2017). Online health information seeking, i.e. seeking online for information about one's medical condition, prognosis, and/or treatment options, can reduce uncertainty and/or increase understanding about one's health situation (Cotten & Gupta, 2004). Thus, acquiring online health information can improve patient outcomes and support informed decision making. Nowadays, almost half of the older adult Dutch population over 65 years old (51.8%) uses the internet to seek for health information (CBS, 2020) and previous research showed that more than half (60%) of the patients diagnosed with cancer searched for online information about their illness (van Eenbergen, 2020). Although engaging in online health information seeking can be helpful for patients of all ages, seeking online health information might benefit older patients in particular because it can reduce the negative consequences of age-related declines.

For patients, online health information can serve different purposes. First, patients' information needs are relatively high before consultations with healthcare providers in which treatment decisions will be made (Vogel et al., 2008). For example, patients often turn to the internet to find information specifically to support them in making a decision about their treatment (Linn et al., 2019). Sometimes, patients are offered specific online decision aid instruments by healthcare institutions, in which benefits and harms of different treatment options are presented, to help them make such treatment decisions (Stacey et al., 2017). However, if patients are not provided with specific instruments or still experience high information needs after using such instruments, these needs will possibly drive them to seek additional online health information to prepare for the upcoming consultation (Linn et al., 2019; Tan & Goonawardene, 2017). Second, after consultations with healthcare providers patients can experience information needs that arose as a result of discussing their illness or treatment with the healthcare provider (Puts et al., 2012). For example, patients could use the internet to check upon the information they received during consultations or to find additional information (Linn et al., 2019; Puts et al., 2012).

Online health information as complementary source to information received during medical consultations has the potential to increase patients' knowledge about their medical condition or treatment options, and could thereby positively influence cognitive, affective and behavioral patient outcomes (Lambert & Loiselle, 2007; Tan & Goonawardene, 2017). For example, online health information can increase knowledge and recall of information regarding illness or treatment options (Castro et al., 2016; Tan & Goonawardene, 2017). Feeling well-informed, because of the online health information found, could decrease anxiety levels (Jiang & Street, 2017; Lambert & Loiselle, 2007) and

empower patients to actively participate during consultations with healthcare providers (Tan & Goonawardene, 2017), which could subsequently increase their satisfaction with encounters with healthcare providers (Jackson, 2005). Furthermore, several of these patient outcomes have proven to be important for making informed treatment decisions, such as satisfaction (Bol et al., 2013; Bol et al., 2014; Park & Lim, 2007), information recall (Gaston & Mitchell, 2005), and patient participation (Vogel et al., 2009).

### **Age related difficulties with seeking online health information**

Previous research hardly focused on the effects of online health information seeking in older cancer patients (Castro et al., 2016; Gaston & Mitchell, 2005; Jiang & Street, 2017; Lambert & Loiselle, 2007; Tan & Goonawardene, 2017). Even though online health information seeking in older patients could lead to positive outcomes, both cognitive and motivational aspects of age-related changes in older patients can complicate the process of seeking online health information. First, older patients' cognitive decline in working memory and information processing capacity (Bruine de Bruin et al., 2012; Finucane & Gullion, 2010; Mata et al., 2007; Mata et al., 2010; Mata et al., 2012) may cause older patients to experience difficulties with evaluating, understanding, and recalling the health information found online (Sparks & Nussbaum, 2008; van Gerven et al., 2002). The age-related reduced cognitive functioning causes older individuals to experience difficulties with understanding factual and numerical medical information (Hibbard et al., 2001). Moreover, from a motivational perspective, according to the socioemotional selectivity theory, emotional objectives become more salient than cognitive objectives when the end of life is near (Carstensen, 2006; Lockenhoff & Carstensen, 2004). Thus, older individuals tend to rely less on factual information and more on social and emotional information (Becker, 2004; McInnes & Haglund, 2011). The age-related cognitive and motivational changes complicate seeking for and navigating through online health information (Bolle et al., 2016).

These age-related difficulties with seeking, processing, understanding and recalling online health information can hamper possible positive effects of older patients' online health information use. For example, misunderstanding online health information has been found to increase confusion (Anderson et al., 2003; Linn et al., 2019), which could lead to distress and anxiety (Baumgartner & Hartmann, 2011; Rising et al., 2015), possibly making older patients less comfortable to participate during consultations. This is problematic, since older patients already tend to engage less during consultations (Goss et al., 2015) and active participation during consultations can enhance informed decision making (Vogel et al., 2009). In addition, these age-related difficulties could negatively

influence information recall, and thereby also hinder informed decision making further (Bopp & Verhaeghen, 2005; Gaston & Mitchell, 2005; Marteau et al., 2001; McGuire, 1996).

It is still unclear how older cancer patients' online health information use influences patient outcomes such as anxiety, patient participation, satisfaction with the information, information recall and informed decision making. Thus, age-related factors should be considered while investigating if the previously found positive effects of online health information also emerge for older cancer patients. The first aim of this dissertation is, therefore, to gain insight into the effects of spontaneous online health information seeking of cancer patients on patient outcomes, while taking age into account.

## **Developing online health information tools for older cancer patients**

Unfortunately, health information that older patients with cancer come across online is not necessarily adapted to their abilities (Bolle et al., 2016; van Weert et al., 2016), which further reduces the chance of positive consequences and could make online health information seeking problematic for older patients with cancer. However, since approximately half of the older individuals use the internet to find additional information, the internet is a potential promising medium for health information provision. To mitigate the possible negative consequences of older cancer patients seeking for online health information, online health information tools should be specifically developed for, and provided to these patients. For the development of such targeted online health information tools, the way in which the information is presented should be adapted to patients' age-related impairments. Based on the specific age-related changes in cognitive functioning and motivation, two communication strategies seem especially promising to incorporate in online health information tools aimed at older patients with cancer.

### **Presenting online health information in multimedia or multimodal format**

The first communication strategy is based on the multimedia principle, described by Mayer (2002). According to the cognitive theory of multimedia learning, presenting health information in multimedia format is more effective in terms of learning than information presented via one media format (Mayer, 2002). Multimedia information can be divided into information comprising multiple media presentation modes, for example a visual presentation mode (i.e. animations, videos, photos or illustrations) and a verbal presentation mode (i.e. written or spoken text), or information comprising multiple sensory modalities, for example auditory information and visual information

(Mayer, 2002). For clarity purposes in this dissertation, information comprising multiple media presentation modes will from now on be called ‘multimedia information’ and information comprising multiple sensory modalities will from now on be called ‘multimodal information’.

Addressing the age-related cognitive declines, the cognitive theory of multimedia learning states that multimedia information is processed via different processing channels, for example information that will be processed verbally, such as spoken or written text, combined with information that will be processed visually, such as illustrations, decreases the risk of cognitive overload in one of these processing channels, resulting in less overall cognitive load (Mayer, 2005; Paas et al., 2005; van Gerven et al., 2002). With regards to multimodal information, the modality principle states that auditory and visual information are processed through separate sensory systems. By providing information that addresses more than one sensory system (i.e. hearing, seeing, feeling), cognitive overload in one of these systems is again less likely to occur. Researchers have demonstrated that multimedia information can increase satisfaction with health information and in turn improve information recall (Bol et al., 2014). Besides, previous studies showed that multimodal information is also effective in terms of increasing satisfaction with the information and information recall of online health information (Bol et al., 2013; Bol et al., 2015; Meppelink et al., 2015).

Older patients are expected to particularly benefit from the multimedia principle and the modality principle since age-related limited cognitive functioning could be bypassed by presenting multimedia or multimodal information which could decrease cognitive load (Paas et al., 2005). Considering age-related motivational issues, multimedia and multimodal information could increase satisfaction with the information (Bol et al., 2013; Bol et al., 2014; Dunn et al., 2004) and motivation to process information (Bekker et al., 2013), possibly improving information recall (Petty & Cacioppo, 1986). These positive effects on satisfaction and recall could subsequently improve making informed treatment decisions (Gaston & Mitchell, 2005; Marteau et al., 2001).

### **Presenting online health information in narrative format**

The second communication strategy focusses on addressing age-related declines by presenting online health information as narratives, or information presented in a personal and conversational style (Bilandzic & Busselle, 2011; Kreuter et al., 2010; McQueen et al., 2011). From a cognitive perspective, presenting information in narrative format can improve learning. According to the indexing theory, linking new information to similar information already stored in an individual’s memory helps with correctly recalling this information later on (Chank & Berman, 2002). In a narrative, new pieces of information

are linked to narrative elements that are similar to ideas and experiences already existing in an individual's memory. Thereby, presenting information in a narrative format can help patients to organize complex medical information, making it easier to recall this information later on (Davidhizar & Lonser, 2003; Schank & Berman, 2002).

From a motivational perspective, narrative online health information can positively influence satisfaction with the information (Bol et al., 2013), which in turn can increase motivation to process information (Bekker et al., 2013) and thereby improve information recall (Petty & Cacioppo, 1986). Especially, since older patients rely more on affective information than on cognitive information (Peters et al., 2007; Peters et al., 2008), presenting online health information in a narrative style fits their preference for affective information, possibly increasing motivation to process the information. Therefore, including narrative information could positively facilitate effective information processing and increase informed treatment decision making for older patients with cancer.

Previous studies showed that multimedia or multimodal and narrative information can be effective in increasing satisfaction (Bol et al., 2013) and information recall (Bekker et al., 2013; Bol et al., 2015) within the context of online health information, yet these studies did not necessarily focus on the value of multimedia or multimodal information and narratives for older cancer patients, compared to younger cancer patients within the context of medical decision making. Therefore, the second aim of this dissertation is to test two promising communication strategies, i.e. multimedia/multimodal information and narrative information, in an online decision aid tool, in terms of satisfaction, information recall and informed decision making, to improve online health information provision for (older) cancer patients.

## **Promising features in online health information tools for older cancer patients**

To further increase the effectiveness of online health information tools for older patients with cancer, specific features that address the reasons why patients use online health information should be considered. As described above, online health information is mainly used by patients to inform and prepare themselves before consultations (Linn et al., 2019; Tan & Goonawardene, 2017) or to check information or search additional information after consultations (Puts et al., 2015). Therefore, online health information tools specifically developed for older cancer patients should also serve these purposes.

Several features are promising to support patients in preparing for consultations with healthcare providers. First, adding structured lists of questions about the disease, medical tests or treatment options, also called question prompt lists (QPL), could be especially

effective to stimulate patients in participating actively during consultations (Brandes et al., 2015; Dimoska et al., 2008). Providing patients with such a QPL feature is known to positively influence question asking by patients during consultations (Driesenaar et al., 2020) and improve recall of the information discussed during consultations (Brandes et al., 2015). In addition, the use of QPL by patients could result in lower anxiety levels before and after the consultation (Brandes et al., 2015). Second, adding a decision support feature with questions patients could use to weigh advantages and disadvantages of different treatment options could help patients prepare for the decision making process (Stacey et al., 2017). Such decision support features have the potential to improve knowledge and informed decision making (McAlpine et al., 2018; O'Brien et al., 2009; Stacey et al., 2017).

To offer older patients the possibility to check information provided during consultations, an audio-facility feature, i.e. a feature that creates the possibility for patients to listen back to an audio-recording of their consultation, could be valuable (Driesenaar et al., 2020). Such audio-facilities are known to be positively evaluated by patients (Driesenaar et al., 2020) and can be especially beneficial for older cancer patients who may find it hard to recall information given during consultations with healthcare providers (Jansen et al., 2008; Nguyen et al., 2018).

Lastly, implementing a self-tailoring feature in online health information tools might be valuable for older cancer patients. A self-tailoring feature allows for the tool to be adjusted to, or tailored to, specific individual differences in information preferences (Bol et al., 2020). Such a feature is expected to be especially effective for older cancer patients because it can increase attention and comprehensibility, and thereby improve satisfaction with and recall of the information presented in the tool (Nguyen et al., 2017; Nguyen et al., 2018). This leads to the third aim of this dissertation; to systematically develop and implement an online health information tool for (older) cancer patients including promising communication strategies and features, and evaluate the tool in terms of patient outcomes.

## **Aim and dissertation outline**

The overall goal of this dissertation is to improve online health information provision for older cancer patients. To achieve this goal, this dissertation addresses three main aims. The first aim is to gain insight into the consequences of spontaneous online health information seeking of (older) cancer patients, on patient outcomes that are important for informed decision making. Second, this dissertation aims to test two promising communication strategies for (older) cancer patients, i.e. multimedia (written verbal information combined with illustrations) and multimodal information (spoken verbal

information combined with animations) and narrative information, within an online decision support tool, in terms of patient outcomes related to informed decision making. The third and final aim is to develop and implement an online health information tool for (older) cancer patients, including promising communication strategies and features, and to evaluate this tool in terms of patient outcomes related to decision making. In all studies described in this dissertation, online health information is seen as an information source used by patients to gain additional knowledge, aside from information provision during consultations with healthcare providers, to make informed treatment decisions. Therefore, throughout this dissertation, online health information is evaluated in terms of patient outcomes related to informed decision making.

## Outline

This dissertation consists of four chapters with each chapter addressing a different study to achieve the goal of improving online information provision for older patients with cancer. In **chapter 2**, results of a clinical, observational field study are described, which provides insight into spontaneous online health information seeking behavior of (older) cancer patients and its consequences. In **chapter 3** and **chapter 4**, two experimental studies are described in which communication strategies that could improve online health information for (older) cancer patients were tested. In the first experiment the effectiveness of animations with spoken verbal information and narrativity of the information were tested, whereas in the second experiment the effectiveness of a static illustration with written verbal information and narrativity of the information was studied. **Chapter 5** describes the development, implementation and evaluation of an online health information tool for (older) cancer patients in a clinical pilot RCT. See Figure 1.1 for a visualization of the studies.

In the clinical field study described in **chapter 2**, first, it is investigated which patients engage frequently in spontaneous online health information seeking, taking into account demographic (i.e. age, gender and education level) and psychosocial (i.e. cancer-related stress, anxiety levels before the consultation and coping style) patient characteristics. Second, it is studied how spontaneous online health information seeking influences patient outcomes (i.e. patient participation during a consultation, anxiety after the consultation, satisfaction with the consultation, and recall of the information provided during the consultation), and whether these effects differ depending on the patient's age. The goal of this study is to observe and better understand the consequences of (older) patients spontaneous online health information seeking on patient outcomes related to informed treatment decision making.

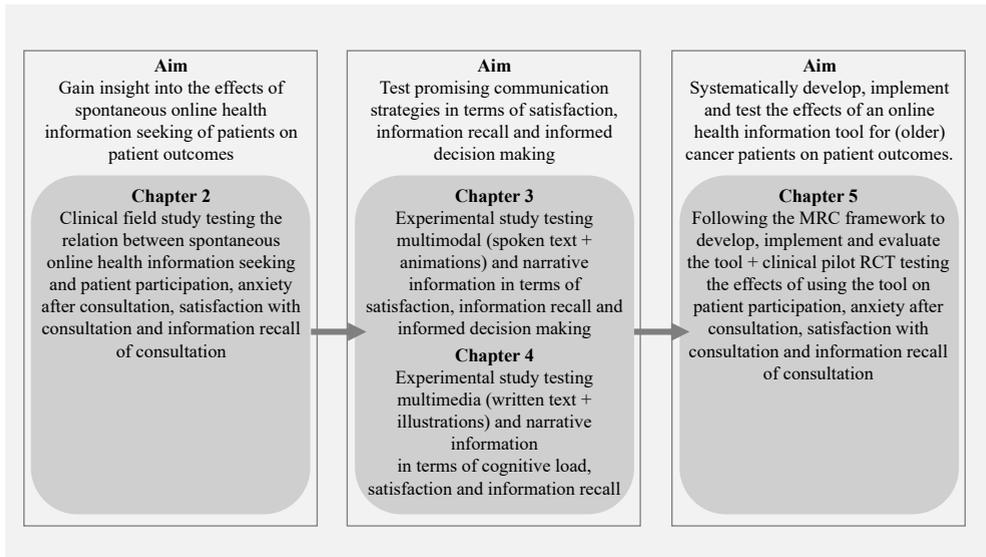


Figure 1.1. Dissertation outline including aims and studies.

After gaining insight into (older) cancer patients' spontaneous online health information seeking behavior and its consequences, **chapter 3** and **chapter 4** focus on improving online health information for (older) cancer patients. Both of these chapters describe an experimental study in which two promising communication strategies to present online health information to (older) cancer patients, multimodal or multimedia information and narrative information, are tested in terms of outcomes related to informed decision making. In **chapter 3**, the effects of multimodal (spoken verbal information combined with animations) and narrative information are investigated in terms of satisfaction with the information, information recall and informed decision making, while taking into account patients' age. In **chapter 4**, the effects of multimedia (written verbal information combined with illustrations) and narrative information are investigated. The study described in **chapter 4** functioned to get a deeper insight into underlying processes explaining why multimedia and narrative information presentation strategies could be effective by looking at the role of cognitive load. Besides, in this chapter differences in patient characteristics (age and decision-making style) are taken into account to get a better understanding for which patients these strategies could be most beneficial. Furthermore, a secondary goal of **chapter 4** is to replicate the results of **chapter 3** with regards to narrative information and expand the results of **chapter 3** with regards to multimedia information instead of multimodal information by testing a comparable, but more affordable strategy (verbal information combined with cognitive or affective illustrations rather than animations).

These previous chapters lead to **chapter 5**, describing how an online health information tool, the Patient Navigator, was developed for (older) cancer patients, implemented and evaluated, following the four phases of the MRC framework. The Patient Navigator includes promising communication strategies and features that could further increase the effectiveness of the tool. Patients who receive the Patient Navigator evaluate the tool in terms of user experience (i.e. satisfaction, involvement, cognitive load, active control, perceived relevance of the tool) and their usage is monitored by a built-in tracker. It is specifically investigated whether usage of the Patient Navigator is effective in improving patient participation, decreasing anxiety, increasing satisfaction with the consultation, and improving information recall of the information given during the consultation.

In the final chapter, **chapter 6**, the results of the previous chapters are summarized and reflected upon. The results of this dissertation will be discussed in light of the already existing body of literature, while providing directions for future research and presenting practical implications for improving online health information provision for (older) cancer patients.