SUMMARY
Chapter 1 presents the general introduction of this thesis. First, this chapter provides a description of head and neck cancer and its treatment options, as well as a description of the impact of this type of cancer on patients’ health related quality of life (HRQOL). Secondly, the use of patient reported outcome measures (PROMs) to measure HRQOL in clinical practice is described as well as supportive care services and self-management options. Specific attention is paid to enhance accessibility of supportive care services and self-management through eHealth. Participatory design principles are described that are expected to optimize the effectiveness and usefulness of the eHealth applications. In chapter 1 the two main eHealth self-management applications in this thesis are presented: OncoQuest and Oncokompas. After this introduction, the goal of this thesis is described: to investigate the usefulness of online applications to monitor HRQOL by means of PROMs in HNC survivors, in terms of needs, usability, feasibility, adoption, usage, reach, satisfaction and long-term implementation, and factors that may influence the usefulness of these applications. Also, the hypotheses of this thesis are presented: (1) not all cancer survivors are reached by PROMs, but PROMs are mainly used by cancer patients with many symptoms and needs, (2) survivors are positive towards eHealth applications, but independent use is limited, and (3) by using participatory design principles in the development of eHealth applications, the feasibility of these applications is optimized.

In Intermezzo OncoQuest, the first of the two main (eHealth) self-management applications that were investigated in this thesis, OncoQuest, is described. OncoQuest is a touch-screen computer assisted system to monitor health related quality of life via patient reported outcome measures. It is usually followed by a consultation with the nurse to discuss the results of the screening. OncoQuest is available at the outpatient clinic in a separate consultation room with dedicated touch screen computers.

Chapter 2 describes the long-term follow-up of implementing PROMs in clinical practice using OncoQuest to monitor HRQOL in HNC survivors investigated via a mixed-methods design. The usage rate of OncoQuest and the subsequent nurse consultation were calculated among HNC survivors who visited the outpatient clinic for regular follow-up appointments. Differences between ever-users and never-users of OncoQuest were investigated, as well as the content of the nurse consultation. Reasons for not using (barriers) or using (facilitators) OncoQuest and the nurse consultation were explored from the perspective of HNC patients, and of head and neck surgeons.
Usage rate of OncoQuest was 67% and subsequent usage of the nurse consultation 79%. Tumor subsite and tumor stage were significantly related to usage of OncoQuest. The most frequently discussed topics during the nurse consultation were global quality of life (97%), head and neck cancer related symptoms (82%), other physical symptoms as pain (61%) and psychological problems as anxiety. The conclusion of the study was that 5 years after implementation, usage of PROMs in clinical practice combined with a nurse consultation is durable. This study contributes to better insight into long-term follow-up of implementation, thereby guiding future research and projects that aim to implement PROMs in clinical practice to monitor HRQOL among (head and neck) cancer patients.

Chapter 3 reports on the potential increase in Internet use and Internet use to search for cancer related information in HNC survivors between 2007 and 2015. It also describes the survivors that are most likely to use Internet, preferences of survivors towards future use of eHealth, and the use of eHealth in 2015. HNC survivors completed questionnaires. Factors associated with (cancer-related) Internet use were investigated using stepwise logistic regression analyses. Results showed that Internet use among HNC survivors increased from 53% in 2007 to 79% in 2015. The Internet was used to search for information on cancer by respectively 46% and 59% of these survivors. In 2007, survivors that were most likely to use the Internet were younger survivors, and survivors with a tumor originating from the oral cavity. In 2015, younger survivors, survivors with a higher educational level and survivors with a partner used the Internet more often. Also, in 2015 survivors with a higher educational level used the Internet more often to search for information on cancer. Future use of eHealth was appealing to many survivors in both samples (2007 range: 21%-68% and 2015 range: 16%-71%). The use of eHealth in 2015 was limited (range: 0-10%). The results of this study indicate that Internet use among HNC survivors has increased strongly. Internet was especially used to search for information on cancer. Since many survivors were interested in future eHealth use, attention should be paid to ensure adequate awareness among HNC survivors.

Following participatory design principles, in chapter 4 the needs of cancer survivors towards an eHealth application monitoring quality of life and targeting personalized access to supportive care were investigated through a qualitative study. In total, 30 cancer survivors (15 HNC, 15 breast cancer) were interviewed regarding their unmet needs during follow-up care and the potential of an eHealth application. Data were
analyzed independently by two coders and coded into key issues and themes. Cancer survivors mentioned they felt unprepared for the post-treatment period, and that often their remaining symptoms remained unknown to HCPs. They also mentioned that referral to supportive care services was suboptimal. An eHealth application had various advantages according to survivors interviewed; insight into the course of symptoms by monitoring, availability of information between follow-up appointments, and receiving personalized advice and tailored supportive care options. Cancer survivors identified several unmet needs during follow-up care. Most survivors were positive towards the proposed eHealth application and expressed that it could be a valuable addition to current follow-up cancer care. The study results provide insight into barriers that impede survivors from obtaining optimal supportive care. This study also provides insight into the characteristics needed to design, build and implement an eHealth application targeting personalized access to supportive care from the survivors’ perspective.

Chapter 5 describes the perspectives of HCPs toward follow-up care and the possibility of an eHealth application in follow-up care, that monitors HRQOL by means of PROMs, followed by personalized advice and feedback on available supportive care options. The study consisted of three steps. In step 1, HCPs were interviewed on current follow-up care and the anticipated value of an eHealth application. In step 2, a prototype of the eHealth application was developed following the results from the current needs assessment among HCPs and the previous needs assessment among cancer survivors described in chapter 4. In step 3, cognitive walkthroughs (CWs) were conducted with the HCPs to investigate the perceived usability of the application. Several barriers in current follow-up care were identified by HCPs, such as difficulties in detecting survivors’ symptoms, survivors’ perceived need for supportive care, and a lack of time to discuss opportunities of supportive care with survivors. An eHealth application was expected to be of added value to follow-up cancer care, and HCPs expected it could support survivors in obtaining supportive care tailored to their needs. The CWs of the prototype of Oncokompas emphasized the importance of tailoring care. HCPs considered the navigation structure of Oncokompas to be complex. The opinion of HCPs towards the optimal strategy to implement the application in clinical practice differed (as a self-management application vs. a supported self-management application), but all HCPs agreed that the application should be incorporated in the HNC care pathway to ensure all survivors can benefit. The conclusion from the study was that HCPs experienced several barriers in directing patients to supportive care. They
were positive toward the development and implementation of an eHealth application and expected it could support survivors in obtaining supportive care tailored to their needs. The CWs revealed several points for optimizing the application prototype and developing an efficient implementation strategy. Including HCPs in an early phase of a participatory design approach is valuable in developing an eHealth application and an implementation strategy meeting stakeholders’ needs.

In *Intermezzo Oncokompas*, the development cycle of the self-management application Oncokompas is described. In Oncokompas, cancer survivors can monitor their HRQOL via PROMs, which is followed by automatically generated individually tailored feedback, and personalized advice on supportive care. Also, the results of the usability study that was conducted with Oncokompas are described.

In *chapter 6* the feasibility of Oncokompas was investigated among HNC survivors, through a pretest-posttest design study. A survey was conducted among survivors before providing access to Oncokompas, and two weeks after, followed by an interview by a nurse. Implementation was defined as the percentage of participants that actually used Oncokompas as intended. General satisfaction was assessed based on the mean score of 3 study specific questions: 1) general impression of Oncokompas, 2) the user-friendliness, and 3) the ability to use Oncokompas without assistance (10-point Likert scales). Furthermore, satisfaction was measured with the Net Promotor Scale (NPS). Oncokompas was found feasible with a good adoption grade (64%), implementation grade (75-91%), and mean satisfaction score of 7.3, and a positive Net Promotor Score (1.9). No relationship was found between socio-demographic and clinical factors and HRQOL with satisfaction. The study revealed several facilitators and barriers regarding the feasibility of Oncokompas. In conclusion, Oncokompas was found feasible, but several areas for improvement were mentioned, including balancing the time it takes to use Oncokompas, measurement precision, and tailoring towards personalized advices.

Finally, in *chapter 7*, the main findings, methodological considerations and clinical implications are addressed and recommendations for future research are given. The main findings as described in this chapter follow the hypotheses that were stated in the introduction. First, this chapter elaborates on the finding that the use of PROMs in clinical practice by means of a computer-assisted PROMs system (OncoQuest) is feasible and durable in clinical practice, and that mainly survivors with many
symptoms and supportive care needs seem to use this application. Secondly, the option is discussed of a home-based online self-management application to overcome the logistical barriers that may impede survivors from using an application at the outpatient clinic. To improve survivors’ HRQOL, feedback following PROM collection is essential; therefore an online application should provide automated tailored feedback to be of additional value. Recommendations for future research include further investigation of (possible moderators that influence) the effectiveness and barriers and facilitators regarding adequate implementation of interventions like OncoQuest and Oncokompas, to enhance the reach and adoption of these applications in routine care.

Overall, it is concluded that both a computer-assisted PROMs system at the outpatient clinic (OncoQuest) and an online home-based application (Oncokompas) are useful tools that supplement supportive care provided by health care professionals.