Addendum

**Impact Paragraph**

The impact of being diagnosed with esophageal cancer (EC) is high, because patients have to deal with the consequences on physical and nutritional status and ultimately on quality of life, especially during the preoperative period. A digital self-management support tool (DSMST) could be a solution to support EC patients in their self-management during this period. However, there is still a lack of research focusing on digital interventions to support self-management in patients with (esophageal) cancer. Hence, there’s a demand for new knowledge regarding the experiences and needs of self-management supportive care of patients with potentially curable EC planned for surgery and to investigate their preferences towards DSMSTs. Therefore, the main aims of this thesis were to:

I. Explore the effectiveness of digital self-management support interventions in the care plan of cancer patients
II. Evaluate the outcome of a web-based self-management intervention for esophageal cancer patients in the preoperative phase
III. Investigate the (digital) self-management support needs and requirements of esophageal cancer patients in the pre- (and post) operative care.

This thesis has provided an improved understanding of the (digital) self-management support needs and requirements of esophageal cancer patients during the pre- (and post) operative phase.

**Self-Management (Support) for Patients with Esophageal Cancer**

To define optimal support for patients during esophageal cancer care, both the patient and the HCPs perspective is needed. While HCPs aim to provide the best available care from a ‘medical point of view’, patients know what is best from a ‘personal point of view’.

In this thesis, a core information set was developed that includes the most relevant self-management information topics to support self-management in the preoperative phase of patients with EC, by performing two Delphi studies and combining the perspectives of patients and HCPs. The core information set should be used in the adaptation of patient education materials (flyers, patient information leaflets) and during consults, because in this core set also the patient’s perspective is explored. Furthermore, when HCPs and patients continue to blend their perspectives, they can learn from each other’s perspectives and take them into account in the future. Moreover, the way we addressed this improvement to define optimal support for patients with esophageal cancer may also be suitable to optimize support for patients with other types of cancer.
Given the growing emphasis on patients’ ability to manage their own health, it is crucial that the information they receive suits their needs and is provided through the relevant source. Therefore, a number of aspects are also important:

For patients, it is important to continue to indicate their needs, for example during consultations. Every patient is different, with his or her needs, and over time these needs may also change. Only when a patient continues to indicate what is important, the healthcare professional can adapt accordingly. In addition, it is also important that patients’ experiences are shared outside the consulting room, i.e. increasing involvement of patients in the education of HCPs and students. Active involvement of patients helps learners develop new knowledge, skills and attitudes contributing to person-centeredness and can make education more responsive to patients’ needs [1].

Patient associations can also play an important role in the acquisition of knowledge. First of all by adapting the general information shared with patients based on the Delphi studies, but above all by drawing patients’ attention to the importance of self-management, and indicating their needs, so that HCPs can respond accordingly.

Self-management support requires prepared, proactive multidisciplinary teams. That is, multidisciplinary teams that understand the rationale for self-management support and hold positive beliefs about the individual’s ability to self-management. In addition, they should have the knowledge and skills to provide such support [2]. Therefore, it is important that self-management and self-management support and the use of digital technology become part of the basic education of all HCPs involved with esophageal cancer patients, as well as in postgraduate education.

**Digital Self-Management (Support) for Patients with Esophageal Cancer**

With regard to the results in this thesis, differences between patients with esophageal cancer in their expectations and needs regarding self-management, self-management support and DSMSTs are found, indicating that no single approach will meet the needs of all patients at all points in time. It is of interest to adopt a diversity of types of support, with regard to the increased desire to deliver person-centered care and the fact that no one approach will meet the needs of all patients at all points in time.

The development of a new (digital) self-management support intervention to support patients with EC may be informed by the results from the different studies in this thesis, in which source, content and intensity are tailored with respect to the characteristics of the patient and their individual needs. The findings of this thesis provide important
insights that can offer starting points to address this challenge for future research, development and implementation of new interventions.

**Dissemination of Knowledge**

Dissemination of knowledge was performed by informing HCPs (e.g. surgeons, dieticians, physical therapists, oncologists, oncological nurses/case managers, nurse practitioners/physician assistants, gastroenterologists, radiotherapists) involved in the studies about the results, through presentations of the results under open-access licenses in scientific journals, and through presentations of the results to specialized nurses of V&VN (Dutch professional association of nurses and caretakers), and at national and international conferences.

Knowledge was also shared within education: as part of this thesis, Fontys ICT students were given the opportunity to develop a digital tool together with Fontys nursing students. The project allowed the students to look beyond the very boundaries of their own field, which provided a unique experience and is a very instructive experience for the future. Furthermore, the new knowledge gained with regard to self-management and self-management support and the use of digital technology in healthcare was used directly in the basic education of physical therapy students. In addition, teachers involved in the basic education of paramedic students were informed through presentations of the study results. Lastly, in 2020 a care innovation center (‘professionele werkplaats) was established at the Catharina Cancer Institute of the Catharina Hospital Eindhoven. This care innovation center forms an open and professional authentic learning and research environment, that enables ongoing innovation [3]. This innovation center is a collaboration between the Catharina Cancer Institute and Fontys University Eindhoven and has created a place for learning, together with professionals, students and teachers from reflection. This involves 2 nursing departments (surgical oncology and multidisciplinary oncology) where HCPs intensively collaborate with a large group of students for the purpose of research, education and innovation. The experiences and results from this thesis will thereby be used as a basis for further research within this innovation center, with the innovation center’s research lines focusing on the same main themes as in this thesis: self-management and digital care.

**Next Step Forward**

The question arises which part of the care path still needs to be performed by HCPs, and which part might be well done by others, like peers or by using technology. Future
research is needed to find an optimal combination of types of support, in which source, content and intensity are tailored with respect to the characteristics of the patient and their individual needs. To take the next step forward, we suggest using the previous studies as modules to focus on rapid prototyping, which means turning ideas into an actual product that is then tested, iterated, and refined, based on user feedback [4].

1. Eijkelboom, C., et al., Twelve tips for patient involvement in health professions education. (1873-5134 (Electronic)).