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SOCIAL SERVICES, HEALTH AND SPORTS

HEART FAILURE MATTERS

Producing web-based patient education material for
Health Village

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<p>Abstract</p> <p>Digital services can be used as an additional method together with traditional treatment to support the daily life and self-care of the patients with chronic diseases. Chronic heart failure is a serious chronic disease with poor prognosis and high mortality. Motivating and comprehensive methods to educate patients daily life and self-care are important in increasing the heart failure patients' well-being and ability to live with the disease. Developing web-based patient education is one way to increase healthcare accessibility when it may be limited due to long distances, health care availability or due to individual factors.</p> <p>This thesis was performed as a development work and aimed at producing web-based material for Heart Failure in Health Village portal. Health Village portal is built together by all five Finnish Hospital Districts as a part of Virtual Hospital 2.0 project to support the health of citizens, provide information and tools both for the patients and the professionals. The objective was to produce educational, motivating and practical web service for patients aiming to improve their quality of life by increasing their empowerment in daily life and thus increasing engagement in self-care. The other purpose was to create a modern and practical guide for the professionals to support patient education.</p> <p>This development work was based on theoretical framework, clinical expertise and was done together with patients involved in the planning, performing and evaluating phases. Heart failure website provides information on the causes and symptoms of heart failure, the treatment options and self-care. It also includes videos, peer stories, quiz and exercises to demonstrate the ways how to deal with the disease. Web service is available in https://www.terveyskyla.fi/sydansairaudet/tietoa-sydansairauksista/sydämen-vajaatoiminta.</p> <p>Producing sustainable and valid web service requires a thorough plan to maintain and update the service and good practices and technologies to promote accessibility. Development also requires active involvement of end-users. In the future, it will be important to increase the awareness of the heart failure patients and their relatives together with the health care professionals to use the Heart failure website.</p>			
<p>Keywords Heart Failure, Patient Education, Self-care, Health Care Digitalization, eHealth, Web Service Development</p>			

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<p>Tiivistelmä</p> <p>Uudet digitaaliset palvelut täydentävät perinteisiä hoitokäytänteitä pitkäaikaissairaiden potilaiden hoidossa lisäämällä uusia mahdollisuuksia omahoidon seurantaan ja toteuttamiseen. Krooninen sydämen vajaatoiminta on vaikea sairaus, jonka ennuste on huono ja kuolleisuus korkea. Sydämen vajaatoimintapotilaiden arjessa selvymistä sekä elämänlaatua voidaan parantaa monipuolisten ja motivoivien ohjausmenetelmien käytöllä. Verkkopohjaisen ohjauksen kehittäminen on yksi tapa lisätä terveyspalvelujen saavutettavuutta etenkin Suomessa, jossa maantieteelliset etäisyydet ovat pitkät, terveyspalveluiden saatavuus vaihtelee ja toisaalta ihmisten mahdollisuudet saavuttaa palveluita voivat olla eri tavoin rajoittuneet.</p> <p>Tämä opinnäytetyö toteutettiin kehittämishankkeena, jonka tavoite oli tuottaa verkkopohjainen ohjausmateriaali sydämen vajaatoiminnasta Terveyskylä.fi verkkopalveluun. Terveyskylä on rakennettu yhdessä viiden Suomen sairaanhoitopiirin kesken Virtuaalisairaala 2.0 hankkeen aikana. Sen tavoitteena on tukea kansalaisten terveyttä tarjoamalla tietoa ja tukea, hoitoa potilaille sekä työkaluja terveydenhuollon ammattilaisille. Tämän kehittämishankkeen tarkoitus oli toteuttaa opettavainen, motivoiva ja käytännöllinen verkkosivusto, joka auttaa sydämen vajaatoimintapotilasta voimaantumaa arjessa sekä sitoutumaan omahoitoon, parantaen näin myös elämänlaatua. Tarkoitus oli luoda myös uusi, käytännöllinen ohjausmenetelmä terveydenhuollon ammattilaisille.</p> <p>Kehittämistyö perustuu teoreettiseen tietoon sekä terveydenhuollon ammattilaisten osaamiseen ja erityisesti potilaiden osallistamiseen suunnittelu- toteutus- ja arviointivaiheisiin. Sydämen vajaatoiminta sivusto sisältää tietoa vajaatoiminnan syistä, oireista, hoidosta ja omahoidosta. Lisäksi siellä on videoita, tietotesti sekä harjoituksia, jotka auttavat havainnollistamaan arjen selvitymisessä. Verkkomateriaali on saatavilla osoitteessa https://www.terveyskyla.fi/sydansairaudet/tietoa-sydansairauksista/sydämen-vajaatoiminta.</p> <p>Kestävän verkkopalvelun tuottaminen edellyttää huolellista suunnitelmaa sivuston ylläpidosta ja kehittämisestä sekä sellaisia menetelmiä, jotka tukevat verkkopalvelun saavutettavuutta. Verkkopalveluiden käyttäjät tulee ottaa mukaan kehittämiseen. Tulevaisuuden haasteena on lisätä sydämen vajaatoimintapotilaiden, heidän läheistensä sekä ammattilaisten tietoisuutta verkkopalvelusta sekä sen käytöstä.</p>			
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1 INTRODUCTION

Heart failure (HF) is one of the most common causes of hospitalization in Finland (Lommi, 2014). It is a severe disease with poor prognosis. The incidence of disease is increasing as the population ages. This might be partly explained partly by more effective treatment methods leading to prolonged life of the patients. Effective treatment requires seamless health care chains, good cooperation between primary and special healthcare together with patients' self-care. One of the most important part of the good care is timely, effective and individual patient education and empowerment. (Heart failure, Current Care Guidelines, 2017).

Patients should be more involved in their own treatment. Health education in the media, the Internet and social media plays an important role as a source of information of health and diseases. It is important to provide right information for the people through various communication channels. Digital solutions and new communication methods should be developed. (Larivaara, 2016).

Demographic challenges are affecting people's health in Finland as in other European countries. Today's challenge for healthcare is increasing costs and more attention needs to be paid to the introduction of cost-effective methods for health and social care (Massimi et al. 2017; Larivaara, 2016; Finnish Government, 2016). Reliable information on health, illness, self-care and peer groups can provide significant savings in health care (Hyppönen et al, 2018, 6). Using digital and other telemedicine technologies to encourage patients to self-monitor at home and to communicate with healthcare providers can reduce healthcare visits and costs (Lupton, 2013).

Another new aspect in health education is that healthcare professionals are seen more as health coaches than health supervisors. Patients are expected to take more responsibility for their own health. Nowadays, people also require digital services provided by healthcare. (Finnish Government, 2016; Danish Ministry of Health, 2018).

Digitalization of health care is also part of WHO and European Commission goals to support the coverage of health services (European Commission, 2018; WHO, 2016). Finland is an advanced country in terms of digitization and healthcare. Ministry of Social Affairs and Health of Finland established The National Digitalization Guidelines in 2016 which aims to improve health and well-being through digitalization. One method is to promote easily readable health information from one reliable internet forum. (Finnish Government, 2016).

Digital services like Health Village portal in the Internet complement traditional treatment chains and are particularly well suited for example for education and monitoring the quality of life, symptoms and lifestyle during treatment and follow-up (Virtual Hospital 2.0, 2017a). The Virtual Hospital 2.0 project is a joint venture between the five Finnish University Hospital Districts to develop specialized healthcare services by utilizing digital solutions. It is one of the key projects of the Ministry of Social Affairs and Health of Finland. All five Finnish University Hospital Districts are participating in the project coordinated by the Helsinki and Uusimaa Hospital District (HUS). The aim of the Virtual Hospital 2.0 project is to bring healthcare services to all Finns regardless of their residence and incomes, thereby increasing the equality of the citizens. One of the main targets of the project is to develop Health Village webportal and this development is still ongoing. (Ministry of Social Affairs and Health of Finland, 2017; Virtual hospital 2.0, 2017b).

During this development work a multiprofessional team in Kuopion University Hospital participated in the national Virtual Hospital 2.0 project producing material of the nature, the treatment and self-care of HF to Health Village web portal. The aim was to provide information in easily understandable, interesting and motivating way. It is known that increasing the patients empowerment and motivation to selfcare their quality of life can be increased and hospitalization decreased.

The purpose of this thesis was to find out the factors that influence in the production of appropriate and useful websites especially for patients with HF, their relatives and all other citizens. Developing sustainable, customer-oriented and accessible websites requires both multiprofessional and re-evaluating working methods, in which the customers will be involved at an early stage.

Dear reader, when reading this thesis, the information may already be out of date. The reason for that is that digitalization is improving tremendously fast and learning and understanding of the production of Health Village material is growing all the time. The Heart failure website has probably been updated since finishing this work, and not all the websites are similar to the ones presented in this paper. This indicates that the Virtual 2.0 project is not only a forgotten venture alongside the other development projects, but a truly evolving and growing network of professionals with a new dimension in their daily work, which is to build a functional and useful digital healthcare service together with end-users.

2 HEART FAILURE MATTERS – PATIENT IN THE CENTER OF PATIENT EDUCATION

2.1 Heart failure leads to human suffering and significant costs in health care

In simple terms HF is a syndrome caused by insufficient blood flow to the body due to impaired cardiac function. HF is associated to typical symptoms (e.g. tiredness, dyspnea, limited exercise) and findings (e.g. pulmonary congestion, elevated jugular pressure and peripheral edema). (Heart failure: Current Care Guidelines, 2017).

HF leads to human suffering as well as significant costs. HF is a "multiplier" syndrome that can be caused by different heart diseases such as coronary artery disease, hypertension or valvular disease. (Heart failure: Current Care Guidelines, 2017). HF affects quality of life more than many other chronic diseases and the severity of disease is reflected in recurrent hospitalization periods as the disease progresses. In addition to physical limitations, the quality of life can be reduced due to heart failure in the mental as well as the social dimensions. After discharge, about half of the HF patients are readmitted to hospital within a half year. Pulmonary congestion is the most often the reason for re-hospitalization. (Nieminen, etc. 2015). Patients with congestive HF have also major risk for depression (twice or three times compared to the normal population) which may complicate treatment increasing clinical events, hospitalizations and higher risk of mortality (Rustad, et al. 2013). Both psychologic and physiologic factors cause fatigue which is a common symptom among HF patients but not as usual as dyspnea, chest pain or edema (Williams, 2017).

Chronic HF is a big issue not just in the Finnish healthcare, but it is a global health problem; average or even more than 26 million people suffers from it and the prevalence will increase because of population is aging (Savarese & Lund, 2017). In generally years of life are lost due to cardiovascular diseases in both developing and developed countries (Huttunen, 2015). Among cardiovascular diseases, ischaemic heart disease is still one of the leading cause of death in Finland, although the number has decreased over the last 40 years (Statistics Finland, 2018). It is estimated that 0,4-2% of the population suffer from HF in Finland, corresponding prevalence of more than 100,000 patients. Furthermore, the incidence of asymptomatic HF may be up to twice as high (Lommi, 2014). The incidence of HF in elsewhere of Europe and in the USA is at the same level (Savarese & Lund, 2017).

Chronic HF often presents as an end-stage of heart disease. Most patients are old and after the symptoms have arisen, the prognosis is poor. It is estimated that 30 to 50% of the patients with the most severe degree of the disease, will die during the first year after the diagnosis (Lommi, 2011, 305) and the average life expectancy is about 2.4 years (Heart

failure: Current Care Guidelines, 2017). Even in the milder forms of HF, nearly half of the patients die within five years from the occurrence of symptoms (Lommi, 2011, 305). Most often the cause of death is cardiovascular, mainly arrhythmia, sudden death or worsening of HF (ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure, 2016).

In 2010, approximately 43,000 Finns received reimbursement for HF drugs (National Institute for health and welfare, 2014). HF is estimated to cause approximately 1-2% of all healthcare expenditure in Europe and two thirds of the costs are generated by hospitalization (Lommi, 2014). There is no accurate statistics of the patients with HF and the associated costs of the treatment because of varying manners of the HF diagnoses. In the Finnish version of the ICD-10, the syndromes describing the HF (I50.0, I50.1, I50.9) are used with varying manners in different centers, and the register may contain the diagnostic codes of the etiological diseases. (Heart failure: Current Care Guidelines, 2017).

During the last 6 months of their life, the HF patients spend on average 25% of the time in hospital. Three quarters of the total cost of the treatment for HF are caused by hospital care (Heart failure: Current Care Guidelines, 2017). In 2017, the cost of the treatment for HF patients were over 2 million euros in Kuopio University hospital (ASSI-report, 2018).

2.2 Good self-care is an important part of successful treatment of heart failure

Treatment of HF depends on the severity and cause of the disease. Treating well the etiology of HF, lifestyle modification, motivation to self-care, regular medication and sometimes device therapies or other interventions are the key issues for surviving with the disease. Life expectancy can be improved, symptoms relieved and hospitalizations reduced by successful and seamless treatment chain. The symptoms of HF are varying and the treatment is challenging requiring both primary health care, special medical care, and commitment of the patient and the relatives to the treatment. (Heart failure: Current Care Guidelines, 2017.)

HF self-care means to take special care of one`s own health and well-being including healthy diet, exercise, refraining alcohol and smoking, prevention of other diseases, regular use of medication, monitoring of symptoms regularly and surviving with severe disease in daily life. It is essential that the patient can identify symptoms of worsening of HF and start the treatment immediately. The early treatment may reduce hospitalization. (Content of self-care guidance in nursing patients with heart failure: Nursing guidelines, 2018; Heart failure: Current Care Guidelines, 2017).

Patients with HF benefit from regular follow-up and monitoring of biomedical markers which ensure safe and efficient medication and early detection of disease progression. Research has shown that physical training improves exercise tolerance, quality of life and decreases hospitalization caused by HF. (ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure, 2016).

2.3 Patient education of the heart failure patient

In the treatment of HF, the key intervention in sense of nursing is to optimize self-care. By pursuing good management of the disease, reduction of mortality and treatment costs can be achieved. The implementation of self-care requires that the patient has sufficient knowledge and understanding of his or her own disease and of the treatment options to be able to make decisions to better lifestyle. Patient motivation for the implementation of the treatment can be improved by increasing the knowledge and by regular monitoring. (Content of self-care guidance in nursing patients with heart failure: Nursing guidelines, 2018). Ideally, for hospitalized HF patients, the patient education should begin before the discharge. The patient education should be personalized and possible co-morbidities that may influence on adopting information has to be taken into account. (ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure, 2016; Content of self-care guidance in nursing patients with heart failure: Nursing guidelines, 2018). Regarding the patient education, the emphasis is on adopting self-care to the patient's normal life, as well as actively involving the patient's relatives in learning self-care as early as possible. (Content of self-care guidance in nursing patients with heart failure, Nursing guidelines, 2018).

Lainscak et al. (2007) have studied the patient education with HF patients (n = 3261) based on interviews performed by healthcare professionals. The study showed that patients could remember only 46% of the contents of the patient education. The patients best remembered the education of the diet and exercise and least the information about influenza vaccination and NSAID medication. Overall, only 67% of the patients followed the instructions which they remembered. (Lainscak et al. 2007). It is known that those patients who did not follow non-pharmacological instructions like exercise recommendations or weight control were in a higher risk of mortality or HF related hospital readmission (van Der Wal et al. 2010).

Patients with HF have difficulties recognizing the symptoms of the disease from the signs of normal aging. Patients have difficulties in self-care, especially in the early stages of disease, when they do not yet have an idea of what the disease is and therefore they may

also have difficulties in understanding the information they receive. In addition, patients with HF have more problems with cognitive functions, such as learning new things, memory, perception and concentration, compared to healthy people at the same age. (Content of self-care guidance in nursing patients with heart failure, Nursing guidelines, 2018).

According to Dao Le (2016) barriers to effective self-care can be divided into three themes. The first one is poor communication which includes lack of patient support and respect and seeing the patient as an impersonal human. The second one is the lack of information, especially the lack of explaining the nature of HF, the medications and their side effects and the importance of dietary sodium intake. And the third one is poor continuity of care which means frequent changes of healthcare providers or conflicting advices from different professionals, difficulties to access or consult the health care provider. (Dao Le, 2016). Studies have also shown that chronic disease monitoring and self-care exhausts and depresses patients. Some HF patients, for example, refuse to use new digital health techniques, because constant self-observation always reminds of the existence of the disease and causes discomfort. (Lupton, 2013).

A systematic review by Kent et al. (2011) was published of multiple intervention strategies, which were compared to conventional treatment: the use of supportive education, video education, and motivating interview and telephone empowerment. Interventions that included keeping the journal appear to have the greatest effect on the weighing behaviors for HF patients. Patient empowerment and motivating interview have shown to be important for HF self-care interventions and should be considered for further research. However patient education using alone has shown to be less effective than when used in combination with other interventions. (Kent et al. 2011).

According to European Society of Cardiology (ESC) guidelines (2016) key topics of self-care and professional behaviours to optimize learning and facilitate shared decision making are listed in Table 1.

TABLE 1: Key topics of self-care and professional behaviours (ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure, 2016).

Education topic	Patient skills	Professional acts
HF disease and individual status of HF	Understands the cause, the symptoms and progression of HF and is able to make realistic decisions (also	Provides information Recognizes the barriers of learning Sensitive and individual communication

	about the end of the treatment)	
Symptom monitoring and self-care	Monitors and recognizes symptoms and signs of HF. Knows how and when to contact the healthcare.	Teaches the patient to understand the symptoms and signs of HF (e.g. weight gain). Teaches the patient to increase the diuretic dose and/or to contact the health care if self care does not help.
Pharmacological treatment	Understands the indication, dosing and side effects of drugs. Recognizes side effects and knows when to contact the health care.	Provides written and oral information of pharmacological treatment. Ensures that the patient understands this information.
Devices and interventions	Understands the indication, aims and complications of the procedures and implanted devices. Knows when to contact the health care.	Provides written and oral information about the procedures and regular follows the devises.
Immunization	Receives immunization against influenza and pneumococcal disease.	Advices about the local immunization practices.
Diet and alcohol	Avoids excessive fluid intake. Fluid restriction may be considered in patients with severe HF. Monitors the body weight and prevents malnutrition. Eats healthy foods, avoids salt intake, avoids obesity. Avoids alcohol.	Gives individualized information of fluid intake. Recognizes malnutrition and treat malnutrition if necessary. Helps in the management of obesity if necessary. Gives tailored advices of alcohol.
Smoking and recreational substance use	Stops smoking and taking recreational substance use.	Recognizes and helps the patient to stop smoking and recreational substance use. Guides the patient to weaning therapy if needed.
Exercise	Practices regular and safe exercise.	Guides in regular and safe exercise.
Travel and leisure	Prepares the travel and leisure activities according to physical capacity. Understand the basics of safety travelling.	Guides for safe travelling (fluid intake, sun, heat, flying, drugs etc) Guides how to travel with implantable cardiac defibrillator.
Sleep and breathing	Recognizes the problems with sleeping and their relationship to HF and knows how to optimize the sleep.	Provides advise of the timing of diuretics, environment of sleep and sleep device support. Recognizes sleeping disorders and treat them.
Sexual activity	Is able to have sex without symptoms.	Provides advice about sexuality and partnership. Gives advise about pharmacological treatment of erection problems.
Psychosocial aspect	Recognizes possible psychological and depression symptoms and understands that they may affect into adherence of HF treatment.	Regularly communicates on of the disease, treatment options and self-management. Involves the family and carers into HF management and self-care. Provides psychological support (spesialist) if necessary.

Detection of HF can be difficult and may be delayed, since the symptoms may resemble other diseases or patients can believe that their symptoms are associated with normal aging or poor exercise tolerance (Partanen & Lommi, 2014). HF can be diagnosed in an outpatient clinic or sometimes in a emergency care unit but the final diagnose and a treatment plan should be made in the special care unit where an appropriate patient education is also available. Treatment and follow-up can be carried out, either in primary health care or in special health care according to individual treatment plan. (Heart failure: Current Care Guidelines, 2017).

The current recommendations do not address where and who should give the patient education related to self-care. Furthermore here are no comprehensive studies about the current status of the education of HF patients in Finland. Usually patient education is provided by both physicians, nurses, physiotherapists and pharmacists. Because patients' counseling contains usually a lot of information, the information should be provided in small parts, if possible, and also in several steps (Lommi & Partanen, 2014). The key elements for the success of self-care of HF patients and successful management of the disease are multiprofessional cooperation and coordination of different types of care. In the year 2018 an updated recommendation for self-care patient education was published. It is important to harmonise the self-care patient education of HF in Finnish health care according to evidence based practice. (Content of self-care guidance in nursing patients with heart failure: Nursing guidelines, 2018).

The third sector, such as the patient organizations like Finnish Heart Association, have also a big role in the treatment and support of HF patients. They provide both rehabilitation, guidance and peer support. (Finnish Heart Association, 2018). There are lot of written material available of the heart diseases provided by health care and patient organizations. Information about rehabilitation and of the costs of the treatment are provided by Kela and patient organizations.

2.4 Web-based patient education material for patients with heart failure

Currently, there are several websites that provide information about HF. In the Internet, Google a search by the word "heart failure" ("sydämen vajaatoiminta" in Finnish) provided over 125 000 results. The first page (the first 10 matches) included the Finnish national and European guidelines as well as the patient organization's webpages like Sydän.fi. In summary: reliable information from reliable websites are available in the Internet in 2018. From these websites the patient organization's webpages provides more user friendly and interesting information about HF and they also contain peer stories and support. Current

Care Guidelines (Käypä hoito -suositukset) provided by Duodecim give mostly scientific information but there are also patient friendly versions about general information of HF available (Duodecim, 2019). Because heart patients have asked more for possibilities of chat conversation and peer support, in 2017 the Finnish Heart Association launched a chat for heart patients (Sydän-chat in Tukinet). A heart chat can be accessed by registering with an anonymous symbol and signing in the site when the Sydän-chat is running. The chat room guides to a discussion of a predefined theme at a predefined time of the month. (Tukinet, 2018).

The term "e-learning" can be defined as an educational tool provided in any electronic form. Synonyms for e-learning are computer-assisted learning, online learning and web-based learning. E-learning increases access to education and cost-effectiveness and the advantages are interactivity and flexibility of studying. (Sinclair et al, 2015).

In a small Danish study (Kristiansen et al, 2017), the patients with HF were asked to describe what information they feel they mostly needed at the time they were diagnosed with HF. The aim of the study was to find out if the peer patients could help in designing web-based patient education material. The study showed that anxiety and fear of death and furthermore, the new situation with the disease were the most important reasons for patients to seek information of the disease. These feelings were also the reasons affecting patient's ability to absorb information. Patients hoped to get more information on the control of the disease and its symptoms. They were worried about the severity of the symptoms. They needed information on medication and adverse effects that many patients had experienced. It is not always clear whether the symptoms are caused by the disease or by medication. (Kristiansen et al, 2017).

The patients clarified what are the important issues when designing web-based patient education. It was important to them that the patient education was focused, appropriate for age, and the language was clear and understandable. The text must not be too scary to be read even though it is a question of serious disease and the prognosis is poor. Video material was considered as good support for the text. Many patients sought for the peer support. Frequently asked questions and answers were told to be useful. Also, online conversation or chat service with healthcare staff was hoped. The study showed that there is a wide variety of needs within the patients and the patients should contribute to the designing of the patient education material for the Internet. (Kristiansen et al, 2017).

3 DIGITALIZATION OF HEALTH CARE IMPROVES CITIZEN 'S HEALTH

Digital health refers to a wide range of different eHealth technologies as well as of advanced computing sciences in the fields of the "big data", genomics and artificial intelligence (WHO, 2017). According to European Commission the digital health is a wide concept which can be seen as a tool that use different kind of ICT solutions to prevention, diagnosis, monitoring or management of health (European Commission, 2018). The reform of all digitalisation policies should be based on the fact that electronic services enable people to do things better and in a different way (Korhonen, 2017). Digitalization enables change management and knowledge-based management. This includes the change of behavior and attitudes. Above all, digitalization is part of the social and health care and its implementation. (SoteDigi, 2019).

Many terms are used of the digitalization of health care. eHealth refers using wide range of information and communication technologies (ICT). This include e.g. telemedicine, electronic health records (EHRs), mobile health (mHealth) applications referring mobile wireless technologies, electronic prescribing systems (EPS) and other web-based health services for health and care (WHO, 2017). Telehealth term is used when ICT is used to support long-distance clinical health care or in health education both for professionals and patients, in public health or in health administration (HRSA, 2019).

In this thesis, the terms of "eHealth" or "digital health" are used to refer the use and development of web-based health services and "web-based patient education material", which in terms is referring to varied learning material in the Internet.

3.1 International and national e-health policies and strategies

Digitalisation is not an intrinsic value but is intended to improve citizens' health and health services and their accessibility even beyond the country's borders within the EU. The European Commission promotes digitalisation of health care through political guidance and financial and technical strategies. (European Commission, 2018). In addition WHO (2016) declaim that e-health and ICT possibilities must seen as an essential and central component, not an add-on, in health strategies globally.

Objective of digital health services is to improve citizens' health by making health information available using digital health and care tools. The aim is also to increase healthcare quality and accessibility by making digital health and care as part of EU countries' health policy, financial and technical strategies. Involving professionals and patients into the

strategy, design and implementation is essential making digital health and care tools more effective, user-friendly and widely accepted. (European Commission, 2018).

For a long time, the Finnish state has been developing a functional e-health service system, taking into account the development policy of the European Commission's eHealth objectives and strategies. The aim has been to develop services together with customers, thus increasing the opportunities for reliable information and enabling patients to access and view their own health records. This has an intention to increase the participation of the citizens. (Iivari & Ruotsalainen, 2007). Citizens' activity in life management and self-care is increased by producing reliable welfare information and services which are openly available for everyone (Finnish Government, 2014).

The Finnish government's key project, "Promoting health and well-being and reducing of inequalities" is designed to promote health and care especially for the most disadvantaged people (Larivaara, 2016). Bringing health services near the customer is an opportunity to give equal support for everyone despite of their residence or time. Another Government's key project; "Customer-oriented services" aims to increase the citizens opportunity to be a part of development work in digitalization. (Ministry of Social Affairs and Health of Finland, 2017; Finnish Government, 2016).

The government has several ongoing projects to increase digitalization in healthcare. Few important parts of the whole reform of Personal Care Services are 1) ODA (Self-care and Digital Value Services) project 2) Wellness check and training 3) Intelligent symptom navigators 4) Wellness plan for clients who needs long-term care or services and 5) Health Village (Virtual Hospital 2.0.). ODA and Health Village will use the national health recourse archive – KanTa in the future. (Korhonen, 2017).

Despite the fact that Finland is one of the model countries in eHealth in the Europe and in the world, health digitalization arises also many concerns and needs for development. The Workshop Report Peer Review took a stand on eHealth strategy and action in Finland and made a note in their report 2013 that the focus of patient self-care, is insufficient. More services such as new treatment pathways, strategies of chronic disease management and patient empowerment should be made. The workshop reviewers were concerned of how to get the healthcare professionals to participate the health care improvement and cowork with in "communities of patients and health care providers". (EHTEL, 2013).

In Northern Savo Hospital district and in Kuopio University hospital there are a few strategic goals supporting the development of national and international health care digitalization. These are 1) to increase the access to the information in the Internet, to promote the

e-business and mobile services and 2) to support a patient's health care chains between social, healthcare and special health care at both regional and national level. Critical success factor in implementing the strategies is to have the patient to participate to the processes. (PSSHHP, 2014).

3.2 Benefits and challenges of eHealth services

The study in 2017 led by National Institute for Health and Welfare explored 4495 visits in Finnish e-services and users experiences of the visits. It was found, that 86% to 88% of the population use e-services in Finland. The results showed that the use has increased from 58% in 2014 to 68% in 2017. The use of national services, especially exploring personal data and requests for prescriptions, had increased strongly. The use of web services to support self-care was also quite extensive. (Hyppönen et al, 2018).

The study found that citizens using web-based services (12% of respondents, 14% of those using social and health care services) saved an average of 1.37 visits per customer during a year. Those who had received support for lifestyle change (nutrition, exercise, smoking, alcohol, etc.) saved 2.40 visits and those who had sought reliable information for their own health, illnesses, their symptoms and treatment, saved 2.37 visits. In addition, the perception of how much one visit costs and takes time was also collected. The cost estimate for one visit including travel and other expenses, cost in average 43€ and takes in 2.3 hours. (Hyppönen et al, 2014).

According to WHO the potential of eHealth services is significant but the suitability for different patients and populations varies, as is the assessment of digital services, scalability and integrations between the different eHealth systems. The reasons for the challenges are multiple. One is that small pilot projects are carried out without a proper plan or supervision. The other is lack of integration of individual applications to the existing national eHealth strategies and electronic health records. There is also lack of cross-sectoral approach between ministries of Government, between different national agencies and private sector when designing and assessing e-health solutions. (WHO, 2017).

Gordon and Hornbrook (2018) performed research of the skills of web-based health information technology users, of their experiences and preferences. The study focused in people aged 65-79 participating in the Kaiser Permanente Medical Care Program in Northern California in the USA. The aim was to assess how ethnic background and age affects on engagement with web-based health services, counseling or mobile technologies. (Gordon & Hornbrook, 2018). The conclusion was that those seniors who were in higher risk of

chronic diseases have more difficulties in accessing the healthcare and are thus especially vulnerable. The same group was less likely to adopt the use of different eHealth technologies. (Gordon & Hornbrook, 2018.) Same kind of results were found in a Finnish study. People who experienced their state of health and quality of life to be good had experienced the least obstacles compared to those with poor health and quality of life or those with long term diseases. The regular use of digital services, high education level, positive attitude, easy access and availability of digital services and residential living area predicted the use of eHealth. Importantly, age was not a significant explanatory factor for the use of eHealth. (Hyppönen et al, 2018).

Patient education is not a challenge only in the online world. Regarding many chronic diseases, attention has been given to support patient self-care and way of life to improve functional capacity and health. Nurses play a key role in supporting self-management. Studies have shown that nurse-led patient education among patients who have diabetes or cardiovascular diseases has positive effects on glycemic control, blood pressure levels and LDL-cholesterol. However, improvement in the patient's quality of life or mortality could not be demonstrated. Furthermore, the efficacy of self-care methods in patients with multiple diseases has not been demonstrated. The reason for that might be that patients with multiple diseases have interactions between the diseases and their treatment. This makes self-care more challenging. (Massimi et al, 2017).

3.3 Accessibility of eHealth services

Accessibility is closely related to digital services. In order to achieve accessibility, the design of digital services should use practices, technologies and methods which are easy to reach by different devices and other tools. Accessibility is part of the "design for everyone" principle, which means taking into account different users and their needs. (Ministry of Finance, 2018).

The Accessibility Directive and subsequent national legislation require authorities to make digital services accessible. The Government's proposal for a law on digital services has been submitted to Parliament on 3.5.2018. Application of accessibility requirements will be sent on 23.9.2019. The accessibility of digital services is based on the Finnish Equality Act (Finlex 1325/2014), European Directive on Web Accessibility and European standard EN 301549 which came into force in autumn 2018, by obligating all public sectors to make their web services and mobile applications accessible for all. (Ministry of Finance, 2018).

Web Content Accessibility Guidelines (WCAG) 2.0 defines how to make web content more accessible to people with visual, auditory, physical, speech, cognitive, language, learning or neurological disabilities. By following these guidelines, the usability of the web service will improve, not only for the people with disabilities and elderly but also for all other users. (W3C, 2008).

By designing web-based services and health information it is important to take into account the digital accessibility. Before educating the patient to use web-based material the healthcare professionals should assess patient's eHealth skills and accessibility for digital services. (Gordon & Hornbrook, 2018).

4 OBJECTIVE AND AIM OF DEVELOPMENT WORK

Objective of this development work was to produce new web-based patient education material for HF patients in Health Village webportal. The aim of this development work was to increase the possibilities of self-care and give new tools for healthcare professionals for patient education.

My personal goal was to understand the management of project work in the context of multiprofessional and national co-operation, to understand the possibilities of digitalization to develop the health care process in patient education and to understand the designing of accessible web service involving the patients in the design and evaluation process.

5 DESCRIPTION OF DEVELOPMENT WORK

This thesis was done as a development work including theoretical material and project work where web-based patient education material was produced during Virtual Hospital project in 2017-2018.

The aim of the Virtual Hospital project was to provide customer-oriented, specialised digital health services, to improve the quality of services and to streamline the duration and cost-effectiveness of the process. The most visible element of the project for the citizens is the Health Village webportal (Terveyskylä.fi). It provides health information and support for citizens and tools for healthcare professionals. In Health Village the customer receives counselling, service guidance, peer support, symptom navigators and treatment pathways. In personal patient treatment path, the patient can receive remote support and care, rehabilitation and follow-up at various stages of disease. (Virtual hospital 2.0, 2017a; Ministry of Social Affairs and Health of Finland, 2016). Elements of Health Village is presented in Figure 1.

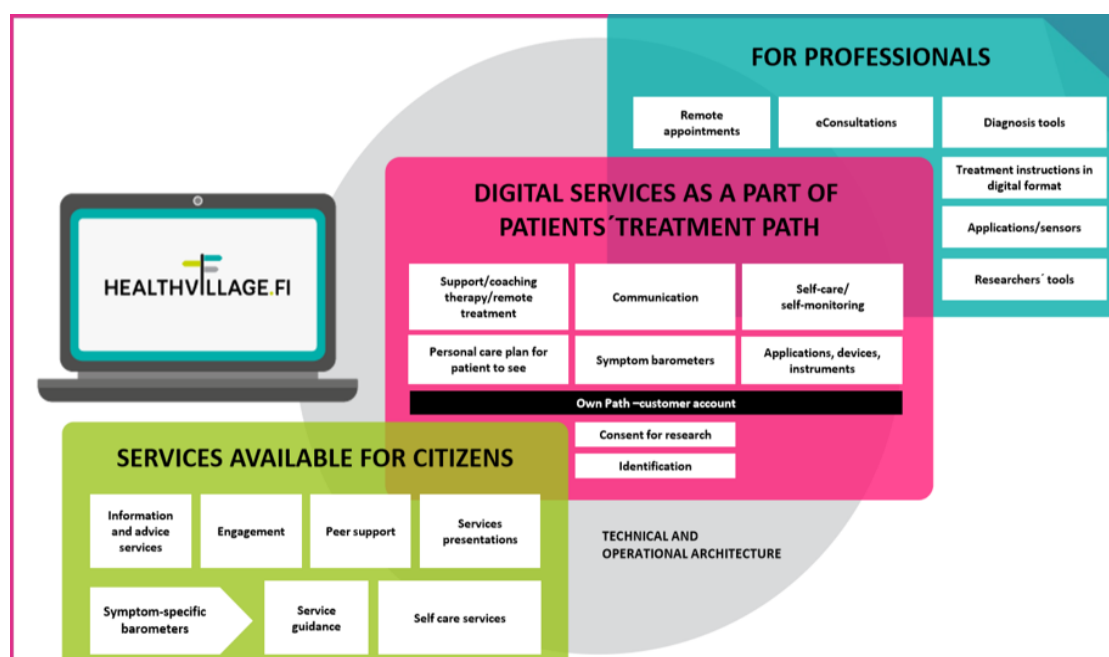


FIGURE 1: Health Village (Virtual Hospital 2.0, 2019a)

Health Village webservice is developed with patients and citizens so that it can provide timely, meaningful, and inspirational help (Virtual hospital 2.0, 2017a). European Commission highlights that the participation of citizens and professionals in the development work has been seen to increase the user-friendliness and implementation of digital services (European Commission, 2018). Health Village portal is one of the Governments' key projects.

The Government Program Digitalisation of the Public Services -project supports Health Village with six million euros of a total of 12 million euros budget. The rest of funding comes from the five hospital districts in Finland and Helsinki and Uusimaa Hospital District was the coordinator of the project. (Virtual Hospital 2.0, 2017b).

Health Village is a kind of virtual village of different hubs or houses where each hub is related to different disease or health topic such like Heart hub or Brain hub (Figure 2). There are over 30 hubs available in 2019. (Virtual Hospital 2.0, 2019b). Heart Hub offers information about heart diseases, treatments and examinations, normal heart function, selfcare, a few quizzes and services provided by University Hospitals and Finnish Heart Association (Heart hub, Health Village, 2019).



FIGURE 2: Health Village.fi Hubs (Virtual Hospital 2.0, 2019a)

Kuopio University Hospital is actively involved in both regional and national ICT projects and is a key player in the reform of the Northern Savo Social and Health Services. Kuopio University Hospital is also promoting innovation and strong expertise by using lean methods to improve quality and productivity of health services. (PSSHP, 2017). Hospital is committed to Virtual Hospital venture with other Finnish Hospital Districts to develop new digital health services (PSSHP, 2019). In summary, modern and innovative technological solution of Health Village portal supports hospital's strategic goals.

The decision to participate in the Virtual Hospital project and development of Heart Hub was made in summer 2017 in Kuopio University Hospital. I was invited to join the project in June 2017 to carry out the project coordinator tasks and to build the content of HF web-service in the Heart Hub. Before that, I was asked if there were needs for development

work or research projects at my workplace in Kuopio University Hospital Heart Center. The task to coordinate the digitalization project was offered at the same time when I was accepted for the master's degree programme. The permission for the thesis in Kuopio University Hospital was given on 24.1.2018. Virtual Hospital 2.0 project funded my work as well as technical costs and production of video material. Heart Center funded some other costs like computer and accessories, a cell phone and workspace.

I have been working with HF patients all my career but patient education of HF patients has not been part of my current job. During the summer and autumn 2017 after the preliminary discussions about Heart failure subproject, I performed a literature review of HF, digitalization and patient education. At the same time the concept of Virtual Hospital and project management became familiar to me. Issues related to this Bachelor's thesis were clarified and I decided to do this development work by using project management methods. The actual work of the project coordinator started on the 2nd of January 2018. Before and during the project I attended to the training sessions designed for Virtual Hospital 2.0 participants, such as Content producer training, Communication coaching, SharePoint content delivery training and Video production training etc.

The objective of the development work is to create a practical output such as patient education material. The service or product is being built, tested and developed in a context of clinical practice. The most important thing in this kind of practical thesis is that it combines clinical work with research. (Vilkkä & Airaksinen 2003, 9). During this development work I have used project management methods and I have illustrated the phases of the development throughout the project. The project is goal-directed, unique and progressive work including interdisciplinary network and predefined time and financial resources (Salonen, 2013; Nicholas & Steyn, 2012, 20).

This thesis consists of two parts. In the theoretical part, the concepts of HF are discussed, as well as patient education and digitalization to be able to better understand the design of web-based education of HF patients. In addition to theoretical data, I used project working methods to develop a new digital service. I organized a brainstorm for patients to get to know the patient point of view. I also organized idea seminar for the health care professionals where we shared some writing assignments and decided of the content of the websites together. I was the main writer of the material and designer of the websites, but the material was edited by the other professionals, the doctors and nurses, the heart association and the patients. After the development of the Heart failure website it was published in Health Village.

5.1 Phases of the development work

In this thesis I describe the development work through project phases. The project phases can be described in cycles, including concept creation, definition, execution and operation phases like in Systems Development Cycle model (Nicholas & Steyn, 2012, 87). At the first phase the people, the technical specifications, costs, management and important project phases should be defined before concept approval (Nicholas & Steyn, 2012, 89). It is notable, that the process consists of different phases and tasks that partially overlap to each other. However, some other phases require the completion of the previous phase. After all, the requirements of the project cannot be necessarily be defined at the beginning of the project but requires to going back to the previous phase. (Nicholas & Steyn, 2012, 140). In the beginning and during the project (6 months) I also described, with other colleagues working among the Virtual Hospital 2.0 project, a marketing plan to increase awareness and use of Health Village web service. I made a website testplan to evaluate the usability of Heart Failure websites. These themes continued to mature throughout the project. Certain steps of the project, such as producing videos reminded more like a linear process, where a manuscript was made and video was shot, edited and finally published. However, sometimes going back to the previous phase was necessary. The schedule and different phases of this development work is described in figure 3.

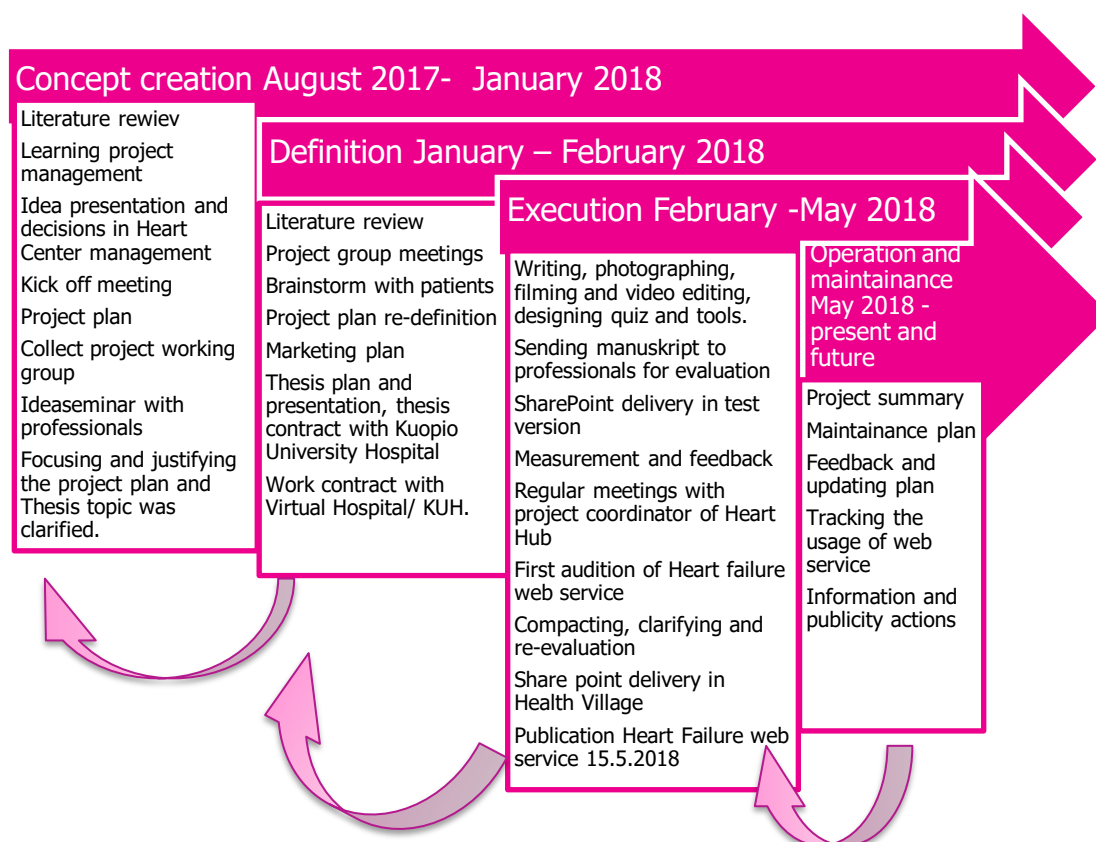


FIGURE 3: Schedule and working phases

5.1.1 Concept creation

The concept of the Health Village and its goals had previously been defined, but I introduced it to our staff before the focus of the Heart failure webpages was defined. During the initial phase of the work, I made a review of the literature about HF, digital health and patient education of HF patients as well as challenges in education and of the problems that HF patients face due to the disease. I invited the experts to a meeting and set up a project team together with the project manager.

Project team is a multiprofessional group of people who are selected to work temporarily following the project goals. The team is led by the project manager or/and project coordinator. (Nicholas & Steyn, 2012). The project requires project work skills, teamwork skills, project management, and understanding of the content of the project (Salonen, 2013). Although a temporary project team was "set up" for this Heart failure project, some of its members will remain long-term developers and system maintainers after the project is over. Heart Center gave an opportunity for employees (e.g. specialized heart failure nurse) to work in the project. Staff from Heart Center, nurses and physicians who were part of the team gave their expertise and time. The other project members were worked in the project at the same time with their own work. The rehabilitation material was developed by a physiotherapist who is specialized in heart diseases in Kuopio University Hospital Rehabilitation Services.

Virtual Hospital 2.0 project organization is wide and it is coordinated and managed by Helsinki and Uusimaa hospital district. However, this development work focuses on describing the sub-project of Heart failure. Responsibilities of the project team, project members and their roles are described in Appendix 1: Responsibilities and roles of Heart failure sub-project. Main head coordinator of Heart Hub was working in Helsinki University Hospital, and there was a local project group in Kuopio University Hospital.

The objectives of the project were decided after pre-evaluation. At the first phase, I estimated the costs as well as the strengths and challenges of the project. I made the project plan and SWOT analyze and introduced it to the project group. The project group decided that the project should proceed because 1) the number of patients living with HF is increasing and 2) new tools to help coping with the long term disease need to be offered and 3) Kuopio University Hospital and Heart Center were committed to Virtual hospital project and development of Heart Hub in Health Village.

5.1.2 Definition and planning – important phases

It appears that two definitions needs to be made. The first one is the result of the project and the second is the estimation of the workload and effort needed to achieve the result. Both are equally important and lack of analyzing the effort may lead problems in coordination, resources and schedules. Focusing just in the effort and recourses may instead lead fail in meeting the requirements of the service. Involving participants and communities in identifying the needs improves the likelihood that the system will meet its requirements throughout its life cycle, thereby increasing the sustainability (Nicholas & Steyn, 2012, 127).

Definition of the project started after the National Heart Hub kick off meeting in Kuopio where the project members of all five University Hospital met at first time face to face. My work included also cooperation with the third sector. Finnish Heart Association was involved during the sub-project as a commentator and I arranged meeting with local heart association, Savon Sydän to make Health Village familiar to them and their customers in early stage of the project. Participation of the patients in early stage as giving opinions and comments have increased the usability and interest of the websites. Brainstorm with five HF patients was held at the beginning of the project in Kuopio University Hospital in January 2018. I invited the patients to the brainstorm during rehabilitation group meeting which met regularly in Kuopio University Hospital. The brainstorm lasted for about two hours and included a preliminary frame, of the themes to be discussed. I made notes during the discussion which increased my understanding of the needs of the patients as well as the specific issues that the disease arises. I redefined more detailed list of requirements since new issues had raised in addition to the literature rewiev and discussions with the professionals before.

The project plan, team members, budget, schedule, customers and other key stakeholders, their needs and requirements I described in the project group meeting in February 2018. Our aim was to provide and implement accurate web-based education material about the disease, it`s symptoms, treatments, rehabilitation and monitoring in interesting and motivating way. The objective of the total project was to

1. increase citizens' knowledge of HF in varieble and interesting ways
2. empower, engage and motivate patients in self-care
3. increase citizens and professionals awareness of Health Village webservice.

When preparing an action plan, the main elements and the connections between them need to be clarified and processed into a logical format so that the project goals can be

achieved (Nicholas & Steyn, 2012, 391). In designing webservice for HF patients I found that several factors need to be taken into account to achieve the project goals. Four different perspectives can be seen: 1. the perspectives of the patients and their families, 2. the perspective of the professionals as producers of the Heart failure web service but also the users of the websites, 3. technical implementation and 4. (web-based) patient education. Context map of the key issues and views of designing of the webpages is introduced in figure 4.

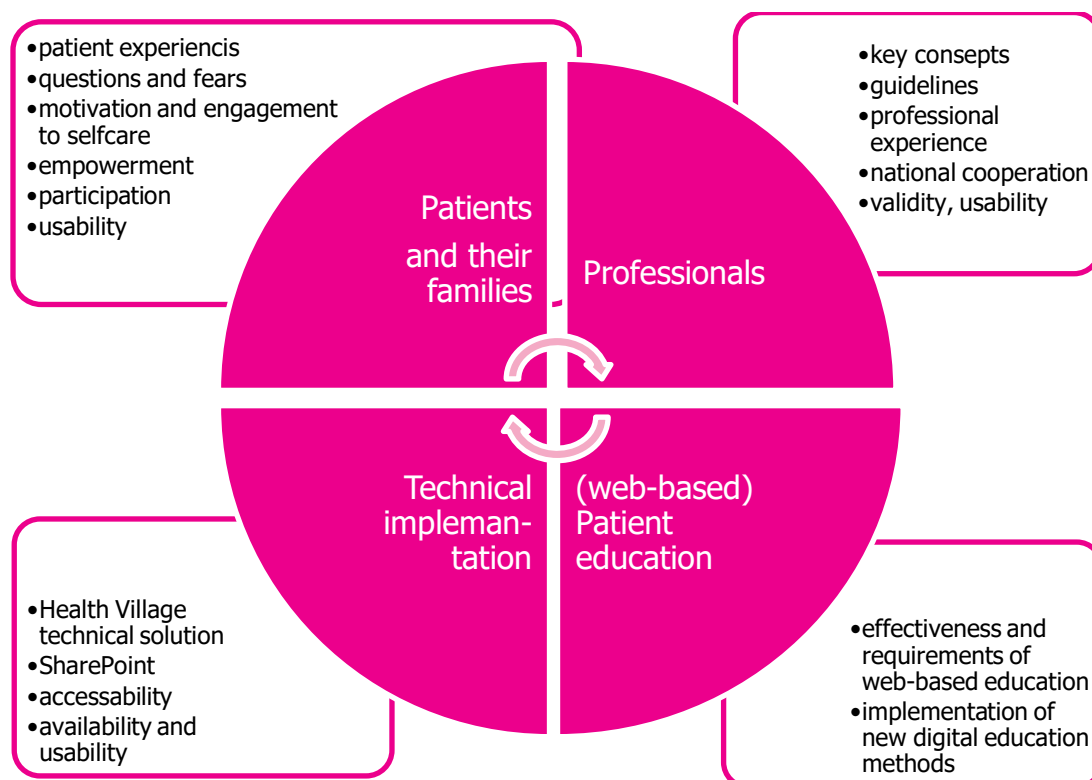


FIGURE 4: Context map of designing web service for heart failure patients

5.1.3 Project execution and control

Project work includes cross-disciplinary and cross-boarder organizational tasks (Salonen, 2013; Nicholas & Steyn, 2012, 20). Locally my work included arrangement and planning the meetings with health care professionals, photographer and video production team. The Heart Hub is planned, produced and maintained in national cooperation with other hospital districts. Each hospital district was responsible for a specific part of the project and we communicate and commented ongoing work regularly by meetings and messages. Meetings were usually arranged via LYNC and there was secured internet platform in HUS extranet which offered material about Health Village for project members and a platform to share manuskripts, plans and contracts.

Networking capability refers to the ability to include collaborators outside the project group into the process, such as financiers or technological companies with whom the project can be improved. They can bring their own vision and experience to the project. This requires a co-operative capability and a vision of who would be useful for the project. (Uruena, etc. 2016). In the early stage of the project, I looked for students who would be interested in co-operation. There were nursing students from Savonia University of Applied Sciences involved who did video presentation about educating the observation of edema in HF patients as their thesis work. It was launched in Health Village Heart failure pages and in their thesis Health Village was introduced for many future health care professionals. (Mustonen et al. 2018). I supervised the students during their thesis and attended in the presentation of the thesis.

In design phase of a project, specifications are documented in different forms like sketches and drawings (Nicholas & Steyn, 2012, 390). For example, for this project I wrote manuscript of the contents of the website with a specific template. Furthermore I made manuscripts for the videos. When the project plan is set into action; the system proceed from an idea to a finished product (Nicholas & Steyn, 2012, 90). Together with HF nurse we planned a heart failure quiz and symptom evaluation tool. I chose some pictures from the files and photographer took new ones. After filming the videos, it was edited together with Kuopio University AV-team. My work included also documentation, sharing tasks for project members, content development, collecting information, merging, simplification, harmonization and visualizing of the content of Heart failure webpages, and finally exporting the data to the Internet.

I asked a written consent from the patients and the professionals to agree to perform in the videos and images, license papers and contracts with students were archived in the local Kuopio University Virtual Hospital project archive. The Heart Hub had previously made the agreements with Finnish Heart Association to link from Heart Hub to their website.

The execution phase includes design, production and implementation (Nicholas & Steyn, 2012, 390). When the project is at the end of the execution phase, the system is implanted into the end-user environment (Nicholas & Steyn, 2012, 90). At an early stage, after the texts and the themes were created, I transferred the contents of the Heart failure webpages to the SharePoint 2010 test platform. In the test environment, I could demonstrate how the content looks like and I was able to make changes and corrections as

needed, before the publication. The test environment could be read by all Heart Hub project coordinators and they had an opportunity to comment the pages. One of the patients who had participated in the brainstorm also read the test version and gave me feedback. I also went to the office of the Visually Impaired - Northern Savo association in order to read through the test platform with an automatic screen reader. Unfortunately, the screen reader could not be used with my personal computer. The Heart failure project team and the Heart Hub project coordinator together finalized the structure of the website into its final form. This took approximately one month.

The structure and the main components of the webpages were clarified in a quite early stage of the project. After testing the material, we reduced some headings and contents together with Heart Hub project coordinator, and further clarified the webpages and ensured that all of the essential and important parts are preserved. We removed all the overlapping material and linked it elsewhere in Heart Hub or in Health Village.

Before publication of the material into the Internet, the customer feedback was requested in order to evaluate the content, its usability and how attractive the webservice was both for the professionals, for the Finnish Heart Association and for the clients. For professionals and for the Finnish Heart Association I provided a manuscript of the contents and for the clients I presented a testversion of the website. I collected the feedback and the suggestions into a summary. Feedback was requested from random website visitors, patients and their relatives in Heart Center in Kuopio University Hospital during spring 2018 with some open questions. The feedback was given after exploring Heart failure website according to the client's own interests. Any special instructions for that were not given. There was also a few face-to-face interviews and e-mail feedback after the publication, according to which several improvements were made for the contents and accessibility.

Summary of the feedback and acts of development

- The length of the sentences, structures, paragraphs and pages was developed according to feedback from professionals and communication specialist. The Information Management in Kuopio University Hospital (KYS – Viestintä) proofread the original text and corrected grammatical errors and streamlined some parts of the text.
- The text was summarised and shortened, only essential things were raised up and repetitions were avoided. There is a lot of information in Heart Hub which suites for all patients with heart diseases for example about the diet, exercise and smoking. Those areas of patient education were omitted from Heart failure webservice and only the specific features associated with it were highlighted, such as limiting salt and fluid intake and issues related to exercise.

- The prevalence of unclear or scientific words were either translated in Finnish or explained clearly, for example Palliative care was clarified like Palliative care i.e. symptom relieving treatment (Heart Hub, 2019f). This feedback came both from the professionals, communication specialist and patients.
- A few frightening expressions regarding HF were modified.
- Videos were presented for few patients to receive their feedback about the humorous parts of the videos which were launched only for social media and later in news.
- After the publication, several suggestions to improve the accessibility were received from the Visually Impaired - Northern Savo association. Screen reading software, used by visually impaired, was found to have some difficulties to be used in the Heart Hub website. The suggestions related to technical functionality, such as pop-ups, subtitles of the images and page order were received (Heinonen & Kumpulainen, 2018). Technical changes were sent to Health Village Technical Support. No re-feedback was received afterwards.

Information Management in Helsinki University Hospital was responsible for the technical implementation and publication of the webservice and served a technical advisor and responsible of accessibility and the overall consistency of the entire Health Village platform. Heart Failure webpages were published in 15.5.2018.

Major function of the project management in execution phase is to control the progression of the project (Nicholas & Steyn, 2012, 395). Project evaluation relies on variety sources and it measures and collects of information, including written and oral reports, site visits, conversations, and informal and formal reviews (Nicholas & Steyn, 2012, 456). Monthly reporting as well as the final report and the various scripts have been archived and sent to the Virtual Hospital archive in HUS Extranet. I evaluated the status of the project monthly and sent a report to the project coordinator of Heart Hub. I evaluated the subproject's 1) schedule 2) content 3) economy 4) risks 5) resources and 6) stakeholders monthly with help of a scale: green = no deviations, yellow = small deviations from plan, requires follow-up and red = significant deviation from plan requiring immediate actions. The number of visitors on the website was monitored monthly and by regions. The Virtual Hospital reports the results and progress to the Ministry of Social Affairs and Health.

5.1.4 Operation and maintenance phase

In the operation phase the system is deployed; the customer takes over to operate the system and maintain it (Nicholas & Steyn, 2012, 90). While the timetable and the steps I

have presented in linear model in figure 3, this development and ongoing maintenance phase is rather cyclical process like in figure 5.

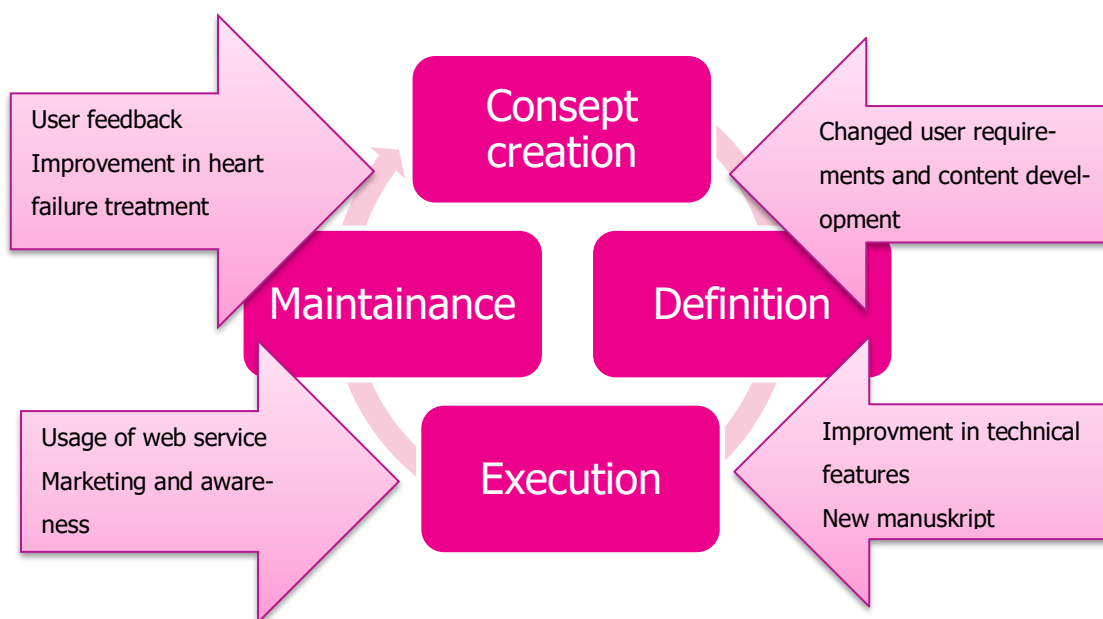


FIGURE 5: Cyclical proses in developing and maintainanse of Heart failure web pages

For systems, such as daily used Health Village webservice, maintenance phase may last for years or decades. In that case the phase includes not only operation and maintenance but also improvement and enchancement to keep the service viable and useful (Nicholas & Steyn, 2012, 455-456). The feedback and redefining user needs and possible changes in the treatment of HF are needed during maintenance phase. Also Commission of the European Communities (2002) underlines that in the maintenance phase clear and regular updating of the site, with date of up-date clearly displayed for each page, is relevant and regular checking the relevance of the information should be made. In maintenance phase, the content should be rewritten and modified. Also, the constantly evolving technology and understanding of the patient education methods provide opportunities to develop the web-site. This make maintenance of service cyclical ongoing proses that must be implemented in daily workflow.

Some months after delivery, functional output should be evaluated to assess its performance in the user environment. This post-installation review serves a variety of purposes, such as revealing for the system's designers, in this case developer of webservice, which pages are frequently viewed and which are not, how the end-users use the service or is there some lacking or useless information. (Nicholas & Steyn, 2012, 455-456). React and Share -feature collects reactive and written feedback from users in Health Village. The service allows us to assess which pages should be further developed and where there is need

for improvement. The user can use the buttons at the bottom of the page (Figure 6). "Useful information" and "Just this is what I'm looking for" options give the user the opportunity to share the page on Facebook, Twitter or other social media. When I checked React & Share in September 2019, there were no open development ideas in feedbacks.

The screenshot shows a feedback form with the following elements:

- Header: "Up-dated 8.3.2019 7.39"
- Question: "Was this content helpful to you?"
- Response count: "Answers 25 PCs"
- Four buttons for feedback:
 - "Useful information" (thumbs up icon) with 15 votes
 - "Just this I'm looking for" (checkmark icon) with 5 votes
 - "Unclear information" (X icon) with 3 votes
 - "I need more information" (question mark icon) with 3 votes
- Section: "Give us feedback on content!"
- Text input field: "Write your feedback.."

FIGURE 6. React & Share

If we want to evaluate the benefits of e-learning, it can be done according to Kirkpatrick's four levels model. Model looks at the students' reactions and whether the learner is satisfied with the e-service, assess the learner's level of knowledge, assess the behavioral changes and last but not least evaluates the effects of the results, such as cost benefit or quality improvement. (Sinclair et al, 2015). The purpose of the second feedback was to assess benefits and accessibility of the Heart failure webservice. I collected feedback by email with more specific questions from five Savo Heart Club members in spring 2019. Questionnaire (ANNEX 2: Questionary for users of Heart failure webservice) was aimed to find out the usability of the website, the utility of the videos, pictures and links, and whether issues was understandable. What reader has learned after visiting website was asked with few questions about weight measuring and physical activity.

Respondents either totally agreed or mostly agreed with the statement that the front page had a clear view, webservice was easy to navigate, information was easy to read, links and pictures were interesting and useful, enough information about the causes of disease and prevention of infections. Respondents were able to answer correctly, questions when contact health professionals, why weight should be measured, what kind of exercise patient with HF can do and when it should be avoided. Respondents agreed that there was enough information about the treatment, the instructions for self-care were clear and motivating. All of them would recommend the webservice. Few recommendations about useful links was received but feedback did not arised other specific suggestions for further improvement.

Communication during about the web service during the project and maintenance phase is important to increase local healthcare workers awareness of new webservice. It is known that patient's participating in self-care and interacting between the patient and professional depends on quality of social and health digital services and how citizens can adopt those services in daily practice (Hyppönen et al, 2018, 3). Therefore, healthcare professionals must have the ability to guide the patient to the right service and know what web-service contains. Purpose of local meetings in Kuopio University Hospital Cardiac ward was to promote the skills of nurses and doctors to use a new web portal in patient education. End of the year 2018, I arranged a meeting in cardiac ward to discuss about how the health care staff has used Health Village webpages in patient education and motivated them to use it in the future. Nurses had not actively used webpages and preferred oral and printed educational material better. Instead, they have mentioned the patients who had smartphone or tablet on their own that Health Village is safe and will offer good information about heart diseases. Discharge nurse met most of the patients and remind them about Heart Hub before the discharge.

At the beginning of project work and maintainace phase my work included also regular meetings with other members of Virtual Hospital project group from "other Hubs" in Kuopio. The purpose was to learn from each other about digitalization, project working, and the promotion of the usage of eHealth services in different clinics at the hospital. I was also part of the Virtual Hospital project team in Kuopio University Hospital to increase local awareness of the Health Village.

To increase publicity, I presented Health Village in Kuopio cardiological nursing meetings in spring 2018 and in February 2019. There were dozens of nurses present from a wide area of North Savo, both hospitals and health centers. I held seminar speech in Joensuu cardiological multiprofessional meeting in spring 2018 to raise awareness about digital health and Health Village. Kuopion University Hospital's Virtual Hospital project group held small events around the Northern Savo Hospital District and I visited in four health centers and gave one interview to local newspaper. The national Health Village advertising campaign in April 2018 included television advertising and one weekend annex in tabloid at Easter time. I wrote two short texts for annex. After the publication Heart Failure webpage, I wrote some news in Health Village web portal and facebook to promote its use.

Health Village and Heart Hub are in different stages in different regions in Finland. Total visitors and sessions in Heart Hub in October 2019 were 22 815, there were 19 291 users and 41 527 pages were viewed within one month. Helsinki is clearly leading user statistics (8 983 sessions) and Kuopio was the last in the top 10 listings (278 sessions). (Analytics,

2019). Although the number of users is proportional to the population, there is clearly room for improvement in the use of Heart Hub portal in the Kuopio region.

Health Village is also in social media, in Facebook and Twitter. The Heart Hub release something interesting news regularly to attract more visitors to webpages. A woman called "Terttu" is funny old lady with HF and she acts in short films to tell visitors about her disease. We produced and released four short videos in Facebook about Terttu and in Heart Hub News during summer 2018 and winter 2019 to invite readers to the Heart Hub (Heart Hub, 2019e).

5.2 The output of the thesis

The output of the thesis was Heart failure website including 12 web pages of information and two educational videos which are available in address <https://www.terveyskyla.fi/sydansairaudet/tietoa-sydansairauksista/sydamen-vajaatoiminta>. HF quiz and two patient stories and 4 humorous videos about Terttu with heart failure, can be found in web address <https://www.terveyskyla.fi/sydansairaudet>.

The website was built using SharePoint 2010 publishing system, in the Health Village web portal. SharePoint 2010 is a versatile media platform owned by Microsoft that allows to create websites, share and store information securely (Microsoft, 2019). Technical support was given from HUS Informatics.

The accessible webservice is easy to use and provides adequate instructions to operate the site. Its content is easy to reach, forms fill up quickly and clickable areas large enough. The text should be easy to read, user interface intuitive and guiding, structure understandable and whole logical. (Eu, 2016; Papunet, 2018). The design of the content structure and graphics are based on the entire Health Village web portal structural and graphical design. It is important that the website uses high contrasts in color to distinguish text and background, making it easier to read (Association of Visually impaired, 2018).

The Heart failure websites were opened in the Heart Hub under main title "Information about Heart Diseases". Selected topics in websites were based on the theoretical basis for the education of a patient with HF and on the ideas that patients have brought during the project. Main topics and realization are introduced in Appendix 3 comparing them to previous ESC Guidelines about key topics on self-care (Table 1) and how the topics was implemented on the site. Main titles in Heart failure websites were 1. *What causes heart failure?* (this site was removed in the October 2019 update and moved under the "Treatment"


heading) 2. *Symptoms*, 3. *Diagnostic tests and follow up*, 4. *Treatment*, 5. *Selfcare* and 6. *Frequently asked questions*.

The purpose of the titles is to divide a large area of knowledge from HF into smaller portions and guide the readers to navigate in the webpage. The usability of the webpages is further enhanced by the fact that the amount of information on one page is limited. Too much complexity makes it difficult to understand content relationships and it may be difficult to find the main points of the text. Logical and hierarchical headings help browse and perceive the entire content of webpage. (Association of Visually impaired, 2018).


In addition to topics, two stories were produced in the *Experiment Stories* section, Soile's and Anna Liisa's experience stories about living with HF. Soile's story was a written story and Anna Liisa's story was a video. Earlier studies have shown that peer support is needed among people with HF (Kristiansen et al, 2017). Link to Rehabilitation Hub about HF and exercise and funny but educational Quiz are mentioned in the front page in Figure 7 (Heart Hub, 2019a).

Heart Failure


Heart failure is not an independent disease but a syndrome. It occurs when the heart's pumping power is weakened and the heart is unable to pump blood into the body's normal needs. Heart failure causes symptoms such as shortness of breath and loss of performance. The disease develops gradually and may affect the quality of life of the person affected and the daily living depending on the severity of the failure.




Heart Failure - video
Treatment of heart failure is focusing both the care of the reasons and prevention the symptoms.




What causes heart failure?
Reason can be high blood pressure, coronary artery disease or heart valvular disease.




Symptoms
Shortness of breath, exhaustion and swellings are typical symptoms of heart failure.




Diagnostic tests and follow up
Aim of the follow up is to evaluate the effectiveness of drug therapy, the need of new treatment possibilities and success of self-care.




Treatment
Different device therapies are available in addition of self-care and drug therapy.




Self-Care
Self-care includes healthy lifestyle, compliance with medical treatment and self observation.



Frequently Asked Questions
Is there any questions? You can find answers for frequently asked questions here.



Experiment Stories
Watch the video about Anna Liisa and the life with heart failure.



Test Your Knowledge
Test your knowledge in Quiz.

FIGURE 7: Front page of the Heart Failure webservice (temporary translation in English)

We developed playful but complementary HF quiz to measure the knowhow of readers and to repeat previous information. It included 20 questions about HF and 4 alternative responses, one of which is always correct. There are two straw cards available which can be used once during the game. With the cards participant can remove two answer options or use the hint. (Heart Hub, 2019b).

We developed also various exercises aim to activate the reader to carry out self-care and to monitor HF symptoms. Heart rate monitoring - exercise will also guide the reader to the Heart Association web pages to watch a video tutorial. Because detection of HF and worsening of it can be difficult for patients (Partanen & Lommi, 2014; Kristiansen et al, 2017) it is one of the most important things to guide for the patients (Content of self-care guidance in nursing patients with heart failure: Nursing guidelines, 2018; Heart failure: Current Care Guidelines, 2017). Every effort to help patient to recognize the symptoms and worsening of HF was done with a new tool, like Practice to monitor Your symptoms (Heart Hub, 2019c). However, when designing self-tests or symptom assessment tools in healthcare, software that guides for certain health-related activities, can be considered to be a medical device. In such cases, medical devices must bear the CE marking of conformity. (National Supervisory Authority for Welfare and Health. 2015). We avoid to design a medical device because in our symptom detection tool, patient answers the questions, receives a certain score and prompts to regularly monitor the symptoms and seek treatment if symptoms and scores increase but we do not give actual health related advices.

I selected photos to support the text content. There were a certain number of purchased rights to Mostphotos picture service and part of the photos were also taken by the Kuopio University hospital photographer for example Training to calculation liquids (Figure 8). The images are also intended to enliven the text and maintain the reader's interest.

Practice to calculate the amount of liquid consumed with meals.

Exercise 1: Calculating liquids. Task 1:
How much do you estimate the amount of liquids in your breakfast?

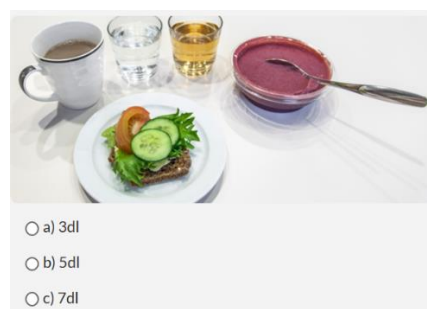


FIGURE 8: Training to calculate your liquids (Heart Hub 2019d)

The website uses a lot of headers and short paragraphs. Long texts are readable in the Spread and View more options to let the reader open an additional data box by selecting

the title. Previous and Next page helps to navigate in website. Navigating in the website can be made easier to make the path visible hole time by navigation tool, top of the page and on left. Reader knows "how deep" in the site he is and on the other hand, the menu on the left gives a hint where the reader can navigate next.

The structure and functions of the page should be conceivable without the visual interface. The entire content of the site must be accessible and executable on all keyboard functionalities, as some of the users may be visually impaired browsing webpages on the computer using keyboard and mobile scans. Navigation link texts must match the main headings of the content of the target pages. Clear and unique link texts are especially important for screen reader users who often navigate the page by moving from one link to another. (Association of Visually impaired, 2018). The Heart failure website also guides reader to other related topics in the Heart Hub. Other Health Village Hubs offer good, expert knowledge such as Rehabilitation Hub, Peer Support Hub and Infection Hub where the reader is directed from related topics. The reader is also directed to other useful and reliable sources such as the Finnish Heart Association and Duodecim websites to read the relevant research results of the current topic. The user is also guided to HeartFailureMatters.org webpage provided by European Society of Cardiology which offers reliable information and interesting animations in many languages. In the bottom of each webpage there is also navigation section and general information about Health Hub service, Users guide, terms and responsibilities, Co-operators and Feedback.

Search Engine Optimization (SEO) means that website is edited better for search engines and searchers. In Finland Google is most used as a search engine. Goal is to get a webpage search result at the top of Google's search results with selected keywords. In addition to SEO, content marketing and marketing through social media are essential to improve visibility. Content marketing means unique content that differs from others. The keyword is the Title, which is the title of the page that is displayed in the top bar of the browser. In order to improve visibility, priority is to create releable, well built and versatile content, which distinguish from other similar pages by its excellence. (Nippala, 2018, 8-12)

Using the meta description system can improve the searching of health-related information. The presence of a keyword in the meta description tag is important and the description should be unique on each page. The meta description means a well-descriptive phrase for the website placed in the HTML. It appers under page's URL after search results. (Nippala, 2018, 8-12). So, when the citizen writes "heart failure" ("sydämen vajaatoiminta" in Finnish) or something related to it, he/ she gets many search results and quickly gets an idea of what each webpage contains. I defined metadata and sufficient

keywords to help the reader find information about HF. Google search ranked our Heart failure webpage in sixth and seventh in early November 2019 (Google, 2019).

6 DISCUSSION

Many people suffer from HF in Finland and the incidence is increasing because the population is ageing (Lommi, 2014). The cost of treating a patient with HF is expensive (Lommi, 2014; Heart failure: Current Care Guidelines, 2017) and patients' quality of life is significantly impaired by a variety of symptoms and reduced physical performance (Nieminen, et al. 2015; Rustad, et al. 2013; Williams, 2017). Quality of life, prognosis and hospitalization rates can be improved by a good adherence to self-care and it requires that patient have sufficient knowledge and skills to act in daily life (Content of self-care guidance in nursing patients with heart failure: Nursing guidelines, 2018). Because many citizens use the Internet as a source of health information (Hyppönen et al. 2018) the development of reliable, high-quality and accessible web-based educational material is central to improve patient education.

The main objective of this thesis was to produce educational, motivating and practical web service for HF patients to increase their empowerment in daily life, adherence in self-care and thus improve their quality of life. In addition, the purpose was to create a new, usable education method for professionals and spread information about Heart Hub for all end-users. Together with professionals and patients, we managed to reach the objectives of producing interesting web service, that is available for everyone. It is already in use. The future, however, will show if the use of web service is really useful. The question is, will HF patients, their relatives and professionals use the service and if they benefit from it e.g. due to increase patients' quality of life or empowerment in daily life activities.

6.1 Evaluation of quality and reliability of the development work

Quality implies fitness for the intended purpose like system performance, safety, reliability and ease of use the product (Nicholas & Steyn, 2012, 322). The ability to evaluate means that organization is able to assess the user group needs, both patients and healthcare professionals who will use the eHealth service. Adequate scientific and technological standards must be assessed and reached with designing and implementation of eHealth technology. (Uruena et al, 2016). Part of quality is also an estimation of the economical value of the service and absence of defects (Nicholas & Steyn, 2012, 322). Quality control is an ongoing process, including inspection, testing, and problem solving (Nicholas & Steyn, 2012, 343).

In 2002, the European Commission published the Criteria for Health-related websites. The aim was to provide both publishers and users with guidance on how to meet the quality

requirements and what the website user can expect from the website. The quality requirements concerned both the open pages that are read and the healthcare services that are being produced. (Commission of the European Communities, 2002)

During this development work, I have tried to both reach high-quality output and ensure sustainability and continuity of service. The end-users and HF experts have participated in the definition, execution and evaluation phases. The webpages have been updated regularly and healthcare staff and public have been encouraged to adopt the new service. Estimating economic benefits is a challenge, but it can be thought that at least the production of written instructions and their costs will be reduced. Of course, if the website brings health benefits, it is also economically significant. I have used the following European Commission Criteria for evaluation quality of the websites.

6.1.1 Transparency, honesty and authority

According to Commission of the European Communities, sources of all information and the date of publication should be stated in the website. The names and credentials of all people / organizations that produce the information should be mentioned. (Commission of the European Communities, 2002). Publication date of original or up-dated text is stated in every page in Health Village web service. This is, however, a quite new feature that was not used at the beginning when the Health Village service was opened. The fact, that every site has not the source or writer of information reduces reliability of the site. Instead, author has been stated in the general information of Health Village and the information is provided by the University Hospitals. Therefore, a reader can assume that text is reliable and updated.

In addition, transparency means that the name of the person or organization, physical address and electronic address of the webpage provider are clearly stated. The purpose of the site, target audience and transparency of all sources of funding for the site must be clearly defined. (Commission of the European Communities, 2002). These quality requirements are clearly met on Health Village webservice (Health Village, 2018a).

6.1.2 Privacy and data protection

Data Protection legislation defines privacy and data protection practices and the processing of personal data, including those processes that are invisible to users. (Commis-

sion of the European Communities, 2002). Heart failure website doesn't collect any personal data and that's why the data protection issues are not relevant to evaluate. Security is regularly ensured by automatic threat scanning and by an independent security repositories security check (Virtual Hospital 2.0, 2019b).

If customer wants to sign up to Health Village Personal health path service to use self-care programs or digital health path, the personal data will be collected. There is clear statement how Health Village deals with customer's personal information. When the customer sign up, the data will be registered with the Helsinki and Uusimaa Hospital District (HUS) customer records and HUS is the controller of customer information. If customer uses the service as a part of the treatment relationship, the registrar is the hospital district or other health care unit which provides the customer's care. HUS provides and maintains the Health Village service and acts as a handler of the personal data. (Health Village, 2018b).

6.1.3 Accountability

Accountability means that feedback from the website users have been taken into account and responsibilities of website provider are defined. Editorial policy means a clear description of the selection of content (Commission of the European Communities, 2002). There are no comments on the selection of the content or of the feedback received of the Heart failure website. However, on the website several links are provided where an additional source can be found, in which the subject is dealt with depth or slightly differently.

Heart failure websites are created together with professionals and patients. The publishing material is created based on scientific knowledge and good practices. Heart failure websites are evaluated by both patients, patient organization and health care professionals.

The following sources has been used when selecting content of the Heart failure website

- Finnish Current Care Guidelines (2016)
- Clinical guidelines of European Society of Cardiology (2016)
- Finnish Nursing Recommendations (2018)
- Self-care book for Heart failure patient (Kuopio University Hospital, 2016)
- Other Research Data collected from patients (Dao Le, 2016; Kristiansen etc, 2017)
- Brainstorm session with heart failure patients in Kuopio University Hospital (Soininen, 2018a)
- Professional experiences and knowledge including writings, discussions, e-mails and feedback (Soininen, 2018b)

The reader is initially told that Heart Hub is an eHealth service developed by healthcare professionals (Heart Hub, Health Village, 2019). Altogether 1,500 health care and ICT-professionals from the five Finnish university hospitals have been building the Health Village service (Virtual hospital 2.0, 2019c).

It is possible to give user feedback directly for the producer in bottom of every website. Feedback will be handled either in technical support or between content developer depending on character of feedback. (Health Village, 2018c). React & Share -feature (FIGURE 6) is a new and useful tool to give instant feedback easily. In Heart Hub, there is pre-agreed update responsibilities (Leino, 2019), and the page's updater is responsible if feedback on content is displayed.

Responsible partnering means that all links and partners referred to on the website are trustworthy and who themselves adhere to good publishing practices (Commission of the European Communities, 2002). Where ever the links to other sites have been used, the original information was evaluated by professionals and the links and their providers are clearly mentioned.

6.1.4 Accessibility

Accessibility of a website is important. According to the Commission of the European Communities (2002) and the Association of Visually Impaired (2018), particular attention should be focused on physical accessibility of the website, searchability, readability and usability. E.g. Web Content Accessibility Guidelines (WCAG) 2.0 provides a clear guideline for producing accessible web content. Following these guidelines will ensure that the web-service is accessible to all people in general, but also to those with different kind of disabilities, such as visual or hearing impairment, learning or cognitive difficulties, motor problems, or any combination of these. (W3C, 2008).

In the case of a specific type of target audience, the presentation and content of the data must be appropriate for that audience (Commission of the European Communities, 2002). It is good to keep in mind that many people who use health services are elderly and may already have cognition flaws and are not familiar with the digital devices (Sepponen & Kettunen, 2013, 349-373). Especially among HF patients there might be difficulties for using digital services. Therefore accessibility should be payed careful attention. The patients involved in the development of these webpages were of all ages, active and already specialists for their own health. Reliability could have been increased by having websites evaluated by older patients with HF, such as home care clients.

As earlier mentioned, several suggestions for improvement of the accessibility were received from Visually Impaired - Northern Savo association (Heinonen & Kumpulainen, 2018). In addition, general website building guidelines were used, and user feedback was sought to improve accessibility of the website. However, there are still some weaknesses in Heart Failure webpages at the moment. The videos have no subtitles at the moment. This issue resolves at a time when the videos will be translated during winter 2019-2020. On the other hand, HF video explain the main points of HF briefly but the same information exists also in the text (Heart Hub, 2019g). The video associated with the observation of edema is very visual and, in that sense, understandable for the most people (Heart Hub, 2019h).

The accessibility of the Heart failure site has been reviewed once before an update in October 2019. Here, the accessibility was further improved by converting one of the instructions from image to text so that the screen reader can also interpret it. Also, for some of the pictures, the text equivalents were changed to more descriptive for those who use screen reader. E.g. in Figure 10 "A middleaged man is walking path and leans against a stone holding his chest".



FIGURE 10: Symptoms (Heart Hub, 2019i)

Usability and readability have been further improved especially for mobile devices, because over 50% of user use mobile phone to browse Heart Hub (Analytics, 2019). Splitting page content into different pages or using Read more feature to hide some text, deleting some texts or linking elsewhere to Health Village were the most visible improvements in October update.

Accessibility will further increase when Heart Hub will be translated into Swedish during the year 2020. In the future, the site should be translated at least into English in multilingual and -cultural Finland.

6.1.5 Quality awards for Health Village

One example of the quality of the Health Village service is that it was awarded in Future Developers Competition in 2018 (Suunnannäyttäjät). In the competition, digital projects and experiments to facilitate everyday life for citizens, were searched. The Health Village service award was justified by the fact that its remote services make special health care services "local services" that are available 24/7 to the citizens. Particular merit also was the use of scientific research and modeling of inclusion in the development of the website. (Suomidigi, 2018). The Health Village also won the Outstanding ICT Achievement Competition Grand Prix at the HIMSS-Elsevier Technology Contest for Digital Health. The aim of the competition was to find ICT solutions that improve patient care and address major challenges facing hospitals. (Keränen, 2019).

6.2 Evaluation of ethics of development work

Some decades ago, the ethical debate in health care arose mainly due to the rapid development of medicine and information technology and widespread concern about patients' rights. Individual responsibility and freedom gain new content as the medium of communication changes. People can easily find information about their problems and ways to participate in treatment and services. On the other hand, this includes the seed of inequality: how to secure sufficient information for those who cannot use new tools of obtaining information. (ETENE, 2012).

Ethical reflection in the social and health field is based on the dignity of the human in all action. It includes fundamental human rights, self-determination and freedom of choice. Care and service require patient involvement and consent meaning that the patient must have freedom of choice and autonomy. The starting point is always the customer's best interests, which means that the care and service are reliable and safe, and the actions is based on knowledge and professional skills. The interaction between both clients and professionals and between professionals is respectable and humane. In their work, health professionals take into account the age, level of development and resources of the patient, and pay special attention to vulnerable patients such as children, the elderly and people with disabilities. Social and health care professionals should be able to update their knowledge and skills adequately and have possibility to develop their working practices. (ETENE, 2012).

In this development work, one important ethical consideration focused on how to improve patient participation in their own care, as it has also been found to improve the prognosis

of HF. Although HF patients are usually elderly, the age is not a barrier to receive patient education through Internet (Hyppönen et al, 2018). Because there can be difficulties to adopt health related information especially among of HF patients (Kristiansen et al, 2017; Massimi et al, 2017; Gordon & Hornbrook, 2018; Lainscak et al, 2007), it is important that patients and their needs are taken into account in patient education. Crucially, patient educating takes into account the patient's ability and means to absorb information about his or her own care. The health care professional should evaluate and provide guidance in ways that are beneficial to the patient. It is known that patient with HF needs to learn lot's of new skills to manage with the disease and successful education can be achieved through a variety of methods and steps of treatment chain (ESC Guidelines for the diagnosis and treatment of acute and chronic heart failure, 2016; Content of self-care guidance in nursing patients with heart failure: Nursing guidelines, 2018).

Internationally the professionals expect to hear how Finland justifies and explains its investment and expenditure on eHealth. They want to know how Finland measures the benefits of its system and ensures maximum adaptation by clinicians and citizens. (eHTEL, 2013). Based on the THL FinSote study, it appears that measures to achieve the goals of the social and health care digitalization strategy require measures from social and health service providers, technology providers and national guidance. It is important that service providers develop virtual services in cooperation with different customer groups and ensure that the eHealth services are easily available, accessible and comply with information security requirements. The service provider must ensure that users are provided with sufficient support for the use of eHealth services. That requires professionals to adopt new digital skills to support patients. (Hyppönen et al, 2017, 6). Successful development of web-based services requires solid knowledge of what works, for whom and under what circumstances, especially from the point of view of citizens (Hyppönen et al, 2017, 3; Uruena et al. 2016). During this project I have supported professionals to increase their skills about new web-based guidance techniques, encouraged them to use web-based education and encouraged them to develop webservice.

When it comes to digitalisation change, it is important to understand the multi-professionalism in order to utilize the information, skills and vision of all parties, and that digitalisation can really help employees and organization (Dettmann et al, 2018). During this development work, health professionals has been informed about the website and its benefits has been communicated in various presentations, both locally in the hospital, in wide area of Northern Savo Hospital District, in Savonia University of Applied Sciences and promoting the Health Village nationally for both professionals and citizens. However, there is still much to do to raise awareness and how to use the website in everyday work especially here in Kuopio region.

Involving patients in digitalisation projects is one of the most important ways to increase patient-centeredness and usability of new digital services (European Commission, 2018). Patients have been involved in the early stage of development of websites to ensure usability. Respect for self-determination has been essential during this development work for example when I invited volunteering for interviews in brainstorming session and to write peer stories. Appropriate permissions have been collected from individuals who appear with their own name on the Heart failure website and signed performance agreements are properly stored. The identity of those interviewed in group interviews or surveys has been kept secret. All respondents are dealing with heart disease and the respondents form a heterogeneous group of people of different ages and backgrounds. Therefore, efforts have been made to promote polyphony throughout the development process. Ethical evaluation should focus on the reliability and usability of the website for all groups of people. For this reason, accessibility has been evaluated from a number of points of view. Accessibility should be further promoted in the future, both by making the site more usable and by taking into account the feedback that is given to improve the site. On the other hand, people who may be at the most disadvantage group, who are completely unfamiliar with the Internet or have a poor interest in their own health, have not been sufficiently taken into account during this development work. Indeed, it is challenging to reach out to these groups of people, and to raise their interest in finding and utilizing the health information available on the Internet.

According to ethical standards, all rational choices, resourcing, and division of labor between social and health work communities should deliver the best possible outcomes for clients and patients (ETENE, 2012). This means that in addition to evaluation of the end-product, I have to evaluate the quality of working methods and appropriate use of the resources during the project. It is necessary to clarify that, giving workforce for half year for coordinate this project is not cheap for the hospital. Nor is it irrelevant cost in today's society when every resource for health care needs to be critically evaluated and lay outs of workforce are ongoing in several hospital districts (HS, 2019). Critical evaluation also includes evaluating timetable and on budget (Nicholas & Steyn, 2012, 343). Although the actual manuscript was ready earlier than expected, text formatting and compression, the quiz, and production of the symptom assessment tool took longer than expected. The whole project, however, was completed earlier than expected. On the other hand, during the period which was planned for the project, other digital patient services for the heart patient were developed. So the time was used effectively. The funding was not exceeded, but the use of the staff was not effective.

The biggest risk during the project work was that the project was side-job for other project team members. Thus, I had a big role in the project which may affect to quality and

continuity of webservice. The sustainability and continuity of websites is one of the ethical concerns. All five University hospitals has agreed on who will update Heart Hub website in the future. Kuopio University Hospital has committed to update Heart failure website and some other sites of the Heart Hub, and these responsibilities are documented (Leino, 2019). The site is intended to be reviewed annually and the employer must arrange working hours for this updating.

6.3 Thesis as a learning process

My personal goal was to increase understanding and skills in project management, presentation, production of digital health services and being part of the national network of digital health.

Jumping into the project ment me entering into completely unknown field without knowing what was coming. Studying in this Master´s Degree Programme has supported the implementation of this project and development work. On the other hand, Virtual Hospital project framework, training and cooperation have brought a huge amount of understanding of the health care digitalization. I was lucky to be involved to this unique project which gave me a lot of responsibility for me, without been professional of heart failure or digitalization.

This development work and project time prepared me to understand the developing process of web-based platforms in multiprofessional teams. During the project I became involved with both the hospital's own and the national digitalization and Health Village development teams. On the other hand, I was part of the group of professionals involved in the patient education and care of HF patients. I also learned how important and rewarding it is to involve end-users, and especially patients, in the various stages of development work. Furthermore, I realized how using digitalization in patient care can be difficult to adopt for both professionals and patients, and how development work must continuous to make the webservice a daily routine in patient education. New tools and skills for project management and understanding my own developmental needs, such as delegate skills, are an important part of learning also. Writing thesis has been a long and sometimes tiring prosess. However, refining and finishing this thesis has made me understand not only new things about the whole development work, but also justifying the work, understanding that constant evaluation is necessary and actually seeing that the development has been in line with quality requirements.

These skills that I learned are in many ways necessary now and especially in the future of digital health care. This development work has given tremendous professional growth and

the starting points to understand and to lead new kinds of projects and it has given also opportunities for new working possibilities.

6.4 Conclusions and future development ideas

Implementation of eHealth technology can be technically successful, but the introduction and adoption of programs into the healthcare professionals' everyday work or patient's real life will necessarily not succeed (Juntunen, 2012,17; Uruena et al. 2016). eHealth projects may remain in "pilot stage" if there are not invested enough in organizational eHealth management skills and practices (Uruena et al. 2016). Leading digital change requires encouragement, inspiration and supporting. Organization must provide and leader have to assign working hours for training professionals to use digital services and these should be user friendly and developed in multi-professional groups. (Sihvo & Hämäläinen, 2018). Health Village webservice and Heart failure websites are intended to be used permanently and require people's commitment to update and maintain the websites. This requires the commitment of the hospital management to provide the organization's employees enough working hours and also financial recourses for development work.

In the future nurses and other professionals should provide information on the Internet even for those patients whose internet use is not so familiar and thus increase equality in health literacy. Because HF and co-morbidities may influence retention of information the guidance should be individually tailored and combined to several guiding interventions in several steps in treatment chain. So, most importantly is to choose a method of guidance where the patient benefits the most and understand the guidance. However, recommendation and purchasing equipment in health care environments should be considered to increase access to safe web-based health information.

Based on discussions in project group meetings during this project there is still lack of guidance especially in emergency care in Kuopio University Hospital. Patient with HF do not meet the specialized HF nurse, although it would be ideally that lifestyle advice should begin prior to discharge for those patients admitted to the hospital. There is a risk that patient never get's proper counselling about the disease and may be rehospitalized because lack of information and adherence to selfcare. Any healthcare professional can guide the patient to Heart failure websites. Using webservice may increase patient empowerment and help professionals to educate HF patients better. Web-based guiding is also cost-effective guiding method if people are aware and have ability to use services.

Future development topics:

1. Improving usability of web service based on user survey and recommendations
2. Organising information sessions for employees who take care for patients with HF in different wards at the hospital and in health centers
3. Increasing awareness of Health Village webportal and health literacy of those citizens who may not have yet been searched health information on the Internet for example at local libraries, shops, restaurants and public events.

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APPENDIXES

APPENDIX 1: RESPONSIBILITIES AND ROLES OF HEART FAILURE SUB-PROJECT

Project team member	Tasks and duties
Project manager and project owner. Chief physician in Heart Center in Kuopio University Hospital.	Responsible for the project goals, planning, implementation, timetable and division of responsibilities.
Project coordinator of Heart failure subproject. Registered nurse in Heart Center in Kuopio University Hospital.	Coordinates the work of the project group. Arrange meetings and brainstorm. Inform and reports about the progression. Produce and edits the contents. Stores the contents in sharepoint online. Collects feedback. Updates and maintains the content.
Specialized heart failure nurse in Heart Center in Kuopio University Hospital	Content expert. Produce contents and material (text) about chronic heart failure. Updates and maintains the content.
Specialized physiotherapist in heart diseases, Kuopio University Hospital	Content expert. Member of Rehabilitation house. Produce material to Rehabilitation hub about exercise in heart failure.
Specialized nurses in acute heart failure in Cardiac Care Unit in Kuopio University Hospital.	Produce material about acute heart failure or worsening of chronic heart failure/ hospital care.
Cardiologists in Heart Center in Kuopio University Hospital.	Produce ideas and content, inspect the contents. One cardiologist presented in videos.
Leader of the development of Virtual Hospital 2.0 project in Kuopio University Hospital.	Developer and coordinator of Virtual Hospital 2.0 in Kuopio University Hospital. Supports the project implementation, organizes and coordinates training and meetings with different project team members.
Administration chief physician in Kuopio University Hospital Head of the Virtual Hospital 2.0. project in Kuopio University Hospital in 2017-2018.	Manager of Virtual Hospital 2.0 in Kuopio University Hospital. Strategy leading, the approval of subprojects and the monitoring of the project and the status.
Project coordinator of Heart Hub in Helsinki University Hospital in 2017-2018.	National Project coordinating of Heart Hub. Reporting to the project management.

APPENDIX 2: QUESTIONNAIRE FOR USERS OF HEART FAILURE WEBSITE

I am assessing the usability of the Heart failure website. It is part of Health Village Heart Hub webservice. Your opinion on the usability and understandability of the site helps me to improve the contents, readability and attractiveness of the site. The website address is www.terveyskyla.fi/sydansairaudet/tietoa-sydänsairaus/sydämen-vajaatoiminta.

Some of the following statements and questions evaluate the practicality of the site and some measure the understandability of the education. Please, mark the title of the page where you suggest changes.

The heart failure section on the front page provided me with a clear view of the content of the website. <https://www.terveyskyla.fi/sydansairaudet/tietoa-sydänsairauksista/sydämen-vajaatoiminta>

Totally agree__ Mostly agree__ Mostly disagree__ Totally disagree__

Development idea: _____

There was enough information on the causes of heart failure. <https://www.terveyskyla.fi/sydansairaudet/tietoa-sydänsairauksista/sydämen-vajaatoiminta/mika-aiheuttaa-sydämen-vajaatoiminta>

Totally agree__ Mostly agree__ Mostly disagree__ Totally disagree__

Development idea: _____

Instructions for preventing and treating heart failure were clear. <https://www.terveyskyla.fi/sydansairaudet/tietoa-sydänsairauksista/sydämen-vajaatoiminta/mika-aiheuttaa-sydämen-vajaatoiminta>

Totally agree__ Mostly agree__ Mostly disagree__ Totally disagree__

Development idea: _____

Tell what symptoms heart failure may cause and when should You search for help? <https://www.terveyskyla.fi/sydansairaudet/tietoa-sydänsairauksista/sydämen-vajaatoiminta/oireet>

The site for treating heart failure provided sufficient and clear information. <https://www.terveyskyla.fi/sydansairaudet/tietoa-sydänsairauksista/sydämen-vajaatoiminta/hoito>

Totally agree__ Mostly agree__ Mostly disagree__ Totally disagree__

Development idea: _____

The instructions for self-care for heart failure were clear and motivating. <https://www.terveyskyla.fi/sydansairaudet/tietoa-sydänsairauksista/sydämen-vajaatoiminta/omahoito>

Totally agree__ Mostly agree__ Mostly disagree__ Totally disagree__

Development idea: _____

In your own words, tell why should a heart failure patient monitor weight regularly?

In your own words, tell what kind of exercise can a person with heart failure do? When to refrain from exercise? _____

It was easy to find information about exercise in heart failure patients.

Totally agree__ Mostly agree__ Mostly disagree__ Totally disagree__

Development idea: _____

There was enough information on rehabilitation and peer support.

Totally agree__ Mostly agree__ Mostly disagree__ Totally disagree__

Development idea: _____

It was easy to 'navigate' on the website, the site was logical.

Totally agree__ Mostly agree__ Mostly disagree__ Totally disagree__

Development idea: _____

Evaluate the necessity, attractiveness and relevance of the images used on the site. _____

Evaluate the necessity and attractiveness of the links on the site. _____

Would you recommend the website to others?

Totally agree__ Mostly agree__ Mostly disagree__ Totally disagree__

Development idea: _____

What information you missed or would you like to say something about the website?

Thank you for your involvement in developing the Heart Failure web site.
Your opinions and answers are valuable and will be taken into account when updating the site in spring 2019.

Sincerely, Katja Soininen

For more information, please contact katja.soininen@kuh.fi

APPENDIX 3: EDUCATION TOPICS IN HEART FAILURE WEBSITE

Education topic	Realization in webpage	Main title of the web page in Finnish and sub-heading/ question (and address, if realization is in other webpage than in the Heart failure webpage)
HF disease and individual status of HF (and the end of life)	Heart failure (+ video) <i>Individual treatment plan can not be done in public websites</i> Worsening of heart failure Palliative care, relieving of symptoms FAQ: What is the prognosis in patients with heart failure?	Sydämen vajaatoiminta (+video) <i>Yksilöllistä hoitosuunnitelmaa ei voida avoimilla sivuilla toteuttaa</i> Sydämen vajaatoiminnan vaikeutuminen; Palliativinen eli oireita lievittävä hoito UKK: Mikä on sydämen vajaatoiminnan ennuste?
Symptom monitoring and self-care	Symptoms Self care Recording of symptoms and quality of life Observation and treatment of edema (video) Action model when symptoms worsen Measuring the weight, blood pressure and the heart rate.	Oireet Omahoito Oireiden ja elämänlaadun seuranta Turvotusten tarkkailu ja hoito (video) Toimintamalli oireiden vaikeutuessa Painon, verenpaineen ja sykkeen seuranta
Pharmacological treatment (side effects)	Treatment: Medicine Medicines to be avoided FAQ: What are the side effects of pharmacological treatment?	Hoito: Lääkehoito Vältettävät lääkkeet UKK: Mitä haittoja lääkitys aiheuttaa?
Devices and interventions	Treatment Worsening of heart failure Device therapies for heart failure	Hoito Sydämen vajaatoiminnan vaikeutuminen Sydämen vajaatoiminnan laitehoidot
Immunization	Prevention and treatment of infections	Tulehdusten ehkäisy ja hoito
Diet and alcohol (fluid intake, salt, weight, malnutrition, obesity)	Liquid restriction and diet Practice: Calculation of fluid intake. Salt, Malnutrition, Obesity, Alcohol	Nesterajoitus ja ravitsemus Harjoitus: Nesteiden laskeminen Suola; Vajaaravitsemus; Ylipaino; Alkoholi
Smoking and recreational substance use	Heart disease and smoking (in Heart Hub)	Sydänsairaus ja tupakointi (Sydänsairaudet talo) https://www.terveyskyla.fi/sydansairaudet/itsehoito/sydansairaus-ja-tupakka
Exercise	Heart failure and exercise (in Rehabilitation Hub)	Sydämen vajaatoiminta ja liikunta (Kuntoutumistalo)

		https://www.terveyskyla.fi/kuntoutumistalo/kuntoutujalle/sydansairaudet/sydämen-vajaatoiminta-ja-liikunta
Travel and leisure	<p>FAQ: Can I travel?</p> <p>FAQ: How much can I exercise?</p> <p>Tips for coping</p>	<p>UKK: Voinko matkustaa?</p> <p>UKK: Kuinka paljon voin rasittaa itseäni?</p> <p>Vinkkejä jaksamiseen</p>
Sleep and breathing	Self care: The quality of sleep (includes information about sleep apnea)	Omahoito: Unen laatu
Sexual activity	<p>FAQ: Why sexual activities feels so difficult?</p> <p>Self treatment: Heart disease and sexuality (in Heart Hub)</p>	<p>UKK: Miksi seksi tuntuu niin vaikealle nykyisin? linkit:</p> <p>Itsehoito: Sydänsairaus ja seksi</p> <p>https://www.terveyskyla.fi/sydansairaudet/itsehoito/sydansairaus-ja-seksi</p>
Psychosocial aspect	Self care: Mental health	Omahoito: Mieliala
Other symptoms/ disorders	<p>FAQ: Why did I get gout?</p> <p>FAQ: I often have often cramps in lower extremities. What helps?</p> <p>FAQ: Having gastric swelling and pain. What helps?</p>	<p>UKK: Miksi minulle puhkesi kihti?</p> <p>UKK: Minulla on usein jalkakramppeja. Mikä avuksi?</p> <p>UKK: Vatsa turpoaa ja tuntuu kipeälle. Mitä voin tehdä?</p>
Driving car	FAQ: Am I allowed to drive car?	UKK: Saanko ajaa autoa?
Difficult terms	<p>FAQ: What means systolic and diastolic heart failure?</p> <p>FAQ: What means EF?</p>	<p>UKK: Mitä systolinen ja diastolinen vajaatoiminta tarkoittaa?</p> <p>UKK: Mitä tarkoittaa EF eli ejectiofraktio?</p>
Rehabilitation	<p>FAQ: Where can I get rehabilitation?</p> <p>FAQ: Where can I get peer support?</p>	<p>UKK: Mistä voin saada kuntoutusta?</p> <p>UKK: Mistä saan vertaistukea?</p>
Lack of iron	FAQ: What means iron deficiency?	UKK: Mikä raudanpuute?