UMEÅ UNIVERSITY

Finding a Common Ground

A pilot implementation of digital self-management support in Swedish primary health care

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To my beloved son Gustav

*"Tell me and I forget, teach
me and I may remember,
involve me and I learn."*

– Benjamin Franklin

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Abstract

Background
Due to an ageing, multi-diseased population, type 2 diabetes (T2D) and other chronic conditions pose a challenge for primary healthcare. To meet such challenges, primary healthcare nurses must adapt to new roles and acquire new skills regarding self-management support. eHealth and digital solutions are suggested to facilitate the increasing need for care in chronic conditions. However, how these solutions are experienced among users has not yet been sufficiently explored. To successful implement new working methods in primary healthcare, it is important to identify prerequisites and barriers that exists.

Aim
The overall aim of this thesis was to explore perceptions among primary healthcare nurses and patients about digital self-management support in T2D and also to develop and evaluate a digital screening instrument assessing individual needs for self-management support. This thesis is based on four papers. Papers I and II aimed to describe perceptions among primary healthcare nurses and people with T2D of using eHealth services for self-management support. Paper III aimed to develop and psychometrically test a screening instrument for person-centred guidance and self-management support. Paper IV aimed to describe diabetes specialist nurses' experiences of a pilot implementation of the instrument labelled the Self-Management Assessment Scale (SMASc) as a basis for person-centred digital self-management support.

Methods
A combined approach was used to collect and analyse data. Data in the qualitative studies were collected by means of focus group interviews (I) and individual interviews (II, IV) as well as participant observations (IV) were analysed using qualitative content analysis (I, II, IV). Quantitative data in study III were psychometrically tested. The participants in the respective studies were in Paper I primary healthcare nurses (n = 24), in Papers II and III people with T2D (n = 11; n = 104) and in Paper IV diabetes specialist nurses (n = 5) and people with T2D (n = 14). All data were collected in a county in northern Sweden.

Results
The overall results constituted a web of mixed experiences and feelings towards using digital self-management support. Primary healthcare nurses described an ambivalence towards the digital development in healthcare (I). Patients as well had mixed feelings, but they also described benefits and potentials leading to increased involvement and empowerment (II). The psychometric assessment of the screening instrument, SMASc, demonstrated high potential and promising

results for clinical assessments on factors affecting self-management behaviours (III). Preliminary results suggest that the SMASc instrument is considered suitable for screening of patients' needs for self-management support (IV).

Conclusions

The results of this thesis suggest that digitalization needs stepwise implementation. Digital tools such as the SMASc instrument can be useful in facilitating identification of patients in need of targeted interventions. However, primary healthcare nurses must be open to discussing patients' emotional adaptation to the disease as well as the knowledge, sometimes not evidence based, the patients may have obtained from Internet sources. Targeted self-management support including person-centred guidance is suggested to be an effective way to achieve patient empowerment.

Keywords

Type 2 diabetes, diabetes specialist nurse, district nurse, diabetes care, primary healthcare, eHealth, digitalization, technology, person-centred care, self-management, self-management support, qualitative research, questionnaire, psychometrics, pilot implementation

Abbreviations

Apps	Applications
BMI	Body mass index
DSN	Diabetes specialist nurse
eHealth	Electronic health
HbA1c	Refers to glycated haemoglobin (A1c), which identifies average plasma glucose concentration levels over the previous 2–3 months
iSMS	Interactive self-management support
mHealth	Mobile health
PHC	Primary Healthcare Centre
SMASc	The Self-Management Assessment Scale
T2D	Type 2 diabetes
WHO	World Health Organization

Svensk sammanfattning

Bakgrund

I och med en förändrad befolkningsstruktur med en allt äldre befolkning står Sverige inför stora samhällsutmaningar. Teknikutveckling samt att vården har förbättrats gör att fler kan leva längre trots sjukdomar, som typ 2 diabetes (T2D). Detta medför en utmaning, i synnerhet för primärvården. För att möta denna utmaning måste distriktssköterskor och annan hälso- och sjukvårdspersonal anpassa sig till nya roller och förvärva ny kunskap om egenvårdsstöd. Elektronisk hälsa (eHälsa) och digitala lösningar föreslås kunna underlätta arbetet med det ökade vårdbehovet vid kroniska tillstånd. Hur sådana lösningar upplevs bland användarna har ännu inte undersökts tillräckligt. För att kunna implementera nya arbetssätt i primärvården är det viktigt att känna till vilka förutsättningar som finns.

Syfte

Det övergripande syftet med denna avhandling var att undersöka personer med T2D och distriktssköterskors uppfattningar och erfarenheter av digital egenvårdsupport samt att utveckla och utvärdera ett personcentrerat digitalt screeninginstrument som identifierar patienters individuella behov av egenvårdsstöd. Avhandlingen baseras på fyra delstudier där delstudie I och II syftade till att beskriva uppfattningar och erfarenheter kring att använda eHälsotjänster för att underlätta egenvårdssupport bland distriktssköterskor inom primärvården samt bland personer med T2D. Delstudie III syftade till att utveckla och psykometriskt testa ett digitalt screeninginstrument för personcentrerad vägledning och egenvårdssupport. Delstudie IV syftade till att beskriva hur diabetessköterskor upplevt en pilotimplementering av ett digitalt screeninginstrument (SMASc) som bas för personcentrerad egenvårdssupport.

Metod

Olika metoder kombinerades för att samla in och analysera data. Data i de kvalitativa studierna samlades in med hjälp av fokusgruppintervjuer (I) och individuella intervjuer (II, IV) samt observationer (IV) och analyserades med kvalitativ innehållsanalys (I, II, IV). Kvantitativa data i studie III användes för psykometrisk testning. Deltagarna i de respektive studierna var distriktssköterskor i delstudie I (n = 24), personer med T2D i delstudie II, III och IV (n = 11; n = 104; n=14), samt diabetessköterskor i delstudie IV (n = 5). All data insamlades inom Region Västerbotten i norra Sverige.

Resultat

Övergripande visade studierna på blandade erfarenheter och känslor kring att använda digital egenvårdssupport. Distriktssköterskor uttalade ambivalens kring den snabba digitala utvecklingen inom vården (I). Patienter med T2D beskrev också blandade känslor men de uttalade tydligare fördelar och den potential som finns i den digitala utvecklingen som kan leda till ökat engagemang och empowerment (II). Den psykometriska testningen av screeningsinstrumentet, SMASc, visar på god potential att användas för klinisk bedömning av olika psykosociala faktorer (III). Preliminära resultat visar också att SMASc-instrumentet av diabetessköterskor anses vara användbart och lämpligt för screening av patienters individuella behov av egenvårdssupport (IV).

Konklusion

Resultaten från studierna i avhandlingen visar att digitaliseringen kan upplevas genomföras för snabbt och behöver implementeras stegvis för att användarna ska känna att de har nytta av den. Ett digitalt verktyg som SMASc-instrumentet kan vara användbart i kliniskt bruk för att underlätta identifiering av patienter som behöver riktade insatser. Sjuksköterskor i primärvården måste dock vara öppna för att diskutera patienternas känslomässiga anpassning till sjukdomen såväl som den, ibland ej evidensbaserade, kunskap patienterna fått från Internetkällor. Personcentrerad egenvårdssupport föreslås vara effektiv och leda till att personer med typ 2 diabetes kan uppnå empowerment och förbättrad egenvård.

Nyckelord/Sökord

Typ 2 diabetes, diabetessköterska, distriktssköterska, diabetesvård, primärvård, eHälsa, digitalisering, teknologi, personcentrerad vård, egenvård, egenvårds-support, kvalitativ forskning, frågeformulär, psykometri, pilot implementering

Original papers

This thesis is based on the following papers, which will be referred to in the text by their Roman numerals:

I.   Öberg, U., Orre, C. J., Isaksson, U., Schimmer, R., Larsson, H., & Hörnsten, Å. (2018). Swedish primary healthcare nurses' perceptions of using digital eHealth services in support of patient self-management. *Scandinavian Journal of Caring Sciences,* 32(2):961-970. doi:10.1111/scs.12534

II.   Öberg, U., Isaksson, U., Jutterström, L., Orre, C. J., & Hörnsten, Å. (2018). Perceptions of persons with type 2 diabetes treated in Swedish primary health care: Qualitative study on using eHealth services for self-management support. *Journal of Medical Internet Research (JMIR) Diabetes*, 3(1):e7. doi:10.2196/diabetes.9059

III.   Öberg, U., Hörnsten, Å., & Isaksson, U. (2018). The Self-Management Assessment Scale (SMASc): Development and psychometric testing of a screening instrument for person-centred guidance and self-management support. *Nursing Open*. doi: 10.1002/nop2.233

IV.   Öberg, U., Orre, C. J., Hörnsten, Å., Jutterström, L., & Isaksson, U. Using the Self-Management Assessment Scale (SMASc) as an instrument for screening self-management support needs in type 2 diabetes — experiences from nurse-led digital self-management support in Swedish primary health care. *Manuscript*

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Introduction

My entry into doctoral studies originated in a meeting with representatives from the Department of Nursing in Umeå and the management of the County Council of Västerbotten to start a joint project that would include the concepts of eHealth, chronic conditions and self-management. In 2014, I had the opportunity to pursue my interest for nursing research in these topics in a project with a purpose of facilitating self-management support for people with chronic conditions by means of eHealth. Type 2 diabetes (T2D) is a chronic and progressive long-term condition which has increased, and is thereby a challenge for healthcare systems (1). New models of care are needed to meet this challenge. The increasing need for cost-effective, time-effective and preventive healthcare is forcing changes in current healthcare systems. Digitalization in healthcare provides new opportunities for supporting people in the management of T2D. This thesis attempts to reflect a person-centred perspective. However, to be person-centred in clinical T2D practice, nurses' perspectives must also be approached. This thesis therefore presents both patients' and nurses' perceptions of digital self-management support in primary healthcare, as well as experiences of development and use of a digital tool to screen for self-management support needs. Standardized methods such as guidelines and digital tools for self-management support can be helpful, but only if they include options to adjust support for every person. Self-management support has in the past several years evolved beyond the practice of just providing patients with information about the disease and disease management (2).

Since this thesis is based on the underlying theoretical assumption that self-management support should be person-centred, it seems important to first focus on what is meant by a person. A person is unique, creative and curious, with feelings, thoughts and beliefs that are shared and nourished through interactions with others. It is in the encounter with others that a person grows, evolves and finds her/his identity (3). A person is defined by other persons she/he interacts with and grows within a social context characterized by mutuality, trust and respect (4). Each person constitutes a meaning maker in interactions with others, and is imbued with resources gained from past engagements as well as with a capacity to reflect about oneself (4). In this thesis, the terms "person" and "patient" are used interchangeably, depending on the context, and the different terms are therefore not viewed as contradictory. In the context of being at home or in a private sphere, the term person will be used to capture the concept of the individual. In the context of being within the institution of healthcare systems, the concept of the individual will be labelled as patient, although in reality, a patient is always first a person. The focus in person-centred care is on the person's

narrative, shared decision-making and on documentation that contributes to the partnership between the individual and the healthcare professional (cf. 5).

Person-centredness is a standard of care that ensures that the patient, as a person, is at the centre of care delivery. The theoretical basis of person-centredness has evolved from a care pathways framework to encompass the philosophy of personalism and has its roots in humanistic psychology and the work of Rogers (6) and Heron (7). To encompass the philosophy of personalism, the concept of "personhood" is suggested to counter a biomedicalised and reductionist view of the person. Personhood is defined as a socially based understanding of the human being in relation to others (4). In person-centred care, health professionals strive to understand the person's everyday life, the social world of the person, including relationships and interactions with others, and also the person's inner beliefs about own values, goals and motivations (8).

Ricoeur (9) describes the capable person – "homo capax" – as an individual with awareness, meaning, self-respect and self-esteem. In Ricoeur's writings about the capable person, there is an important notion about personal responsibility for one's own actions, where responsibility is exercised by remembering and reflecting upon one's actions. This is close to self-management support, which is an important focus in this thesis.

"*eHealth is the single most important revolution in healthcare since the advent of modern medicine, vaccines, or even public health measures like sanitation and clean water*"

Silber, 2003

Background

A rising incidence of an ageing population with multiple chronic diseases is a primary challenge for 21st century healthcare systems, and as a consequence, the employees must prepare for changes in priorities and duties (10).

The number of individuals with non-communicable chronic diseases and multi-morbidity is growing due to the population's rapid aging and longer individual lifespan (10). The number of older people — those aged 60 years or over — is expected to more than double by 2050 and to more than triple by 2100, rising from 962 million in 2017 to 2.1 billion in 2050 and 3.1 billion in 2100. Globally, the population aged 60 or over is growing faster than all younger age groups. By 2050 the number of people aged 80 or over will be tripled, and all major areas of the world, except Africa, will have nearly a quarter or more of their populations aged 60 or above (11). In Sweden the average life span is 84 years for women and 81 years for men (12). A common chronic disease among older people is T2D, which is steadily increasing worldwide (13). Diabetes mellitus (DM), where T2D accounts for 85%–90% of all cases, is one of the most challenging chronic health problems today. The diabetes prevalence is expected to increase from 422 million in 2014 to 629 million in 2045, and DM is the fourth to fifth leading cause of death in most high-income countries (14). In Sweden – though the increase has diminished – in 2017 about 5% of the population were estimated to have DM, which is more than 450,000 persons. Of those, 370,000, mostly with T2D, were treated in primary healthcare (15). An increased number of elderly patients with T2D (13), together with increased personal and societal needs and financial constraints, and today's constant shortage of health professionals, is creating challenges for the welfare system, of which primary healthcare is an important component (16, 17). In these circumstances, eHealth presents both a challenge and an opportunity.

eHealth

eHealth and/or digitalization of healthcare is becoming increasingly important in models to deliver tools for self-management and health communication systems. Such tools and systems – if easily accessible – have a potential to reach a wide population including rural areas, and can become equitable and efficient in healthcare. In addition, the Swedish government and the Swedish Association of Local Authorities and Regions also want to endorse a common vision for eHealth (18, 19). One goal is that, by 2025, Sweden will be best in the world by using the opportunities offered by digitalization and eHealth to make it easier for people to achieve good and equal health and welfare, and to develop and strengthen their own resources for increased independence (19). A strategy to involve patients in

self-monitoring and treatment of T2D, while they are at home, is of crucial importance, and there is a need to optimize the delivery of care, such as through interactive self-management support. eHealth solutions have the potential to modify the way in which people use primary health services, both by increasing access to information and by providing other forms of support remotely (cf. 20). According to the World Health Organization (WHO), eHealth has a potential to strengthen healthcare systems and to improve the safety, quality and efficiency of care (21).

When unpacking the concept of eHealth, the technology infrastructure is shown to offer many different computer/information systems, digital products and services aimed at supporting healthcare professionals and patients in primary healthcare. eHealth applications are rarely embedded systematically within primary healthcare today, since various digital systems lack interoperability. These practices might say something important about how eHealth is involved in self-management support, and how prepared healthcare professionals are for the transition from face-to-face, often annual visits, to digitalized self-management support.

The term eHealth has been in use since the late 1990s (22). eHealth, as a term, derives its "e" from "electronic", an ontogeny it shares with related e-words such as e-commerce, e-business, and e-solutions (23). There are many definitions of the umbrella term eHealth, which is a label on system level of health and healthcare supported by digital or electronic processes (24). eHealth is generally defined as the use of information and communication technologies (ICT), especially the Internet, for health promotion, disease prevention and disease management (23- 25).

Terminology relating to eHealth includes, for example, information technology (IT), which refers to computing technology such as networking, hardware, software and the Internet or the people that work with these technologies (26). Health information technology (HIT) refers to a way of exchanging health information while protecting patients' privacy and improving the safety, efficacy and quality of care (27). This area covers a broad concept that encompasses a range of technologies to store, share and analyse data, and the maintenance of automated and interoperable health information systems (HIS), as, for example, electronic health records (EHRs) for the healthcare sector. HIS are expected to improve healthcare, lower costs, increase efficiency, reduce errors and improve patient satisfaction (28).

Telemedicine, on the other hand, refers to the use and processing of e-mail, tele-consultations and conferences via the Internet and multimedia approaches such

as digital text, audio, video or still images (29) relevant to diagnosis and treatment of medical conditions or to provide health services or aid healthcare personnel at distant sites (30). TeleHealth refers to the use of synchronous (interactive) technologies such as videoconferencing or telephony to deliver medical care and health and disease prevention to patients (31). Home Tele-Health refers to the use of telecommunications by home care providers to link individuals to out-of-home sources of care (32). Mobile Health (mHealth) refers to health, diagnostic and disease control supported and monitoring by mobile devices, such as mobile phones, patient monitoring devices, personal digital assistants and other wireless devices (33). The demand for apps is growing rapidly, and it is estimated that by 2018, 1.7 billion smartphone users worldwide had downloaded an app for health (34, 35).

Within this thesis, Eysenbach's definition of eHealth is used as a term for distance-bridging applications:

> [A]n emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies. In a broader sense, the term characterizes not only a technical development, but also a state-of-mind, a way of thinking, an attitude, and a commitment for networked, global thinking, to improve healthcare locally, regionally, and worldwide by using information and communication technology. (22)

Within this thesis, "eHealth", "digital health" and "digitalization" will be used interchangeably and describe different applications of information, computer or other communication technologies to facilitate a person's health or healthcare.

Health and disease

While eHealth is a term describing electronic healthcare provision from a system level, health is formulated from the perspective of individuals. WHO's definition of health, formulated in 1948, is "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity" (36). WHO asserts that physical and mental well-being is a human right, enabling a life without limitation or restriction. Key aspects of the WHO definition are the inclusion of social well-being and the emphasis on more than the absence of a disease (36, 37). Another definition describes health as a balanced position, an equilibrium that an individual has established within the self and between the individual and his or her social and physical environments. This means that those with a disease or impairment would be considered healthy to a level defined by their ability to establish an internal balance that allows them to get the most out of their lives

despite the presence of a disease, thus, the use of the term "person who has diabetes" rather than a "diabetic" (38). This thesis subscribes to the health definition of Huber et al. (39), formulating health as "the ability to adapt and to self-manage", in the face of social, physical and emotional challenges. Health is no longer defined as a static situation, but is seen as an important and irreplaceable component of health and disease management (39).

Disease, on the other hand, is described as a condition that is diagnosed by health professionals. Disease has a pathological biomedical cause and often known treatment (40). The trilogy of "disease", "illness" and "sickness" is a concept that has been used by researchers to capture different aspects of ill health (40, 41). Illness is often based on self-reported mental or physical symptoms, including severe health problems and limitations for the person to live a normal life (41–43). Sickness is more related to the social role a person is given in society, related to lacking health (40). Different diseases have various statuses in a society, and the medical contexts and do not guarantee equity in sickness. Traditionally, chronic diseases have been ascribed with a lower status than acute ones, and psychiatric diseases lower than somatic conditions (44–46). One such chronic disease is T2D, which in the literature often has been described as correlated with unhealthy behaviour and experiences of shame and guilt (47, 48).

Type 2 diabetes

So-called lifestyle-related chronic diseases – such as T2D, cardiovascular diseases and chronic respiratory diseases – are responsible for 63% of all deaths worldwide, and are at risk of increasing (10, 49). Preventable risk factors have found to be associated with particular unhealthy lifestyle choices and behaviours, such as tobacco, alcohol and drug use, physical inactivity and unhealthy eating habits. These behaviours may lead to obesity, high blood pressure and T2D (10, 50) as well as atherosclerotic cardiovascular disease (51). About 40% of the population in Europe, and in Sweden about 40% of the population older than 15 years, have at least one chronic disease, and at the age of 65 years, two out of three people have at least two chronic diseases (14, 52).

However, both the incidence and the risk of complications from chronic diseases such as T2D can be reduced through preventive efforts. In the last decade medicine and technology have advanced, and the group of older people with chronic conditions has increased. This shift raises new challenges for patients and health professionals, since focus in care must shift from medical treatment to self-management.

T2D is a metabolic chronic disease affecting the metabolism of glucose as a result of relative underproduction and resistance to insulin. A consequence of this is

hyperglycaemia, with disturbances of carbohydrate, fat and protein metabolism (53). People with T2D may be underdiagnosed for a long period, since high blood glucose levels develop gradually over time. The classic symptoms are commonly not obvious in the early states; however, early diagnosis is crucial to good health outcomes. People suffering from this form of diabetes may have insulin levels that appear normal or increased initially. However, the insulin secretion is defective and becomes insufficient to compensate for the increasing insulin resistance (54). T2D is characterized by a gradual increase in glycaemia, where the increase is closely linked with lifestyle factors such as physical inactivity and obesity as well as tobacco and alcohol consumption (55), combined with factors such as older age, family history of diabetes, ethnic predisposition (56) and previous gestational diabetes (57). Long-term complications of T2D include foremost cardiovascular disorders. In patients, and particularly women, the risk for coronary heart disease in T2D is found to be doubled, which also increases the mortality risk (58). Other common complications are retinopathy, nephropathy and neuropathy. Furthermore, T2D is associated with increased risk of cancer, psychiatric illness, cognitive decline, chronic liver disease, accelerated arthritis, and other disabling or deadly conditions (59). As T2D and its complications are largely preventable, the escalating health and financial costs of the diabetes epidemic demands greater investment in diabetes awareness and prevention (60, 61).

Glycated haemoglobin (HbA1c) is the preferred diagnostic measure for both type 1 and type 2 diabetes internationally (62) as in Sweden (63, 64) since 2010. An HbA1c ≥48 mmol/mol is the limit for diagnosis among non-pregnant adults. The current diagnostic criteria for T2D are defined as raised fasting plasma glucose ≥7.0 mmol/dl, or random two-hour plasma glucose ≥11.1 mmol/l. For both methods, repeated measurements are needed for a diagnosis (53, 64–66).

Diabetes is currently divided into type 1 diabetes (about 10%), type 2 diabetes (85%–90%) and a number of less common diseases such as LADA, MODY and secondary diabetes. Frontline researchers, though, have suggested a new diagnosis classification that increases the possibility of predicting the risk of serious sequelae and offering suggestions for different treatment in different risk groups. These studies have suggested that in the future diabetes should be divided into five different subgroups instead of today's main groups, type 1 and type 2, since some subgroups needs more aggressive treatment than others. Despite these new reports the traditional term T2D is used within this thesis, which includes some of the subgroups (67).

Guidelines recommend as the first and basic measure self-management, including maintenance of glycaemic control and necessary lifestyle changes, thereby being the cornerstone of diabetes care (64). Among lifestyle changes, a

particular focus lies on refraining from smoking. Besides that, dietary changes with higher amounts of slow carbohydrates and high fibre are recommended (68). An individualized diet of carbohydrate, protein and fat intake for people with T2D is recommended by professional guidelines to emphasize foods of proven health benefit that meet the patient's preference and metabolic needs, with the goal of identifying healthy eating habits that are feasible and sustainable (68, 69). Furthermore, physical activity on a daily basis is beneficial, where at least 30 minutes every other day is recommended (70). Balanced weight with a normal BMI should be strived for, which for most people with T2D implies life-style change and calorie restriction (71).

Intensive glucose-lowering pharmaceutical therapy is recommended from the debut of T2D. Swedish guidelines recommend the biguanide metformin as initial treatment, particularly in obesity (72). It reduces the risk for heart disease and eye, kidney and neuropathic complications. A disadvantage of metformin is that a lot of people report nausea or diarrhoea as a side effect (73). If the glucose-lowering effect of metformin is inadequate, other pharmaceutical treatment should be added. Glucose-lowering therapy with the previously recommended sulfonylurea and repaglinide is in the latest recommendations toned down, due to the risk of hypoglycaemia. Recommended additional pharmaceuticals are GLP1 analogues, DPP4 inhibitors, SGLT2 inhibitors and possible also acarbose. All of these can be combined, but one GLP1 analogue or DPP4 inhibitor should be chosen, not both. In severe insulin resistance, glitazone could be a choice, but not in heart failure due to a risk of fluid retention. SGLT2 inhibitors are high-lighted as particularly suitable in cardiovascular disease, since they reduce the risk for cardiovascular death. In the latest guidelines insulin treatment is not recommended in early stages of the disease process, since it increases risk of hypoglycaemia and overweight. Insulin is today recommended first when oral pharmaceuticals are insufficient to decrease blood glucose enough, or temporarily in ketoacidosis (72). Also, treatment and treatment goals for comorbidities should be individualized. Besides the glucose-lowering therapy, many people with T2D also are treated for hypertension. In neuropathy the choice is between ACE inhibitors or ARBs and hypercholesterolemia (59). For hyperlipidaemia the choice is between statins or ezetimibe (72). These treatments put great demands on a person who has T2D. Knowledge of the effects and side effects of the treatments is important. Additionally, effective self-management can postpone some of these pharmaceutical treatments.

Having type 2 diabetes

T2D affects multiple aspects of people's daily lives. Optimal management there-fore requires early detection, and patients need to be observant about early symptoms such as tiredness or thirst (59). However, early symptoms can be vague

and not easy to refer to illness. When diagnosed with T2D, people must deal with a variety of problems related to diet, mealtimes, meal sizes and dietary composition. Furthermore, they have to cope with daily physical activity and striving for a balanced weight. To stop smoking is of first priority, which for many can be burdensome but necessary, since it highly reduces the risk of vascular disease (54, 59). Shortly after diagnosis, most people get oral treatment and perform blood sugar testing to learn to balance diet and physical activity in relation to blood sugar levels. When oral treatments are not effective enough, people with T2D have to begin an insulin regime. This implies injections and frequent daily blood sugar testing and adjustment of insulin doses, which for many people adds a lot of burden to a life already too regulated and less flexible (1, 59, 64). Quality of life is often decreased in insulin-dependent T2D, as well as when complications occur (74, 75).

Since T2D is progressive, a diagnosis earlier in life usually imply some kind of long-term complications. The diabetic complications are often asymptomatic, making early diagnosis difficult. T2D is therefore often undiagnosed until these complications have developed (76). Myocardial infarction, for example, some-times debuts before diagnosis of T2D (77). In addition, neuropathy can develop gradually and increases the risk for different kinds of ulcers, especially on the extremities. Foot care and regular foot examinations are therefore important preventive self-management activities (78).

To get necessary support for effective self-management and effective control of diabetes, people with diabetes commonly interact with their healthcare professionals, family members and others close to them (55). Social support is of high priority, since many people may have trouble adapting emotionally to a life with a chronic illness that is, being chronically ill. Being diagnosed with a chronic condition has been described as a disrupting life event in which the condition affects not only a person's physical self but also the sense of identity and social roles. According to Bury (79) and Charmaz (80), this means that self-confidence and self-esteem may need rebuilding (79, 80). Stressful life events apart from the illness (loss of spouse, divorce, etc.) can lead to loss of social support, and might challenge patients' self-management efforts (81).

Living with T2D is something that takes place every day, while the contact with primary healthcare providers is something that occurs occasionally, and initially more often, but this is reduced to annually visits. This places high demands on people living with T2D to deal with their life, disease and self-management, and their ability to respond to fluctuations in blood glucose, dose adjustments and changed habits. All these aspects have effects on health outcomes and well-being in positive or negative terms (82, 83). In light of this, the interaction between

patients and healthcare professionals at the diabetic clinic becomes important in facilitating self-management through self-management support.

Self-management

There is no universal consensus or "gold standard" definition of self-management. The concept self-management has been defined in a number of ways, depending on the discipline and research context (84). The term "self-management" was first used in 1976 in writings on rehabilitation of chronically ill children. It was based on Bandura's Self-Efficacy Theory (85) and highlighted the belief that patients should be active participants in their own care (85, 86). Concerns have also been raised in the literature, in which traditional self-management support fails to incorporate the individuals' capacities into their everyday contexts (87). This is worrying and one motive for this thesis.

Nakagawa-Kogan et al. (88) define self-management as a "treatment that combines biological, psychological and social intervention techniques with the goal of maximal functioning of controlled processes". Kralik, Koch, Price and Howard (89) refer to self-management as the "activities people undertake to create order, discipline and control" in their lives. Lorig and Holman (90) consider in self-management the fact that most people have the "desire and skills" to stay healthy, and also state that in self-management the "key is education in skills [such] as decision-making, problem-solving, finding resources and taking action" (90). Li, Townsend and Bradley (91) state that self-management should be supported rather than taught, which is in line with other studies (90, 92). Barlow, et al. (93) refers to self-management as the "individual's ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition" (93).

The various definitions of self-management have been categorized by McGowan (94) into four kinds of practices were the last category of self-management is most relevant for this thesis:

a) participating in education or treatment designed to lead to specific outcomes,
b) preparation of people to manage their health conditions on a day-to-day basis,
c) practising specific behaviours, and
d) having skills and abilities to reduce the physical and emotional impact of illness with or without support from a healthcare team.

Self-management and self-care are concepts that often are used interchangeably or simultaneously and without explanation (95). Within both concepts, definitions have highlighted the meaning of acquisition of new knowledge and skills (96). Where differences in definitions of the two concepts have been identified, the concept "self-care" describes more about *what people do* because of a health problem (97), such as everyday life activities to maintain life or to satisfy needs (98). "Self-management", on the other hand, has been defined as *the strategies,* such as striving for involvement or activity, which the individual uses in order to live well with an illness (90, 99).

Self-management is in the literature also related to other psychological concepts, for example, "self-efficacy" as well as "patient empowerment", both with relevance for this thesis. Self-efficacy refers to the individual's capacity to produce desired effects (85). Self-efficacy can be defined as a belief that one has the ability to manage a situation and, as such, it has served as a basis for identifying strategies to enhance self-care and succeed in specific situations (85). Self-management is closely related to efficacy beliefs. The concept of self-efficacy is based on social cognitive theory and describes the interaction between personal, behavioural and environmental factors in health and chronic disease (85, 90, 100).

In this thesis, patient empowerment is viewed as an overarching concept. A patient empowerment approach has been defined "*as helping patients discover and develop the inherent capacity to be responsible for one's own life*" (101, 102). Unlike the traditional approach in patient education, empowerment is not something that is done for the patient (103, 104); although diabetes specialist nurses (DSNs) are experts on diabetes care, the individuals are the experts on themselves. Empowerment can be seen as a process of becoming confident, especially in controlling one's life, but also relates to the ability to be mindful and make healthy choices and having the tools and skills needed to act on these choices. Powers et al. (105) suggests that in order for people with T2D to truly be "empowered", they need information to make informed decisions on a daily basis. For individuals to be actively engaged in their treatment planning, they need to have skills for self-management and making behavioural changes as well as social and emotional support (105, 106). It is therefore of importance that DSNs in Swedish primary healthcare have a responsibility for such self-management support, which includes, for example, psychosocial and emotional support. This becomes a problem though, since not all health care providers feel competent enough to address psychosocial problems (107).

Diabetes nursing and self-management support

Primary healthcare nurses with specialist functions, with in-depth knowledge and skills in areas such as diabetes, asthma, chronic obstructive pulmonary disease or incontinence care, are common in Swedish primary healthcare. They have traditionally been responsible for regular follow-ups of patients with chronic diseases, and served as a link between patients and general practitioners when it comes to renewed examinations or adjustments of doses or changes in pharmaceutical prescriptions (108, 109). Traditionally, the professional education and tasks of primary healthcare professionals have been based on a medical model designed not only to treat acute care problems but also to promote good health, prevent health problems and manage ongoing and long-term conditions (110, 111).

DSNs autonomously screen for medical complications related to T2D – for example, laboratory measurements of blood sugar, HbA1c or cholesterol, monitoring blood pressure or renal function, the latter by urine tests for micro-albuminuria or creatinine. Furthermore, the DSN regularly makes foot examinations to detect neuropathy by inspection and palpation of pulses, and also examines possible sensory loss. DSNs also refer patients to eye clinics for retinal scan, and to dieticians and dentists when needed (71). All these parameters are documented in the National Diabetes Registry (NDR), which covers about 97% of all diabetes clinics in hospitals or in primary healthcare in Sweden (15). The statistics from the NDR provide the DSNs with important data and comparisons of care and quality with other clinics.

A need for change in the role of healthcare professionals has been expressed, where DSNs are expected to become coaches of patients in their day-to-day decisions. This is supposed to lead to improved self-management and better outcomes (112-118). Self-management support can be perceived as the assistance nurses provide to patients to encourage daily decisions that improve health-related behaviours and clinical outcomes. This support can be viewed as a set of techniques and tools that facilitate patients choosing healthy behaviours, and is essential for a collaborative partnership in the relationship between the patient and the nurse (119, 120).

This is of importance for DSNs who, besides the medical aspects of T2D, need to be aware of psychological and emotional as well as social issues that may be relevant for patients and their options to accept and manage the disease on a daily basis (121). Patient education has evolved from a previous "teacher and pupil" role taking, which could be seen as the DSN being the "keeper of high-level knowledge" or as a hierarchical "top-down perspective" (122, 123), to become a supportive coach and client relationship for mastery that has a more horizontal perspective. A coach is working more with motivation and striving to get insights

into the kind of intrinsic motivation the "client" has, aiming to improve the outcome. Knowledge is not less important within this perspective but adds to other aspects. For example, knowledge about diabetes and the treatment (124–126) as well as the patients' personal understandings or own views of their disease, which are not similar to knowledge about diabetes, have been reported to be important for DSNs to become aware of, to include in assessments and plans for self-care support (127).

A common statement within primary healthcare nursing and patient education is that "You should start where the patient is." Starting to highlight how patients understand their illness, for example, as only an increased HbA1c value or perceived as a serious or even life-threatening disease, can help the DSN to understand where to start and how to approach the patient (128). Self-management support that includes reflections about the patient's view of disease, the personal impact of diagnosis, the view of responsibility for self-care, the view of space for illness in daily life, and lastly, the future prospects with the disease, has been shown to improve self-management, and in randomized controlled trials has been demonstrated to improve HbA1c. An explanation has been that this kind of support facilitates illness integration and speeds up "turning points" in self-management (129-131).

The DSN's primary task, besides screening for complications, is to support patients with diabetes to reflect upon their knowledge and skills or sometimes also to reframe in order to modify habits and roles to successfully self-manage the disease (118, 132). However, there are also challenges associated with restructuring social roles as well as challenges related to restructured professional roles (133, 134). Self-management support in this thesis therefore highlights more about coaching than education.

One approach that is increasingly recommended and has become a gold standard in diabetes education is group-based support (72, 135-137). However, in the literature and in clinical practice, there are various approaches used in self-management support for patients with chronic illness. One approach is digital self-management support.

Digital self-management support

Self-management is considered a key component of treatment for people with chronic conditions (90). With the increased use of digital technologies (e.g. applications, Internet web pages, patient forums, social networking tools, online games and animated films) in healthcare, digital self-management programs (138, 139) provide a platform for education and support (140, 141). While the delivery of self-management support activities by healthcare providers often is

linked to healthcare settings, digital solutions for self-management support are convenient and flexible for those who live in rural communities and those who work full time (140, 142), and may also reduce delivery costs (143, 144). Digital solutions for health information and support, at a time and place chosen by the individual, are consistent with a person-centred approach (145, 146).

When reviewing the literature on person-centred digital self-management support interventions in T2D, there were few studies were found. There are reviews concerning digital self-management support interventions. A review about interactive computer-assisted technology included results from 26 studies. In the review it was highlighted that using digital resources depends on the acceptance of the patient in using digital support if it is to succeed. Furthermore, the results pointed to the importance of long-term (>1 year) studies for follow-up on eventual sustainable effects on HbA1c. Also highlighted was the importance of including ethnic minorities and those from lower socioeconomic status groups to determine whether these interventions are equally effective in these groups (147).

In a review and meta-analysis concerning effects of mobile phone intervention for diabetes on glycaemic control, shared results from 22 trials provided evidence about significant improvement in glycaemic control and self-management for T2D patients (148). In another review and meta-analysis addressing computer-based intervention to improve self-management in adults with T2D, 16 different studies were included. The main findings reported that computer-based diabetes self-management interventions appear to have a small beneficial effect on blood glucose control. The largest effect was seen when patients used mobile phones. In this review, it was highlighted that better designed and tailored solutions are needed to improve other aspects of T2D self-management (149).

A qualitative study from 2018 concerning digital health interventions for adults with T2D with a focused on patient perspectives on diabetes self-management education and support highlighted that if interventions continue to be focused merely on information and medical management, they may not be sufficient to meet the needs of patients with T2D. Participants in the study highlighted that there were more aspects in life to handle than just food, diet and medical management. For these patients, emotional and role management were more important. They requested that the features of a digital self-management support intervention include an emphasis on emotional and role management, using the latest evidence-based guidance, as well as providing access to peer-generated and professional advice (150).

A review evaluating the effectiveness of digital self-management support for people with asthma, however, showed beneficial effects on outcomes, but no information about the socioeconomic status of participants was given, except that

people over 65 years of age were excluded. Furthermore, no information was given about the cost-effectiveness of the ten digital asthma interventions included. The review highlighted that the patients' views on using digital self-management support were lacking, and this was seen as a weakness, since the patient perspectives would be invaluable to inform future interventions (142). In another review concerning digital support for the self-management of people with low back pain, it was reported that white, female, well-educated and middle-aged people were predominant in the nine interventions that were included. Because of this, the results of the interventions could not be generalised and no conclusion could be made, even though the interventions showed positive effects on outcomes. It was highlighted that further studies should include a broader range of participants, concerning gender, age, education levels and so forth. It was also reported that no health economic data were included in the interventions. The review highlighted that tailored digital interventions aimed at promoting self-management should be addressed in future studies (151). In a review concerning how digital self-management in chronic physical health conditions is experienced, 30 studies were included. Findings showed that using digital self-management programs did not replace healthcare professionals for the patients, but that it empowered patients to perform self-care. By monitoring their own health data, patients gained self-awareness about their condition and thereby became motivated to engage in lifestyle changes. In the conclusions it was highlighted that digital self-management support programs could be used as tools to tailor support for patients. Concerns about how to support and encourage patients to stay motivated and engage in digital self-management support over time were raised, as the burden of monitoring data seemed to be hindering (151).

A Cochrane review on computer and mobile technology interventions for self-management in chronic obstructive pulmonary disease (COPD) included three studies. Results suggested that people with COPD realized benefits from using digital interventions. Participants demonstrated improvements in self-management and increased physical activity; as well, quality of life increased. However, hospital admissions and exacerbations of COPD did not differ between those who used smart technology and those who did not, and no firm conclusions could be drawn from these three studies (152). In a systematic review of reviews on digital self-management support and education in diabetes, 40 studies were included. The studies presented interventions in both type 1 and type 2 diabetes. Findings showed that digitalized diabetes self-management solutions improved HbA1c. The most effective digital interventions were those that incorporated interactive two-way communication and offered tailored education and personalized feedback. It was suggested that these results should be taken into consideration when designing digital diabetes self-management support programs for the future. It was also highlighted that, related to the widespread adoption of mobile phones, digital support programs could improve the reach of

and access to diabetes self-management education and support for a larger population (153).

However, several studies highlight that low levels of uptake in the target patient groups and reduced user engagement over time is a challenge, as well as the fact that those with an interest in using technology may derive greater benefit from digital self-management support than those who are not interested (139, 154–156). A prerequisite for digital self-management support is to ensure equitable access to digital care for more vulnerable groups in society, who could benefit from digitalized solutions. Furthermore, an acceptance among both patients and health professionals of digital delivery of health of care is needed, which could contribute to complementary ways to improve self-management, empowerment and person-centred care (157). To take part in digital self-management support, patients must also be able to connect to the Internet, and this is a barrier world-wide, and especially for those with lower income and lower socio-economic status.

Internet use in Sweden

A recurring survey by the Internet Foundation in Sweden, IIS, annually contributes facts and insights on how the use of the Internet in Sweden has developed (158). About 98% of Swedes stated during 2018 that they had access to the Internet at home. Access to a computer at home has been found to be 93%, smart mobile phone 90% and tablet 70%. Every other (50%) stated that they had at least one connected object in their home (158). This could be, for example, clocks, televisions or refrigerators. In other words, the Internet of Things is in-creasingly taking place in people's homes. Mobile and wireless technologies, such as embedded cameras and smartphones, bring connectivity to every moment or one's life (159).

In Sweden, about 95% of people 26 to 45 years old searched for medical information online; women searched for information about medicine and health more often than men. Almost half of those who connect to the Internet with their mobile phones use a health or exercise app but these are most commonly used among younger women (158).

Even if an increasing number of Swedish people are connected and using the Internet, more than 1 million still are left in digital exclusion. Age is the clearest link to those who do not connect daily, where three-fourths are over the age of 65 years. Added to this, in order to get in contact with primary healthcare centres (PHCs) with Internet access, Swedish people need a Bank ID. Despite this, a large part of the population over the age of 76 years (77%) do not use Bank ID (158). Fortunately, though, it is in the oldest age group – 76 years and older – that access

to the Internet in the home is rapidly increasing. Just four years ago, not even half of those aged 76 and older had access to the Internet at home. Now it is almost nine out of ten. However, there are more factors than higher age behind the total of 1.1 million people who do not use the Internet daily or at all. They are mostly women, have lower household income, more often live in rural areas and more often have lower education and work in industries dominated by blue-collar workers rather than white-collar. Lastly, they are also more often single, unemployed or on sick leave.

Many also use the Internet as a tool to allow work life and private life to merge together. This means that people, on one hand, use their free time to work online as well as reading e-mails while on holiday, and on the other hand, use the Internet for private matters at work. Not surprisingly, the sector where one works plays a big role in how work and private life are allowed to become mixed with the help of the Internet. IT and communication industries as well as the finance industry are sectors where most people work in their free time via the Internet and also use the Internet for private matters during work time. Almost everyone who works in Sweden uses the Internet at work, ranging from all day to part of the day (158).

For daily Internet use it is clear that most people choose the mobile phone ahead of the computer or the tablet. Only the oldest age group, 76 years and older, more often use the computer daily than the mobile or tablet. Over half (59%) of the oldest (76+ years) do not use the Internet to access information about medicine and health. In the group 66–75 years old, it is 24% who never use the Internet to access information about medicine and health (158).

However, obtaining and understanding health information from the Internet is dependent on people's health literacy levels. Health literacy is a term introduced in 1974 (160) and of increasing importance in public health and healthcare. Health literacy has been defined as "*the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions*" (161, 162). A health-literate individual is more inclined to know how to answer the question "*How do I keep myself well?*" (161). Health literacy, from the patient's perspective, is the cornerstone in enabling them to make informed choices and take care of their health. A person with high health literacy can get, process and understand basic health information and services, and can therefore make appropriate health decisions (163, 164). More specifically, with a high health literacy, they can under-stand and interpret health information provided in written, spoken and digital form. Furthermore, they can understand instructions written on prescribed medicine containers and consent forms, understand a health professional's verbal advice and explanations, navigate complex health systems, communicate

with health professionals, and lastly, find relevant information needed to make choices and decisions (161-162, 165).

eHealth literacy, on the other hand, implies engaging with electronic sources and requires skills. The concept of eHealth literacy is introduced and defined as "*the ability to seek, find, understand, and appraise health information from the Internet and apply the knowledge gained to addressing or solving a health problem*" (166). The behaviour of seeking health information online is continuously increasing (167). However, the quality of information found on Internet can vary dramatically between different sources of information, such as forums, websites, reliable medical information or online groups. Still, nurses should instead of being educators become more of a reflecting partner in evaluating information, since low health literacy and eHealth literacy levels play an important role in people's ability to evaluate the quality of online health information (168, 169). In the light of this, making informed health decisions starts with the ability to process and understand relevant information. It is vital that DSNs working with people with T2D are aware of patients' level of literacy to identify those at risk for poor health outcomes, so they can achieve their individual goals.

Rationale for the thesis

The prevalence of chronic illness is high and rising worldwide. In T2D, medical treatment is intended to reduce complications and mortality. The basic treatment, though, is active self-management, which implies that DSNs are becoming more and more skilled in supporting people with T2D to self-manage their disease. Self-management support based on a person-centred design has demonstrated positive effects on treatment outcomes and health economics.

With recent and rapid advances in interactive digital technologies, eHealth has changed the manner of communication and support between individuals and healthcare providers. eHealth may have a great potential to improve health. However, little is still known, given the potential role of eHealth in primary healthcare, of how DSNs perceive digital eHealth systems and services that are being used to support patient self-management. Preferences for the use of eHealth resources for health information are high among younger people, while persons 70 years and older still use digital resources to a lesser extent. In T2D, the main barrier has been reported to be lack of access to the Internet and poor user-friendliness of Web applications. There is also a knowledge gap in how older people with T2D perceive the use of eHealth services and related technologies for self-management support.

Primary healthcare nurses/diabetes specialist nurses in Sweden play an important role in guiding and supporting people in their self-management efforts. Even though much is known about how the diabetes disease affects people with T2D and how self-management may affect their disease, still, little is known what can improve their self-management. It has been reported that primary healthcare nurses have difficulties in knowing where to focus their efforts in self-management support. Therefore, DSNs responsible for T2D care seem to require a tool to more effectively screen for self-management needs in order to facilitate the DSN as well as the person with T2D gaining insight into problematic areas that can affect their self-management of the diabetic disease.

As of today, many instruments and screening tools have been used in healthcare. However, research on experiences in implementing screening instruments and how these have been embraced and evaluated by caregivers is sparse. There is always a risk that nurses in primary healthcare experience having more and more tasks imposed on them and that they do not realize any benefits from innovations. To address this knowledge gap about nurses' perceptions, it is of importance to gain more insight about how they experience the implementation of a screening instrument in usual care.

Aims

The overall aim of this thesis was to explore perceptions among DSNs and patients about digital self-management support and also to develop and evaluate a digital screening instrument assessing individual needs for self-management support.

Specific aims

Paper I: To describe Swedish primary healthcare nurses' perceptions of using digital eHealth systems and services to support patient self-management.

Paper II: To describe perceptions of using eHealth services and related technologies for self-management support among people with T2D treated in Swedish primary healthcare.

Paper III: To develop and psychometrically test the Self-Management Assessment Scale (SMASc), a screening instrument for person-centred guidance and self-management support of persons with type 2 diabetes.

Paper IV: To describe diabetes specialist nurses' experiences of a pilot implementation of the SMASc instrument as a basis for person-centred digital self-management support.

Methods

Design and settings

This thesis uses a descriptive design, including the psychometric development of an instrument and its pilot implementation. All four studies (I–IV) were conducted in primary care in a County Council in northern Sweden.

The county had in 2018 more than 270,000 inhabitants, of whom almost 80% lived in the coastal municipalities (170), and included 33 PHCs (171). However, there were also a few private healthcare centres in the county, but they were excluded in the studies within this thesis. An overview of the studies is given in Table 1.

This thesis is part of a larger project aimed at implementing person-centred interactive self-management support (iSMS) in primary healthcare (ClinicalTrials.gov - NCT03165084).

Table 1. Overview of papers, design, participants, data collection and analysis

PAPER	DESIGN	PARTICIPANTS	DATA COLLECTION	ANALYSIS
I	Qualitative	Primary healthcare nurses (n = 20)	Focus group interviews 2017	Qualitative content analysis
II	Qualitative	People with T2D (n = 11)	Individual interviews 2018	Qualitative content analysis
III	Quantitative, psychometric evaluation	People with T2D (n = 104)	Questionnaires 2018	Descriptive statistics
IV	Qualitative	Primary healthcare nurses (n = 5) and patients with T2D (n = 14)	Observations and individual interviews 2019	Qualitative content analysis

Participants

Paper I included a convenient sample of primary healthcare nurses (n = 20) working at five different PHCs in Västerbotten. All were registered nurses working as primary healthcare nurses, some with responsibility for diabetes clinics at their PHC. Their work experience as PHNs ranged from 5 to 28 years (median = 23).

Paper II included a sample of people living with T2D (n = 11), three women and eight men who agreed to participate in individual interviews. Their median age was 65 years (range 50–78). The duration of living with the diagnosis T2D among the participants varied from 4 months up to 10 years.

Paper III included a consecutive sample of adults with T2D living with T2D (n = 104), 51 women and 53 men, who were recruited from four PHCs in Västerbotten, and agreed to participate in psychometric evaluations of the SMASc instrument.

Paper IV included a sample of DSNs (n = 5) working at three PHCs participating in the iSMS intervention. Their work experience as DSNs ranged from 1 to 15 years, and they participated in observations (n = 14) and follow-up interviews (n = 5). Within the context of the observations, 14 patients with T2D also agreed to participate. They were five men and nine women, and their ages ranged from 63 to 73 years. An overview of the studies is given in Table 2.

Table 2. Overview of participants, gender, age and work experience

	PAPER I	PAPER II	PAPER III	PAPER IV
Participants	20	11	104	5
Gender				
Female		3	51	4
Male		8	53	1
Age [median (range)]		65 (50-78)		
[mean (SD)]			50.22 (18.9)	
Work experience, years (range)	5–28			1–15

Data collection

Focus group interviews
Focus group interviews (Paper I), with origin in sociology in the 1920s (172) and initially used by market researchers (173) before regaining popularity in the social sciences in the 1990s (174, 175), are commonly used in qualitative health research to explore attitudes towards care and health services, as well as people's perceptions and experiences of illness (176-178). The focus groups interviews, used in study I, were led by UÖ as a moderator asking open-ended questions on a pre-specified topic (179) about the participants' perceptions of using the Internet and eHealth in self-management support of people with chronic conditions. During the interviews, a semi-structured interview guide with open-ended questions with some question areas and probes (180) was used. The dynamics and the interaction between participants in the group was an essential part of data gathering.

Focus group interviews are also a pragmatic and feasible way to collect data within a group instead of performing individual interviews. When divergent opinions were obvious, the participants were asked to clarify their thoughts and encouraged to take time for further discussion and reflection. Even if a focus group's size affects the result, small focus groups may have advantages because of the intimate atmosphere (175-177). The interviews were performed at the PHCs and lasted between 40 and 60 minutes (median = 50). All interviews were digitally recorded and transcribed verbatim by UÖ.

Individual interviews

Individual interviewing (Papers II, IV), is a research data collection method and is the most common way of collecting qualitative data in healthcare research. In interviews, researchers commonly seek to understand participants' experiences expressed through their own words and perspectives (181). The purpose of the individual interviews with people with T2D (Paper II) was to collect in-depth data describing personal perceptions of using eHealth services, while simultaneously avoiding group thinking. During the interviews, a semi-structured interview guide with open-ended questions with some question areas and probes (180) was used. The ambition was to get answers that were more narrative in nature. The interviews performed by UÖ were digitally recorded. The opening question was, "If I say information technology and eHealth, what do you think of?" The interviews were conducted with the participants individually, either in the participants homes (n = 8) or at the University (n = 3), and lasted between 40 and 60 minutes (median = 50). All interviews were digitally recorded and transcribed verbatim by UÖ.

Participatory observation and follow-up individual interviews

Observation is a data collection method used generally to capture the activities of participants as well as to understand when and where things are happening in a given setting (182). The observations focused on the interaction between the DSN and the patient with T2D during consultations. Participatory observations of 14 clinical visits were conducted (Paper IV). The observer adopted an "observer as participant" approach, interacting with participants only if it was necessary to make the participants feel more at ease with the observation process (183). Challenges in using observation were related to adopting the role of participant or non-participant researcher as observer (182). Field notes were used during the observations to identify, label and categorize the types of interaction and any special occurrences observed during the visit. It is fundamental for the quality to also be aware of facial expressions, gestures and movements – key data in the observation situations, which were noted (184). A general semi-structured interview guide was constructed on the basis of what occurred in the meeting between the DSN and the patient with T2D during the observation session. As follow-up,

individual face-to-face interviews (n = 5) with the DSNs were then conducted a few days after the observational sessions. The observations of clinical visits (n = 14) and follow-up individual face-to-face interviews (n = 5) with the DSNs were performed at the PHCs and the interviews lasted for 60–90 minutes (median = 75). All interviews were digitally recorded and transcribed verbatim. The observations and interviews were conducted by UÖ.

Instrument development and use

The SMASc, a screening instrument for person-centred guidance and self-management support of people with T2D was developed and psychometrically tested (Paper III). The screening instrument was developed in two phases. SMASc consists of 10 items where the questions form five subscales/domains, with two questions each. The five SMASc domains are judged as important for effective self-management over time and are labelled knowledge, goals for the future, daily routines, emotional adjustment and social support. The psychometric evaluation provides support for the validity, reliability and utility of the instrument. The content validity of the SMASc is supported by the fact that it was derived from our previous theoretically based work on illness integration and patient perspectives on self-management and person-centred care in T2D. The DSNs were asked to suggest that patients score their needs of self-management support digitally by answering the 10 questions of SMASc on an iPad (Paper IV). The scoring was analysed digitally and resulted in five colour-marked (red, yellow and green) domains that visually aimed to be a pedagogical tool for both patients and nurses, and an indication of where to start and where to focus self-management support. A discussion between the patient and the DSN followed the result, which sometimes could lead to further digital self-management support through recommendations of a website or an app for self-monitoring, described below.

Pilot implementation of SMASc

A pilot implementation is basically a trial run in a realistic setting within a limited time frame, to test and learn about the fit and about necessary changes prior to a full-scale implementation, that is, a small-scale version of a larger project (185, 186). The procedure for the pilot implementation of the SMASc is evaluated qualitatively (Paper IV), and will also be evaluated quantitatively, but not within the frame of this thesis. The process of the pilot implementation study is described in Figure 1.
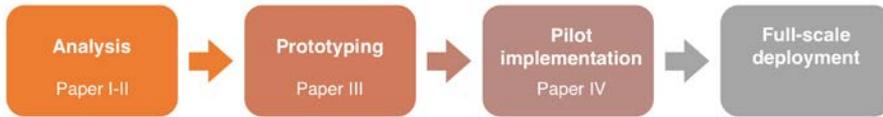
Figure 1. The SMASc implementation process, inspired by J P Bansler.

Analysis

During the planning and design of the pilot implementation, what issues to address and how they would be studied were defined. This included determining where and when the pilot implementation would take place, and which facilities would be included, and also how lessons could be learned during the study as well as how data would be collected. This design was inspired by Glass (187). A one-day preparatory workshop with the purpose of exploring needs and expectations of a forthcoming intervention was held, and was seen as important for the development of the pilot program. Contributors with different backgrounds were invited to the workshop, and in total 27 persons participated. Of these, there were patients with T2D (n = 6), spouses (n = 2), DSNs (n = 9), a physician (n = 1), researchers from nursing and informatics (n = 6) and system developers (n = 3). The workshop included round table discussions, where field notes and menti-meter surveys were used. This procedure is described in more detail in the study protocol for the iSMS project (188) and in another paper (Schimmer et al., submitted manuscript).

The idea of developing a screening instrument for self-management needs arose early in the research group (see Paper III). The starting point was a literature inventory about patient perspectives on self-management and living with T2D together with illness integration and person-centred care. The initial scale was a 28-item instrument, which later was reduced to 10 items (see below). In addition, interviews were conducted with primary healthcare nurses (Paper I) and people with T2D (Paper II), regarding their perceptions of using digital services. Taken together, the results from these studies and the outcome and feedback from the aforementioned activities were the basis for the pilot implementation of SMASc in primary health settings.

Prototyping

The purpose of prototyping was, partly, to develop and psychometrically test the screening SMASc instrument for person-centred guidance and self-management support, and furthermore to design results in a graphic profile on an iPad, and partly to create knowledge about the final design. The initial scale (28 items)

needed to be refined, and this resulted in the 10-item SMASc instrument (Paper III) that assesses five domains important for self-management over time: knowledge, goals for the future, daily routines, emotional adjustment and social support. A psychometric analysis (phase II) was performed and the SMASc was validated. The participating DSNs were offered a one-day group training session, which included role play and study-related information. In addition, they received a two-hour introductory session. The training involved learning how to use the SMASc instrument and interpret the scoring, and how to discuss needs of self-management support in order to develop person-centred plans for self-management support together with patients. Another preparatory activity that was included in the larger iSMS project, but not included in the aim of this thesis, was the development of a website (www.T2D.se). It includes informative texts related to the areas of SMASc, complemented with other aspects of illness integration described by Jutterström (121), and also links to other informative sources and web-based tests.

Pilot implementation

The ongoing pilot implementation aims to collect experiences from both DSNs (Paper IV) and patients participating in the study regarding using SMASC as a basis for person-centred digital self-management support during visits at the diabetic clinic. Based on the SMASc scoring, the DSNs were instructed to recommend the T2D website to patients who could benefit from it. The DSNs could also inform patients about the app MySugr (189), to enable them to self-monitor and evaluate their self-management activities such as exercise, meals and treatment aspects if needed. This pilot implementation strives to gain insights on whether any technical adjustments are necessary before full-scale implementation.

Full-scale deployment

The full-scale implementation awaits completion of the pilot study and finalization of the design, but outside this thesis.

Analyses

Qualitative content analysis
The interview data (Papers I, II and IV) were analysed using qualitative content analysis as described by Graneheim and Lundman (190, 191). Qualitative content analysis is a systematic way to describe variations of content in verbal or written communication (190, 192). The analysis is a process of interpretation that focuses on similarities and differences between different parts of the text and results in

the organization of the data into categories or themes. The analysis was carried out in several steps: First, the recordings were transcribed into text. The transcripts were then read through several times with the purpose of getting an overall sense of the interview content. Qualitative content analysis is not a linear process, but moves back and forward between different levels of data. The text corresponding to the aim was then identified and divided into meanings units. These were then condensed, that is, shortened, but still retained the core message. The condensations were labelled with codes that described the content. The codes were then discussed in the research group and sorted into categories and themes on various levels.

In Paper I, the result is presented as themes, which are more descriptive than categories. Meaning units were coded and, based on similarities and dissimilarities, sorted into three themes, with three subthemes each. In Paper II, the results are reported as categories. Meaning units were coded and compared, which revealed two domains, easily identified during the analysis. These were labelled potentials and concerns, under which the codes were sorted into sub-categories, and further abstracted to categories. The results were finally pre-sented as 2 domains, 5 categories and 12 subcategories. In Paper IV, the results are presented as themes with a main theme. Meaning units were coded and, based on similarities and dissimilarities, sorted into four themes, where each theme had two subthemes. The analyses in the three papers focused on interpretation of texts, and this may result in either categories or themes, or both. Within the analyses in this thesis, categories relate to more manifest content levels and answer the question "what". Themes relate to a more latent content, that is, the underlying meaning, and are more descriptive and answer the question of "how" something is (190-191, 193).

To enhance credibility, all steps in the analysis were discussed by the authors until consensus was achieved. To further enhance trustworthiness, abstracted codes, categories and themes were compared to the original texts, and discussed and reflected upon throughout the analytic process (190).

Instrument development and psychometrics
The SMASc instrument (Paper III) was developed in several steps and psycho-metrically tested with different methods. As a first phase, questions and issues for use were suggested based on an inventory of the literature, and reflected against an expert panel. Members in the research group discussed and came to a consensus about the theoretical framework for the scale development. The research team, together with three patients, performed a brainstorming session to highlight and categorize important concepts related to self-management. Words or concepts were written on a whiteboard and discussed concerning

content and relevance. These words and concepts were then categorized into seven domains, labelled knowledge, routines, will, decision-making, planning, social support and emotions.

Two positive and two negative items/statements were constructed for each domain, resulting in an initial 28-item instrument. As an item analysis, content validity was evaluated using a content validity index (CVI) (194). Five researchers, one professor emerita, two professors and two senior lecturers with expertise in patient perspectives of various chronic conditions were involved, whereby minor rewordings were made. The 28-item instrument was also validated in a convenient sample of teachers (n = 88), resulting in further minor rewording.

To refine the instrument, 138 patients from primary healthcare and hospital-based diabetes clinics were recruited to fill in the 28-item instrument. Explanatory factor analysis of the initial seven-domain instrument was performed. The analysis showed that the items in the different domains cross-loaded, especially among the negative items. This led to an instrument refinement where negative items and cross-loaded items were deleted, resulting in a 10-item instrument distributed in five domains with two items each.

The final SMASc instrument assesses five domains important for effective self-management over time: knowledge, goals for the future, daily routines, emotional adjustment and social support. Each item is scored from 1 (Strongly disagree) – 6 (Totally agree), using a six-point Likert scale. Each domain ranges from 2 to 12, where a low score represents higher needs of self-management support. The instrument cannot calculate a total self-management assessment score.

Factor analyses

As a second phase, the 10-item instrument was answered by 104 people with T2D. A psychometric analysis of data was done, which included an assessment of the items' distributional properties (i.e. distribution in per cent and skewness for each item). A parallel analysis was performed to determine the number of common factors in the instrument. Exploratory factor analysis (EFA) was performed to explore the underlying structure of the 10-item SMASc, while confirmatory factor analysis (CFA) was performed to evaluate the model fit. During EFA, the ten items were forced into a five-factor solution based on the theoretical model, using principal axis factoring as the extraction method with direct oblique rotation (195).

A secondary EFA with eigenvalues over 1 was performed. A CFA was performed to assess goodness of fit. Internal consistency was estimated by Cronbach's alpha.

The SPSS version 23.0 (SPSS Inc., Chicago, IL, USA) and AMOS version 23.0 (SPSS Inc.) statistical software packages were used for statistical analysis. Parallel analysis was performed using FACTOR (Universitat Rovira i Virgili, Tarragona, Spain) version 8.02.

Ethical considerations

The project was approved by the Regional Ethical Review Board at Umeå University (Dnr 2014-179-31M), and conducted according to the World Medical Association's Declaration of Helsinki's ethical principles, ensuring that the basic ethical principles of research involving human subjects were met: respect for the individual, beneficence and justice (196).

Information about the studies was given to the head of primary healthcare in the county council, and to the local PHCs' managers who accepted the performance of the studies. The participants – patients as well as nurses – were invited and informed about the study by phone, in person, and by letter (Papers I, II, III and IV). The participants were informed that their participation was voluntary, and that their responses would be kept confidential and would only be presented as anonymous quotes in scientific publications. All participants signed an informed consent. The patients who participated in the observation session were also informed in advance that a researcher would attend, whose presence they could reject or accept. To further ensure confidentiality, participants' identities were anonymized and replaced with codes in the verbatim transcriptions of the focus group interviews and individual interviews (Papers I, II and IV). For the participants included for the psychometric analysis (Paper III), no personal data were collected, and therefore this study did not require ethical approval (197). The results (Papers I, II, III and IV) are presented at group level, which means that no individual can be discerned. The research in this thesis was not considered to be a risk for harm to the participants. Our experience is that many who participate in research studies find them stimulating and interesting (198). It may also be possible that participation could have been a kind of wake-up call for some participants regarding needs for diabetes self-management. Thus, their participation contributed to a learning opportunity.

Results

The overall results of the papers in this thesis constituted a web of mixed experiences and feelings towards using digital self-management support. PHNs pronounced their ambivalence towards the digital developments in healthcare (Paper I), while patients expressed more mixed feelings and pronounced benefits as well as potentials of using digital resources (Paper II). The psychometric assessment of the screening instrument demonstrated high potential and promising results for clinical assessments (Paper III). In addition, the results suggest that the instrument is considered suitable for screening patients' needs for self-management support and resulted in a change in the conversation between the DSN and the person with T2D (Paper IV). The main results of the studies are concluded under the headings below, "Perceptions of using digital resources as self-management support" (Papers I, II), and "Development and experiences of using a screening instrument for person-centred guidance and self-management support" (Papers III, IV).

Perceptions of using digital resources as self-management support (Papers I, II)

The results in Paper I highlighted three themes representing aspects of PHNs' perceptions of using digital services in support of patient self-management: caregiving in the midst of digital chaos, lacking overview and control in one's daily work and mixed feelings towards digitalization.

Caregiving in the midst of digital chaos (Paper I) – The digital chaos was accentuated by several problems in daily work. The primary healthcare nurses stressed that the many logins on the unsynchronized digitalized systems in primary healthcare were pressing for them; they sometimes had to log out from one system, so they could log in on another system. Lack of interoperability between electronic information systems was common. Subsequently, this was seen as time-consuming and not user-friendly. They also expressed concerns about insufficient training, which meant they were lacking competencies and digital skills necessary to work in the increasingly technological healthcare system. Having the right digital skills was highlighted as a necessity to function and provide care. This was described as *"having neither the time nor skills for increasing digitalization."* Different digital systems were disruptive in the work-flow, and their workplace and routines were changing too quickly. It increased time on documentation; entering information at a computer took time away from delivery of quality patient care face to face. The many new routines, and work-flows made them feel tired, and they longed to work at their own pace. This was described as *"change happening too fast – striving for peace at work."* Nurses

expressed that they preferred to have face-to-face interactions with patients instead of using Internet resources, something they thought could depersonalize care, and patients were seen as losers. They also expressed negative feelings about being more administrators than nurses. These problems were described as *"digitalization seen as threatening the nurse/patient relationship."*

Lacking overview and control in one's daily work (Paper I) – With regard to lacking overview and control, the primary healthcare nurses expressed that they were questioned by informed patients or their relatives, who searched for information on the Internet before the visit to the healthcare centre. This was unpleasant, and they felt uncertain, even if they were experienced nurses. They also felt that they lacked skills and support to manage patients seen as knowledgeable Internet literates. This was described as *"having ones' professional expertise questioned".* Organizational barriers such as lack of new work routines when implementing new eHealth systems, lack of training, a busy working environment and heavy workload together with reduced staffing were highlighted. Tight schedules led to down-prioritized eHealth learning. This was described as *"non-adapted work schedules".* Nurses also lacked involvement in planning, development and implementation of the eHealth systems they were supposed to work in. Subsequently, they felt a gap between those who designed the digital systems and themselves. They also mentioned lacking training and technical support from technicians. Also highlighted were fears that the technology investments were based on finances, choosing poorer digital systems to cut costs. This was described as *"a top-down perspective on learning and implementation".*

Mixed feelings towards digitalization (Paper I) – The mixed feelings had various grounds. The primary healthcare nurses described the fast pace of change and remarked that the traditional view of nursing had changed with increasingly digitalized healthcare. Even though health technologies were perceived as offering important benefits, for example, easy access to health-related information about the patients, nurses still wanted to emphasize that the digitalized healthcare also created more work. Double documentation was common: nurses usually used paper-based documentation in the patient meeting, and afterwards, they entered the nursing documentation into the digital patient record. This was seen as very time-consuming. This was in Paper I described as *"an exciting but exhausting development".* Nurses stated that eHealth made it easy to be updated and knowledgeable on diseases and new treatments, but at the same time they described it as stressful and demanding to be constantly updated. Despite the doubts, no one wanted to shift back from an electronic system to a paper-based system. They also stated that eHealth is changing healthcare and can make primary healthcare more efficient. This was described as *"easy but requiring constant updates".* Nurses mentioned that eHealth had improved

accessibility and communication with their patients, but also that they wanted easier documentation and evaluation to improve patient safety in the digital patient journal. They described information overload: a flood of information and an increasing flow of daily emails that might have negative consequences for quality of care. The participants, though, highlighted that the digitalized medical record systems had prevented many patient risks such as drug interactions and had reduced the risk of allergic reactions. Furthermore, eHealth platforms had reduced errors in ordering and administering medication. This was described as *"contributes to both improved and impaired care quality"*.

The results in Paper II highlighted two domains, potentials and concerns, which represent different perceptions of using digital health services for self-management support among people with T2D. Within the domain potentials, three categories emerged: involvement, empowerment and security. Within the domain concerns, two categories emerged: ambivalence and uncertainty.

Potentials in digital health services for self-management support (Paper II)

Involvement was a clear potential. The patients highlighted the importance of being involved and having influence in decisions that had impact on their health, such as regarding medication and in discussions about their own goals and need of self-management support. Participants expressed that they strived to handle all demands related to T2D, but sometimes social demands made it difficult to prioritize self-management. Some felt they had a key via digital and technological tools that could provide insights and motivation to improve self-management. This was described as *"independence"*. Participants expressed the importance of taking responsibility for themselves and healthier behaviour. Various digital health services helped them to take more action in their self-management and at the same time also accept the consequences of unhealthy choices. Participants mentioned that they had been advised by their DSNs not to trust all information on the Internet. This was described as *"responsibility"*.

Empowerment was another potential. The participants highlighted a number of areas related to eHealth that were found important for the management of the participants' own health. They thought that as well-informed patients, they easily could discuss and request different treatments. Participants saw themselves as knowledgeable, capable and also responsible for their own health and self-management. Using different diabetes apps enabled them to make informed choices, which could lead to better diabetic control, something the use of apps could facilitate. This was described as "*knowledge*". Participants perceived the Internet as providing opportunities, because through web-based portals they

could discuss T2D with people who weren't healthcare professionals. It was suggested that mobile apps supported management of diabetes; at the same time, adult children could be updated online and follow the process at a distance. This was described as "*participation*". Using digital health services and devices increased awareness about T2D among participants and improved their self-management. Participants reported that they usually met a GP and a DSN semi-annually, but due to an increased use of digital technologies, some viewed personal visits at the healthcare centre as unnecessary. This was described as "*engagement*". Participants felt that using digital health services that are available all hours increased their freedom; they did not have to wait until the DSN was available if they had problems or had questions during the weekend. This was described as "*freedom*".

Security was a third potential. Participants highlighted that they experienced digital health services as offering security, by using such components as passwords, encryption systems like a Mobile Bank ID or similar technical safeguards. The participants mentioned that within face-to face visits they sometimes withheld information from healthcare professionals because of confidentiality concerns and might avoid personal visits to the healthcare centre. They described having a feeling that using web-based healthcare services was more secure, with personal log-ins, instead of sitting in the waiting room risking meeting a nosey neighbour or others. They thought that using digital health services was better than making the traditional face-to-face visits. This was described as "*confidentiality*". Participants expressed that lack of privacy was a barrier to visiting healthcare centres in small communities. By using web-based health services, they did not have to advertise their problems to other patients in the waiting room, and thereby, they did not feel as vulnerable and exposed. This was described as "*privacy*".

Concerns regarding digital health services for self-management support (Paper II)

Ambivalence concerning digital health services was a concern. It concerned, for example, feeling a lack of confidence and not being able to manage the technology, and some participants therefore avoided digital devices if they could. Some expressed worries, particularly if they did not have any family members or friends who could support them technologically. Therefore, some preferred face-to-face meetings with healthcare professionals. This was described within the domain concerns as *"insufficient support"*. Participants expressed a lack of digital competence and skills in general and that this combined with poor technological design was a barrier to navigating websites and apps. Some participants also mentioned that they had difficulties using smartphones due to physical problems

such as sight loss or tremor. These issues were summarized and described as *"lack of digital skills"*.

Uncertainty was a second concern that was highlighted among some participants. They felt uncertain as to whether they could trust information they came across on the Internet and were afraid of problems with eHealth services due to unreliable Internet connections. Some participants saw no value in using technology to manage their health, because they did not always trust the quality of the web-based information and whether it provided enough information about diabetes management. Participants also were hesitant to rely entirely on the online information, since the content could be medically incorrect. This was described as *"distrust of information"*. Participants furthermore highlighted lack of Internet access through wired or wireless broadband that made it impossible to rely on using a computer or smartphone for eHealth purposes. They, however, also expressed uncertainty regarding the primary healthcare services, which they thought could not guarantee a totally reliable computer system either. This was described as *"unreliability"*.

The development and experiences of using SMASc (Papers III, IV)

Paper III aimed to develop and test the psychometric properties of SMASc. The initial 28-items SMASc cross-loaded, especially among the negative items, which resulted in a reduction of items to the final 10-item SMASc distributed in five domains with two items each.

SMASc is a valid instrument measuring self-management and needs for self-management support (Paper III) – The SMASc was found to be a valid instrument for measuring the level of need of self-management support of patients with T2D. The instrument is deemed to be useful and enables DSNs to build profiles of people with chronic conditions regarding aspects of self-management and thereby needs for self-management support.

Within the psychometric testing, an initial analysis of the *item distribution* of responses showed skewness in four items (1, 4, 5, 7). Six items (2, 3, 6, 8, 9 and 10) were considered to be evenly distributed. Five experts in the field assessed *content validity*. The CVI for the SMASc was 0.89. A *parallel analysis* based on minimum rank factor analysis was carried out to determine the minimum number of factors in the instrument. The result showed that the recommended number of factors was one. An *initial EFA* showed that items with an eigenvalue over 1 loaded in only one domain. Therefore, a *second EFA* was performed which showed insufficient concordance with the proposed five-factor model.

A *CFA* was performed on the five-factor solution to test its *goodness of fit*. The chi-square was significant ($\chi2 = 46.0$, df = 25, p < 0.006) with a relative chi-square of 1.84. The Tucker Lewis index (TLI) was 0.93; Normed Fit Index (NFI) 0.94; Bentler Comparative Fit Index (CFI) 0.97; and, finally, Root Mean Square Error of Approximation (RMSEA) was 0.09, indicating a good model of fit. The final model is shown in Figure 2, including path coefficients (standardized regression weights and correlations). *Correlations* between the factors were in the interval of 0.54–0.96, and the highest correlation was found between knowledge and emotional adjustment. All of the path coefficients were significant at a p < 0.001 level.
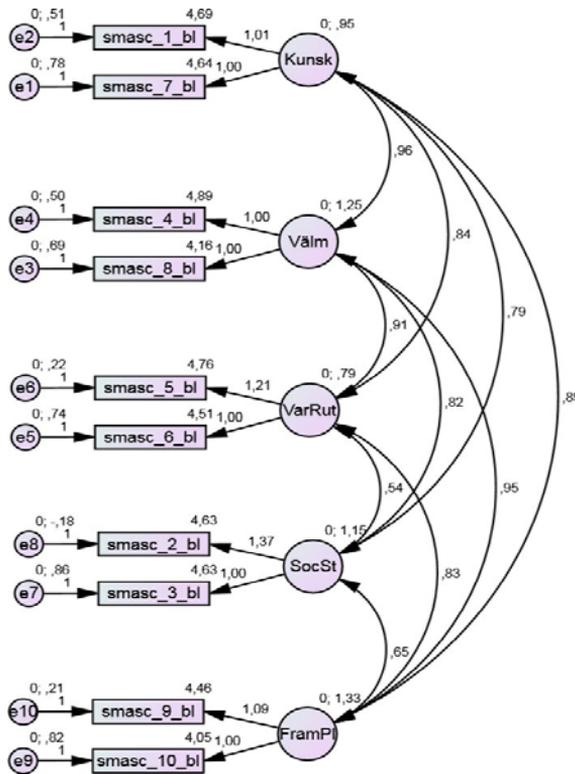
Figure 2. Model of the 10-item version of the SMASc questionnaire with standardized regression weights and correlations (Kunsk=Knowledge, Välm=Emotional adjustment, VarRut=Daily routines, SocSt= Social support, FramPl=Goals for future).

Internal reliability was estimated using *Cronbach's alpha* for respective domain resulting in, for knowledge, $\alpha = 0.727$; goals for the future, $\alpha = 0.848$; daily routines, $\alpha = 0.794$; emotional adjustment, $\alpha = 0.807$; and finally, social support, $\alpha = 0.883$, which indicates a high internal consistency. Cronbach's alpha for the instrument as of whole was 0.925.

SMASc is person-centred and useful for screening and helps both parties to develop (Paper IV) – The results in Paper IV highlighted a main theme and four themes that highlighted the usefulness of the SMASc in clinical practice.

A new way of thinking and acting on patient's term – This was the main theme. The DSNs expressed that using the SMASc led to more in-depth conversations in the meetings with patients with T2D. Screening for patients' needs, or levels of self-management support, was perceived as leading to person-centred support, because it was built on trust and fostered development of both parties. The collaboration and use of the instrument were powerful sources which led to change among both patients and nurses. The following four themes that built the main theme are described in more detail below.

A screening instrument with good potential – The participating DSNs had experienced that SMASc streamlined the patient meeting and fitted into their regular workflow. SMASc took just 1–2 minutes to fill in, and they got the patients' scoring directly. The DSNs found it easy to interpret the results, with scoring points visualized by the colours red, yellow and green. The DSNs highlighted that by interpreting the score and demonstrating it for the patient, SMASc could be used in a helpful way to address important topics that might be meaningful for the patient. This was described as *"an educational, easy-to-use tool".* Prerequisites of using SMASc, however, are truth and honesty, accordingly to the DSNs; otherwise it fills no function. The DSNs verbalized their experience that a few of the patients did not answer honestly on the *SMASc* for various reasons. This was described as *"builds on honest answering".*

Embraces more than medical issues – The focus of the conversations between DSNs and their patients' concerned knowledge, goals for the future, daily routines, emotional adjustment and social support. The screening instrument helped them to focus on more than knowledge and medical issues. The DSNs expressed that the communication was strengthened, and they got a better understanding of the patient's whole situation. This was described as *"the patient becomes more than the disease".* They described the results as being like a door opener in the communication with the patient when it became clear which topics should be addressed in their conversation. The use of SMASc was described as a new way of both thinking and working. The areas with low scoring were those that the DSNs should concentrate on in the conversations with the patients, and it gave them a foundation for improved self-management support. This was described as *"a door opener to address difficult topics".*

Self-management support highly person-centred – The DSNs reported that based on the patient's scoring and the following discussion around it, a variety of topics like personal risk factors, readiness for change, the patient's self-

management needs, preferences and health behaviours were highlighted. The DSNs found it easier to develop individualized self-management plans together with the patient after the introduction of the screening instrument, even though they just had used it for a short while. Furthermore, they considered that it provided them and the patients with prerequisites for a more person-centred care and tailored coaching. It also had become easier to approach the patient to discuss sensitive questions that they earlier might have avoided. This was described as *"conditions for tailored counselling satisfying".* DSNs also described that they thought their discussions with the patients about the low-scored areas seemed to motivate patients to improve self-management compared to before. The DSNs found it surprising when they introduced patients to digital sources for self-help and got positive reactions. This was described as *"patients become more empowered".*

Both parties develop through collaboration – The DSNs stated that using the *SMASc* clarified and made visible also to the patient topics they had not thought of before, such as the future, goals and so forth. This collaborative approach made the patient meeting more person-centred. This was described as *"incentives for self-management and support".* The participating DSNs thought that the instrument was useful because it highlighted reflections, evaluation and feedback on previous efforts that had been made. It indicated changes that had to be made in the patient's own treatment plan and also mirrored how the self-management support had been perceived. This gave both patients and DSNs an opportunity for reframing and changing direction going forward. Annual assessments with SMASc were described as necessary to obtain an accounting of how the patient managed life with diabetes. This was described as *"an opportunity for reflections and reframing."*

Discussion

The overall aim of this thesis was to explore perceptions among DSNs and patients about digital self-management support in T2D, and also to develop and evaluate a digital screening instrument assessing individual needs for self-management support. The main results are summarized in some headings below, highlighting important aspects in understanding prerequisites for digitalized and person-centred self-management support.

A new generation of independent patients

In both Papers I and II, the findings highlight an issue about the new generation of independent patients, and this is not linked to age but to the ongoing digital transformation in healthcare. While primary healthcare nurses in Paper I described the independency in relation to information seeking among patients of today as problematic, patients in Paper II described this independence as beneficial.

Patients in Paper II highlighted several benefits offered by digital health solutions, creating a new level of awareness for the individual. Advantages that were underlined were aspects about the importance of being involved in the decision-making concerning their healthcare that had a positive impact. Similar findings were described in a survey from Italy, which showed that if patients met a health professional who had the ability to listen and discuss information found online, it made them more engaged in decision-making and strengthened their empowerment (199). As a contrast, a study by Fredriksson et al. (200) showed that only 13% of patients in England and 10% in Sweden wanted to be involved in such medical decisions (200).

Patients (Paper II) also valued having access to their health information whenever they wanted, every day. They considered eHealth as an opportunity to take more responsibility for their own care. Information on the Internet empowered them to be active in gaining better control and to manage, monitor or track their health towards their own health goals. This is supported by a study where it was highlighted that technology applications had potential for allowing older adults to manage their own health and ageing in place at home (201). It was also highlighted that by using digital health solutions, they understood more about their disease, health and lifestyle. This led to a better overview of "their disease", and this was expressed as having a positive impact on "outcomes" such as blood glucose levels and so forth. This is in line with other results which show that patients' awareness increased their health status when they used personalized apps and wearable sensors measuring blood-glucose levels, blood pressure and

stress levels, something that transformed patients into empowered healthcare consumers (202). Online access to educational resources was seen as strengthening their understanding of the T2D disease (Study II). Research has shown that people with T2D who seek online health-related information are more conscious about their diabetes self-care compared to non–health-related information seekers (203).

The results from Paper II showed that patients preferred a more active role and wanted to discuss different areas related to their T2D together with their DSNs, as well as discussing their findings on "the Internet". Somewhat divergent views on the usefulness of digital resources to make personal health-related decisions were, though, highlighted. The patients expressed the feeling that DSNs did not always appreciate when they, as patients, had their own opinions about their needs. These results are consistent with another study (204), where nurses perceived critically minded patients, who used Internet for sourcing information, as a challenge. Nurses felt it like it was a "new era" having to deal with inquisitive and enquiring patients.

The patients revealed that it was time saving and comfortable to manage disease-related aspects from "home", and did not always feel a need for face-to-face contacts with healthcare professionals. It was expressed that using the Internet was a good complement to ordinary care (Paper II). This is in line with a study by Greis et al. (205), where patients expressed an interest in digital healthcare services. The patients thought that it was an advantage using online appointments compared to regular consultations, as these were flexible with respect to time and location, and also time saving.

However, some barriers for using digital technology were also noted and high-lighted some ambivalence among patients. This ambivalence concerned lack of knowledge, usability problems and health=related aspects, for example, not being able to manage a smartphone due to eyesight deterioration or tremor (Paper II). Internet-connected computers and smartphones provided new means to search for health information and offered potentials in managing their health and healthcare decision-making. This was also highlighted in a recent study (206) that found that people who possessed digital skills were a step ahead of those who did not. Lack of literacy (i.e., health literacy and digital literacy) was seen as a huge barrier that needed to be dealt with. Even if more elderly adults use the Internet to search for health information, there still remain challenges in solving physical and cognitive limitations (207).

Concerns about uncertain and unreliable Internet connections were also emphasized by patients (Paper II). Even though problems with broadband connections have been highlighted in earlier studies (208, 209), with the

introduction of wireless broadband the Internet has allowed an explosion of low-cost mHealth applications. Digital online and mobile applications offer patients quick access to information and services and thereby enhance diabetes health and healthcare management (210). Another interesting aspect from Paper II was that technical safeguards for authorization on the different digital platforms were perceived as something positive, making the patients feel more secure about using the systems. This finding resonates with a study that suggests that if patients are to adopt eHealth solutions, the use of safe data encryption and authorization is necessary if patients are to trust in digitalized care (211).

However, the primary healthcare nurses expressed that they distrusted the health information patients came across on the Internet, and particularly if there were no "logins" (Paper I). This is partly in line with previous research indicating that online patient information resources seldom provide useful answers, but that the patients nevertheless trusted the answers given by others with similar experiences and perspectives (212). Other studies indicate that low health literacy, but not educational levels, among patients play a role in evaluating online health information (213, 214). In a review it was suggested that patients, on one hand, tend to prefer the Internet for the ease of accessing information, while they, on the other, trust health professionals more for their clinical expertise and experience (215). As a contrast, in a study by Cole et al. (216), results showed that online health information was of "reasonably good quality", and it was suggested that discussion forum websites could be a useful platform in which people could ask health-related questions and receive answers of acceptable quality.

Whether patients actually use digital health solutions will always be a personal matter and will differ among patients. Overall, the interpretation is that patients had a positive attitude towards using technologies that helped them to manage their disease (Paper II). This is in some way contradictory to findings in Paper I, where primary healthcare nurses expressed that they felt ambivalent to patients "googling" on the Internet, which often created extra work for the nurses and led to frustrations. This is in line with another study from the UK, where nurses experienced disruption due to the implementation of TeleHealth as threatening. The main factors that added to the experience of threat and affected their decision to use the technology were change in clinical routines and increased workload, change in interactions with patients and marginalization of clinical expertise (152).

Forced role change among primary healthcare nurses

Papers I, II and IV highlighted the need for role change among nurses in primary healthcare. In Paper I, it was interpreted that this role change was forced. Paper

I showed that the ongoing digitalization in primary healthcare was challenging for nurses. They highlighted that it sometimes was difficult to face well-informed patients who wanted to talk about information they had read "online". The DSNs saw it as their duty to inform the patients "not to believe" everything they read online (Paper I). This is supported by another study, were nurses felt inadequate and embarrassed when talking to well-informed patients (204). The fear of finding untruthful facts on the Internet was also something patients expressed (Paper II), and is somewhat in line with a previous study (217), which reported that patients felt informed when using eHealth resources, but at the same time, they also felt uncertain, since it led to more questions about their health condition and treatment options. However, they also stated that they no longer thought that healthcare professionals were the only "gatekeepers of knowledge".

The DSNs (Paper I) also expressed that they feared losing the personal contact with the patients if their problems were to be handled online, and they therefore preferred traditional face-to-face meetings. In a Swedish study (218), nurses expressed concerns that the increasing digital development would lead to more or less "automatized" care services that could impair the quality of care. It was also highlighted that they did not consider digitalized resources as replacing face-to-face care. The challenges among primary healthcare nurses (Paper I) were related, for example, to the new and many digitalized systems they now had to deal with. The change to digital systems was happening too fast, and they expressed having difficulties with various passwords, inadequate computers, lack of support, and last but not least, inappropriate digital skills. Nurses reported that even if they admitted that they lacked skills, they got too little support and had to "learn by doing". This is somewhat in line with a study (219) that highlights that nurses need to develop computer skills if digital systems are to be implemented in healthcare. This might help to lower the threshold and increase acceptance of eHealth interventions in healthcare settings.

The results in Paper I also showed that the primary healthcare nurses lacked an overview and felt they lost control over their daily work. Some nurses wished to be involved in the development and introduction of new digital systems, as they often had to change work routines in accordance to the digital systems and not the other way around. The various digital systems were not seldom incompatible. For example, information-sharing digital systems were often impossible to use due to a lack of interoperability between different systems. This has also been highlighted in a recently published review (220), where nurses expressed that they lacked the necessary skills and were uncertain how to handle the hardware, which was further exacerbated by continual implementations of new technologies. In addition, since the digital systems were not always tailored to the nurses' daily work (Paper I), their workload increased and job satisfaction declined. The primary healthcare nurses expressed this as trying to care for the

patient in the midst of digital chaos. Previous research (221) states that inter-operability, which is the exchange in health data involving more than one system, is seen as a barrier instead of a facilitator. Increased time is spent on interacting with the digital systems, which decreased their job performance, because they spent less time with patients. Lack of time and increased workload were important barriers to implementing digital resources.

Nevertheless, the nurses (Paper I) had mixed feelings about the increasing digitalization of healthcare. They emphasized that in one way, their jobs had become easier and more effective – it was easy to search for information. Similar findings were reported in previous studies from Sweden (222, 223) that showed more positive attitudes among experienced healthcare professionals compared to inexperienced ones, when new digital systems were implemented. This finding implies that healthcare professionals need to overcome obstacles to enable them to recognize potential benefits that can be derived from implementation of eHealth interventions.

Another aspect of the nurses' role change is that, after implementation of SMASc, seen as a screening instrument, the conversations between nurses and patients at the annual visit to the diabetic clinic had changed and become more person-centred. In Paper IV, the DSNs reported that the use of the screening instrument, which mirrored self-management from a patient perspective, changed their role in a positive way, since the conversation became more equal. In a review (224) on Internet health information and the relationship between patients and healthcare professionals, findings showed that when patients got better access to information through the Internet, they were expected to become more engaged in the health decision-making. Accordingly, healthcare professionals had to adapt to meet the Internet-informed patients and the changing demographics of digitalized care.

Assessing patients' needs using a digital questionnaire

Paper III describes the development of a digital screening instrument, which in Paper IV was implemented as a pilot project in nurse-led diabetes clinics in primary healthcare.

Introducing an intervention regarding digital self-management support among nurses who already are overwhelmed by the negative aspects of eHealth and digitalized care (Paper I) can be challenging. However, this was something we had in mind even early in the development of the instrument. The instrument should be quick and easy to answer and the number of items should be as few as possible, making it easy for both the patient and the nurse to use. Therefore, an early version of the instrument that contained 28 items was reduced to 10 items over

time. The final 10-item SMASc instrument, which was developed over three years, is judged as both valid and reliable to measure five areas important for self-management in T2D; knowledge, goals for the future, daily routines, emotional adjustment and social support (Paper III).

The digital version of the SMASc instrument, where questions are scored from 1–6, has cut-offs in each area where low, medium and high values are calculated and coded with colours, green, yellow and red, in the presentation for patients. The traffic-light colours should be seen as a visual pedagogic tool. Green indicates no need for self-management support, yellow indicates no acute need for self-management support and red indicates need for self-management support.

To the best of my knowledge, there is no existing instrument like SMASc that assesses patients' needs for self-management support and also has a person-centred focus. The most similar instrument is the 27-item Self-Management Screening Questionnaire (SeMaS) (225), which assesses possible patient-related barriers. SeMaS was developed in the Netherlands, aiming to facilitate personalized counselling and support for self-management in patients with chronic diseases in primary care. It uses a graphic profile as a representation of the scoring and assesses disease burden, computer skills, comfort in groups, willingness to self-manage, perceived control over health, self-efficacy, social support, and coping with problems, anxiety and depression. SeMaS has not been translated into Swedish. There are some other instruments available that assess one or more aspects of self-management, but they are more disease-specific, such as the Diabetes Self-Management Questionnaire (DSMQ) (226); the Diabetes Empowerment Scale (DES), which is a measure of diabetes-related psychosocial self-efficacy (227); the Perceived Diabetes Self-Management Scale (PDSMS) (228); and the Self-Control and Self-Management Scale (SCMS) for assessment of self-control and self-management skills (229).

The SMASc was introduced in several steps, and the DSNs had opportunities for training and support if needed. The pilot implementation was found to be surprisingly simple. The DSNs expressed that the instrument simplified their work and they approached patients quite easy. The SMASc is (Paper IV) interpreted to be particular useful in clinical practice, as it enables nurses to build profiles of people with chronic conditions regarding their self-management support needs. It is a short screening instrument that is very useful, easy and quick to complete in daily clinical practice of primary healthcare settings. With the presentation of the patient's score on each domain, the nurse and the patient together can target individual needs for self-management support. Based on results from the SMASc scoring, nurses can also recommend digital self-management support from, for example, information sites on the Internet as well as mobile applications enabling daily procedures. They can also use the results

for face-to-face contacts and for getting closer to the real barriers for effective self-management.

The last step of the implementation process has not been taken. The pilot implementation must be evaluated before the final step is taken. Promising results from our qualitative studies will later be complemented with evaluating quantitative studies regarding effects on, for example, HbA1c, blood pressure and weight, within forthcoming reports. Thereafter, the step of full deployment of the intervention may be considered.

Improved person-centredness in self-management support

In Papers I, II and IV, the importance of person-centredness in self-management support was expressed. To achieve this, the research group initiated the development of the SMASc instrument, based on literature on patients' perspectives on illness, and on the experiences of researchers and patients of needs in relation to self-management. The findings in Paper III showed that SMASc in a person-centred manner mirrors levels of self-management support needs.

The nurses related that the Internet was seen as a valuable resource for accessing health information, for themselves, as well as for T2D patients (Papers I and IV). The DSNs perceived SMASc as easy-to-use and a valuable tool in the patient meeting (Paper IV). Previous experiences of being in digital chaos and other perceived problems when using eHealth resources (Paper I) were re-evaluated by using the SMASc instrument.

Results from Paper II highlighted needs of patients to become more involved in their own care and empowered to take responsibility for their self-management. According to a previous study (230), enhancing self-management is a bridge to reaching quality of life for people with T2D. Some healthcare professionals in the study, though, expressed it as hard to discuss emotional issues identified by patients. Having diabetes is described as being connected to a strong emotional experience for most people. Despite this, adults rarely achieve and maintain life-style changes unless they feel a strong need for them. If the patients do not experience strong feelings about the current situation, the likelihood of a lifestyle change is small. Healthcare professionals are therefore encouraged to create an environment where the patient's emotional experience is validated and can be expressed freely (230). However, aspects such as a lack of emotional adjustment and support and lacking goals for the future can be obstacles for lifestyles changes (107). Traditional approaches have had difficulties tackling this. Emotional and existential aspects of being chronically ill and related demands of daily self-

management are seldom discussed with the T2D patients (Paper IV). The screening instrument SMASc (Papers III, IV) has potentials and visualizes and highlights areas of unmet support needs. SMASc was evaluated by the DSNs as a valuable tool that facilitated conversations with the patients and opened up opportunities for discussion of new and previously unspoken or sensitive areas concerning the patients' self-management and need of self-management support (Paper IV).

Talking about emotional and existential issues is especially important, but seemed to be a new area for DSNs. The focus during the patient visit to the diabetes clinic has traditionally rested on medical measurements and variables registered in the NDR, which the conversations often have been based upon (cf. 114, 231). The focus on emotional management for digital self-management support is of importance: studies show that changes in diabetes-related distress are associated with changes in glycaemic control, probably through changes in adherence to medication, and depressive symptoms are associated with self-management behaviour (232, 233). In Paper IV, it was reported that the DSNs had found it easier to inform patients about the disease, laboratory values and similar topics than to approach sensitive and more personal topics. By using the SMASc, though, the DSNs got an incitement to approach T2D patients in a completely new way, and by that, the "balance of power" shifted to a more equal position. Since the domains in the SMASc embraced more than merely medical issues, the DSNs described that person-centredness increased, and as well the nurse–patient relationship improved, when they came closer to the person (Paper IV). By reflecting on new domains, the conversation opened up, and thereby, the patients and the nurses started to reflect on issues they had not considered before. When the conversation became more balanced, it was perceived by the DSNs that the patients became more empowered. This is in line with a study by Gardsten et al. (82). The participants in that study expressed that their own emotional capability and motivation were the most crucial factors in managing their diabetes. Consistent with person-centred care, the authors state that DSNs must focus on encouraging patients' abilities to mobilize their own personal strengths to maintain self-management. The authors also state that it would be desirable if individual needs for self-management on peoples' own terms were met and beneficially met through a technological service that could reach and connect to a large number of people.

Increasing the focus on emotional management for digital self-management support programs has clinical importance. Studies show that changes in diabetes-related distress correlate with changes in glycaemic control, probably through changes in adherence to medication, though depressive symptoms are correlated with self-management behaviour (232, 233).

To summarize the discussion, nurses as well as patients expressed mixed feelings over digital resources, including resources used in healthcare as well as health information collected from the Internet. On one hand, digitalization could facilitate the work of nurses and the life situation among patients; on the other hand, it is perceived as confusing. However, after implementing a digital tool for person-centred assessment of self-management support needs, digitalization became more comfortable, since it was easy and useful. Simultaneously, the interaction between nurses and patients became more person-centred, where new, more sensitive topics could be brought up and barriers as well as self-management strategies could be agreed upon, which empowered both patients and nurses.

Methodological considerations

The studies in this thesis required a combination of methods, which implied relating to epistemology in a pragmatic way, thus letting the research question determine what method to use. The thesis, however, has an emphasis on qualitative methods. With a combination of methods, qualitative and psychometric, it was possible not only to answer the research question, but also to gain different perspectives on the obtained knowledge (234, 235). Qualitative data used in this thesis were drawn from focus group interviews, individual interviews, participatory observations with follow-up interviews and questionnaires.

Qualitative analyses – trustworthiness

The methodological considerations of qualitative research depend on achieving trustworthiness in the studies (191). When assessing trustworthiness of a study, the concepts credibility, dependability, confirmability and transferability could be discussed (236). These aspects are described separately below, but should be viewed as intertwined and interrelated (190).

Credibility deals with the focus or purpose of the research and confidence in how well data and processes of analysis address the particular aim (237). Selection of context, participants and approach to gathering data has to do with credibility. Furthermore, the choice of participants with various experiences is important in order to shed light on the research question from a variety of aspects. Credibility also concerns choice of the most appropriate method for data collection and the amount of data (190). The choice of participants and the amount of data, that is, interviews and observations, are judged as appropriate, purposeful and satisfying for the chosen analyses, and data could thereby answer the aims of the studies. An aspect is the richness of the data and whether it corresponds to the aims, rather than the number of interviews (238). In striving for credibility of the interviews in Paper I (focus groups), Paper II (individual interviews) and Paper IV

(participatory observations with individual interviews), semi-structured interview guides were designed with follow-up questions and probes. In Papers I, II and IV the interpretation of the interview data was based on the audio recordings and verbatim transcripts that could be compared regarding consistency. In Paper I, (themes and subthemes), Paper II (domains, categories and subcategories) and Paper IV (main theme, themes and subthemes), quotations from the narratives were used to strengthen the credibility (190, 191). All these analyses fitted well into demands regarding credibility.

Credibility also deals with how well categories and themes cover data. In the analyses, all relevant data has systematically been included in the analyses, consisting of sorting data into categories and themes on various levels. The credibility of the analyses has also been demonstrated through use of quotations as examples in the results. Co-authors from different professions and with varying knowledge about the study groups (Papers I, II, IV), were involved in the analytical process, in discussing codes, categories, subcategories, subthemes, themes and main theme. The authors discussed various opinions about coding and categorization until finding an agreement as a way of reaching credibility (cf. 190).

Dependability could be described as controlling factors of instability and the degree to which data may change over time. It also concerns the researchers' decisions about alterations during the process of analysis. Due to a risk of inconsistency, the data collection should not be extended over time. Data collection in all studies in the thesis was concentrated and alterations were not needed. The same areas could thereby be covered among all participants in each study (190). Dependability is also important to trustworthiness because it establishes whether the research findings are consistent and repeatable (233).

Confirmability should in qualitative research be considered in relation to researchers' preunderstandings. It is important that findings emerge from the data and not from researchers' own predispositions (236, 239). Reflecting on one's preunderstanding before interviewing and analysing could help the researcher to be observant of over-interpretations. Within the studies in this thesis, one person, namely the author, interviewed all the participants, and also planned, conducted and transcribed all the interviews. My preunderstanding of the context might have influenced the interviews and also the interpretation of the text. However, I have tried to be open and have sometimes had to conform to the co-authors' interpretations in phases of coding and categorization, when my preunderstanding has been somewhat limiting for me.

Transferability, lastly, refers to the extent to which results might be transferred to other settings (239). It is always the readers who can decide whether the results

are transferable to other contexts, settings or patient groups. To facilitate questions about transferability, the context, sampling, participants, data collection and the analytical processes are clearly and distinctly described (239, 240). Graneheim and Lundman (190) highlight that a vigorous presentation of the findings together with exemplifying quotes could enhance transferability. The interpretation of data in this thesis highlights the most likely interpretation of perceptions among DSNs and patients about digital self-management support in T2D. Whether these results are transferable is up to the reader.

Psychometrics – validity and reliability

Regarding validity, there are important aspects to be aware of when the intention is to develop an instrument (Paper III). To assess a phenomenon like self-management support needs is challenging, and the question concerning validity is whether SMASc measures what it was meant to measure. SMASc was initially developed based on different theoretical concepts relating to self-management, self-management support and person-centred care in T2D, illness integration, self-efficacy and health literacy. As previously described, five experts in the field of self-management assessed content validity. Within the instrument develop-ment process, the initial 28-item instrument was stepwise reduced to a 10-item instrument. During this process, several statistical analyses and reliability tests were performed. Descriptive statistics and reliability estimates were performed. Each item was analysed concerning distribution and skewness of responses. Explanatory factor analysis of the initial seven-domain instrument was performed. Cronbach's alpha was analysed for total scale and domains. The analysis showed that the items in the different domains cross-loaded, especially among the negative items. This led to an instrument refinement where negative items and cross-loaded items were deleted, finally resulting in a 10-item instrument distributed in five domains with two items each. This process descrip-tion demonstrates that the 10-item SMASc was systematically developed in several steps to increase the construct validity and reliability of the SMASc. The instrument is considered useful in clinical practice. It was found to be easy and quick to complete, and showed sufficient goodness-of-fit. The SMASc can help health care professionals to tailor self-management support for people with type 2 diabetes and possibly also people with other life-style related chronic illness. For research purposes and further psychometric testing, it would be beneficial if the SMASc instrument would be expanded to at least three items per domain, as recommended by Costello and Osborne (195).

Limitations and ethical considerations

Qualitative research never aims to quantify. However, we experienced clearly that people with T2D in Paper II were expressing more positive attitudes to digital resources than primary healthcare nurses in Paper I did. The chosen methods though, do not support such findings. We also experienced that the DSNs

participating in the pilot implementation in Paper IV were much more positive than the primary healthcare nurses in Paper I. Nor this can be verified by the chosen qualitative methods and study designs.

My experiences may have to do with the samples. In the pilot implementation study reported in Paper IV, DSNs themselves volunteered to participate, while the primary healthcare nurses in Paper I were asked by their managers to participate. Involving participants who beforehand are interested in eHealth can also lead to response bias. This may be the case in Paper II, where the patients were seen as more being positive towards digital resources. In Paper II, there were also more men than women who participated (3 women, 8 men), which also can be explained by the fact that most participants were recruited after a successful meeting at the Local Diabetes Association where more men participated, possibly since it concerned eHealth and digital resources. The results of Paper II should therefore be regarded with caution, since they may have been different if more women had been included.

Not only ethical aspects but also questions of equity and security have to be considered when digital services are introduced into healthcare. The digital divide is a barrier that has to be addressed. Use of eHealth resources in healthcare may increase the gap between people with low and high socioeconomic status and eHealth literacy levels. eHealth tools are today mainly used by people with higher digital skills and Internet access (241), while most non-users of the Internet are older people with insufficient digital skills or those with lower income. The studies within this thesis have not included such aspects, and therefore, the results may be less transferable to groups of older people or those underprivileged.

Security is associated with the technologies used to collection and transfer personal data. Swedish healthcare is governed by laws and national guidelines to ensure high quality care for the citizens as well as increased patient involvement in treatment decisions (242, 243). As of May 25, 2018, researchers have to take into account the new Act on the General Data Protection Regulation (GDPR), which is intended to protect the fundamental rights and freedoms of individuals, in particular, the right to the protection of personal data. The GDPR applies throughout the European Union (244). Even though GDPR did not exist when this project was initiated, current regulations has been followed.

Conclusion and implications for practice

Digital resources are becoming more common in healthcare but are still a little daunting for the users. Nevertheless, some resources, such as digital screening instruments, can improve and change the care. However, the results of this thesis

suggest that introduction of new digital resources in primary healthcare needs stepwise implementation.

Existing healthcare services focus mostly on providing health information and medical management. Diabetes specialist nurses' focus on biomedical issues, such as variables in the NDR and other measurements, may not be enough to motivate self-management or to adequately meet the wide range of patient needs. Even though the results in this thesis report only a pilot implementation of a screening instrument, they provide information about positive effects that could also be found in a full-scale deployment. By using SMASc in the patient encounter, the DSNs have a tool that can visualize patients' unmet needs in the areas knowledge, goals for the future, daily routines, emotional adjustment and social support. Based on patients' results from SMASc, nurses together with the patients can agree on a person-centred activity plan for future.

In parallel with the technological development, the traditional nursing role is changing. However, if nurses in Swedish primary healthcare are to adapt to the new policies and practices, they need proper training and education on using digital resources. They are also encouraged to be more involved when digital services are developed. It is a challenge to develop digital tools that could support patients' self-management while still maintaining the values associated with person-centred care.

A lot of people with T2D are interested in digital health technologies and services for self-management support. The use of such technologies for person-centred self-management support could strengthen patient empowerment and self-management. Findings within this thesis indicate that patients as well as nurses require training and support to overcome technological barriers. Nurses may need training to adapt and to get insights about the usefulness of a tool such as SMASc. If it is implemented wisely, both nurses and patients could find the use of a digital screening instrument like SMASc as a common ground for discussions of sensitive topics, including emotional and existential aspects of living with a chronic illness.

Results in this thesis also show that the use of the SMASc instrument may contribute to improved self-management through person-centred self-management support. However, to deploy it full-scale in diabetes clinics in primary healthcare requires that it will be prioritized by DSNs and that time will be allocated to discuss patient's more sensitive problem areas during the visits. It also requires acceptance and approval of local managers and preferably also of leaders in higher positions in the regions who want to see positive effects from the digital and technical developments in healthcare.

Although person-centred care is advocated as a model for good clinical practice, and digital resources are expected to compensate for lack of personnel resources, innovations such as SMASc for clinical practice are not always received positively. I hope that the diabetes specialist nurses and patients who have participated in this thesis and found SMASc useful can act as ambassadors and inspire colleagues and people with diabetes to discuss sensitive topics highlighted in SMASc during clinical visits. Such topics may be the real barriers for effective self-management. Instruments such as SMASc may provide one way to bridge the gap between evidence-based medicine and person-centred care.

Future research
The rising number of chronically ill patients and increased workload in care bring along a growing need for structural change within the healthcare system. Within this thesis the Self-Management Assessment Scale (SMASc) has been developed, validated and implemented in a pilot study. Further evaluations using quantitative measures of effects on, for example, HbA1c are planned.

SMASc has been found useful and enables building of profiles of people with T2D, but it is also suggested that it be tested among people with various lifestyle-related chronic conditions. A continued refinement and further testing of the SMASc instrument in various samples and age groups may be needed.

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Ulrika Öberg

"Mobile phones will soon become the most important platform for changing human behaviour. . . . Nothing can stop this revolution".

<div align="right">Fogg, 2010</div>

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