



UMEÅ UNIVERSITY

# **eHEALTH LITERACY AND INTERNET USE FOR HEALTH INFORMATION**

**A study in Swedish primary  
healthcare**

Anna Sjöström

Department of Nursing  
Umeå 2023

**This work is protected by the Swedish Copyright Legislation (Act 1960:729)**  
**Dissertation for PhD**  
**ISBN: 978-91-8070-219-5 (print)**  
**ISBN: 978-91-8070-220-1 (pdf)**  
**ISSN: 0346-6612**  
**New Series Number: 2277**  
**Electronic version available at: <http://umu.diva-portal.org/>**  
**Printed by: CityPrint i Norr AB**  
**Umeå, Sweden 2023**

# Table of contents

|   |      |
|---|------|
| Abbreviations .....                                   | iii  |
| Abstract.....   | iv   |
| Sammanfattning på svenska.....                        | vi   |
| Original papers.....                                  | viii |
| Introduction .....                                    | 1    |
| Background .....                                      | 2    |
| Primary healthcare.....                               | 2    |
| eHealth on the rise.....                              | 4    |
| Use of health-related Internet information.....       | 5    |
| eHealth as a facilitator of person-centred care ..... | 8    |
| eHealth as a hurdle in person-centred care.....       | 11   |
| Bridging the digital divide .....                     | 12   |
| Addressing eHealth literacy.....                      | 13   |
| Assessing eHealth literacy.....                       | 16   |
| Theoretical framework .....                           | 17   |
| Rationale .....                                       | 20   |
| Aims.....   | 21   |
| Materials and Methods .....                           | 22   |
| Methodological assumptions.....                       | 22   |
| Study design .....                                    | 23   |
| Setting.....  | 23   |
| Participants and procedure .....                      | 25   |
| Instruments .....                                     | 26   |
| Data collection.....                                  | 30   |
| Analyses .....  | 32   |

Results .....37

- Views of primary healthcare nurses .....37
- Views of patients with type 2 diabetes.....39
- eHealth Literacy Questionnaire .....42
- Internet use and eHealth literacy of primary healthcare visitors .....44

Discussion.....56

- Summary of the main results .....56
- eHealth as a valuable resource in primary healthcare .....56
- Using health-related Internet information is challenging ...58
- Identifying and reducing obstacles to eHealth literacy.....62
- New roles for patients and healthcare professionals in the digital era.....65
- Nurses’ role as facilitators .....67

Methodological considerations.....69

Ethical considerations.....76

Implications for practice .....78

Future research .....80

Conclusions .....81

Acknowledgements .....82

References.....85

# Abbreviations

|        |                                     |
|--------|-------------------------------------|
| CFA    | Confirmatory factor analysis        |
| CFI    | Comparative fit index               |
| CI     | Confidence interval                 |
| DWLS   | Diagonally weighted least squares   |
| eHL    | eHealth literacy                    |
| eHEALS | eHealth Literacy Scale              |
| eHLF   | eHealth Literacy Framework          |
| eHLQ   | eHealth Literacy Questionnaire      |
| HRII   | Health-related Internet information |
| IQR    | Interquartile range                 |
| NCD    | Noncommunicable disease             |
| OR     | Odds ratio                          |
| PCC    | Person-centred care                 |
| PHC    | Primary healthcare                  |
| PHN    | Primary healthcare nurse            |
| RMSEA  | Root mean square of approximation   |
| SD     | Standard deviation                  |
| SEM    | Structural equation modelling       |
| SRMR   | Standardised root mean residual     |
| TLI    | Tucker-Lewis Index                  |
| VIF    | Variance inflation factor           |
| WHO    | World Health Organisation           |

# Abstract

**Background:** Primary healthcare (PHC) is facing significant challenges in Sweden and around the world. One way to address such challenges is through health-related Internet information (HRII) and other eHealth services, which are resources for high-quality, accessible and cost-effective care. Such resources have been found to assist in improving individual health, especially for people with chronic conditions such as type 2 diabetes. More specifically, eHealth services may play an important role in increasing patients' knowledge, engagement and autonomy in health management, as well as enhancing their self-care practices. However, patients must have adequate capabilities – collectively known as eHealth literacy (eHL) – in order to use eHealth services effectively.

**Aim:** The overall aim of this thesis was to explore eHL and HRII use in the context of Swedish PHC.

**Methods:** Data collection for paper I was conducted through individual interviews with PHNs, which were then analysed using qualitative content analysis. Paper II involved patients with type 2 diabetes who were interviewed individually or responded to open-ended survey questions; the data were analysed using thematic analysis. In paper III, which was a translation and validation study, the data consisted of cognitive interviews and questionnaires predominantly answered by PHC visitors, and employed psychometric analysis methods. The same data from PHC visitors were used in paper IV, in which descriptive and comparative statistics and logistic regression analyses were employed.

**Results:** In paper I, the interviewed PHNs expressed mixed feelings regarding consultations with Internet-informed patients. While they recognised benefits such as increased patient engagement and the support of self-care, their responses focused on the challenges they encountered. These challenges included patient confusion and unwarranted anxiety stemming from HRII, as well as conflicted, time-consuming and unnecessary healthcare consultations.

In paper II, patients with type 2 diabetes outlined their challenges associated with online COVID-19 information, which encompassed information overload, conflicting content and notable emotional impact. They described employing diverse coping strategies to address these challenges, including restricting their information consumption, relying on authoritative sources, actively evaluating source credibility, engaging in discussions with others and applying common sense. In paper III, the eHealth Literacy Questionnaire (eHLQ) was translated and culturally adapted to assess eHL in a Swedish context. The Swedish version of the eHLQ was found to demonstrate robust psychometric properties. In paper IV, it was determined that older age groups (>60) were assessed with lower eHL in several eHLQ domains, including those regarding motivation and ability to use HRII and digital technology. In addition, older age groups reported that eHealth services did not suit their individual needs. Variables that were found to be independently associated with lower eHL across several domains were advanced age and the perception that HRII was not useful or important.

**Conclusion:** Both the patients and PHNs in this thesis encountered challenges related to patients' acquisition of HRII and utilisation of eHealth services. A collective and important objective for healthcare professionals and authorities should be to facilitate patients' HRII and eHealth service usage. Therefore, PHNs and other healthcare professionals should actively encourage open discussions with patients about the latter's HRII findings, recommend credible websites, explore potential barriers to patients' eHealth usage, motivate patients to use eHealth services and suggest ways for patients to enhance their eHL. Healthcare authorities and eHealth developers are suggested to increasingly involve end-users in the development of eHealth services and provide opportunities for customisation based on individual needs.

**Keywords:** eHealth, eHealth literacy, nursing, primary healthcare, person-centred care

## Sammanfattning på svenska

**Bakgrund:** Primärvården står inför omfattande utmaningar, både i Sverige och globalt. eHälsa, som inkluderar hälsorelaterad internetinformation (HRII), betraktas som en viktig resurs för att hantera dessa utmaningar och samtidigt bidra till högkvalitativ, tillgänglig och kostnadseffektiv vård. Olika eHälsotjänster har visat sig kunna hjälpa människor att uppnå förbättrad hälsa, särskilt personer med kroniska tillstånd som typ 2-diabetes. Mer specifikt kan eHälsa bidra till att öka patienters kunskap, engagemang, autonomi och egenvårdskapacitet när det gäller deras hälsa. Dock behöver människor ha adekvata förmågor, så kallad eHälsolitteracitet (eHL), för att effektivt kunna använda eHälsotjänster.

**Syfte:** Det övergripande syftet med denna avhandling var att utforska eHälsolitteracitet (eHL) och användningen av hälsorelaterad internetinformation (HRII) inom svensk primärvård. Studierna avsåg undersöka patienters och distriktssköterskors upplevelser av hur patienter inhämtar och använder HRII. Vidare hade forskningen som mål att undersöka eHL bland besökare inom primärvården, med fokus på sociodemografiska faktorer och användning av internet.

**Metod:** Datainsamlingen för studie I utfördes genom individuella intervjuer med distriktssköterskor, vilka sedan analyserades med kvalitativ innehållsanalys. Studie II involverade patienter med typ 2-diabetes som antingen intervjuades individuellt eller svarade på öppna enkätfrågor; data analyserades med tematisk analys. Data i studie III bestod av kognitiva intervjuer och enkäter som främst besvarades av besökare inom primärvården, och psykometriska analysmetoder användes. Samma data användes i studie IV, där deskriptiv och jämförande statistik samt logistisk regressionsanalys tillämpades.

**Resultat:** De intervjuade distriktssköterskorna såg fördelar med internetinformerade patienter, men framhöll särskilt de utmaningar de stötte på. Dessa utmaningar inbegrep såväl förvirring och onödig oro bland patienter



som inhämtat HRII, som konfliktfyllda och tidskrävande sjukvårdskonsultationer. I studie II beskrev patienter med typ 2-diabetes de utmaningar de mötte när de inhämtade information om COVID-19 på internet, vilka innefattade informationsöverbelastning, motsägande innehåll och känslomässig påverkan. Patienterna beskrev olika strategier för att hantera dessa utmaningar, inklusive att begränsa informationsinhämtningen, förlita sig på myndighetskällor, aktivt utvärdera källornas trovärdighet, samt tillämpa sunt förnuft. I studie III översattes och kulturellt anpassades eHealth Literacy Questionnaire (eHLQ) för att undersöka eHL utifrån olika domäner i en svensk kontext. Den svenska versionen av eHLQ uppvisade robusta psykometriska egenskaper. I studie IV uppvisade de äldre åldersgrupperna (>60) lägre eHL inom flera eHLQ-domäner, inklusive de som rör motivation och förmåga att använda HRII och digital teknik. Dessutom rapporterade äldre åldersgrupper att eHälsotjänster inte passade deras individuella behov. Uppfattningen att HRII inte var användbart eller viktigt hade också samband med lägre eHL i flera domäner.

**Slutsats:** Både patienterna och distriktssköterskorna i primärvården, som behandlas i denna avhandling, upplevde utmaningar kopplade till patienters inhämtning av HRII och användning av eHälsotjänster. Ett gemensamt och viktigt mål för vårdpersonal och vårdmyndigheter bör vara att underlätta patienters användning av HRII och andra eHälsotjänster. Som en del av detta rekommenderas distriktssköterskor och annan vårdpersonal att aktivt engagera sig i öppna diskussioner med patienter om deras HRII-fynd, rekommendera pålitliga hemsidor, identifiera potentiella hinder för patienters eHälsa-användning, motivera patienter att använda eHälsotjänster samt föreslå lämpliga sätt för varje enskild patient att förbättra sin eHL.

## Original papers

- I. Sjöström, A. E., Hörnsten, Å., Hajdarevic, S., Emmoth, A., & Isaksson, U. 2019. Primary health care nurses' experiences of consultations with internet-informed patients: qualitative study. *JMIR Nurs*, 2, e14194.
- II. Sjöström, A., Hajdarevic, S., Hörnsten, Å., Öberg, U., & Isaksson, U. 2021. Experiences of online COVID-19 information acquisition among persons with type 2 diabetes and varying eHealth literacy. *Int J Environ Res Public Health*, 18, 13240.
- III. Sjöström, A. E., Hajdarevic, S., Hörnsten, Å., Kristjánsdóttir, Ó., Castor, C., & Isaksson, U. 2023. The Swedish version of the eHealth Literacy Questionnaire: translation, cultural adaptation, and validation study. *J Med Internet Res*, 25, e43267.
- IV. Sjöström, A., Hajdarevic, S., Hörnsten, Å., & Isaksson, U. 2023. eHealth Literacy and health-related Internet use among Swedish primary healthcare visitors. Manuscript.

# Introduction

In dealing with the challenges in primary healthcare (PHC), eHealth is recognised as playing a pivotal role, serving as a tool to enable the provision of high-quality, accessible and cost-effective care (National Board of Health and Welfare, 2022b; Nergårdh et al., 2018; van der Kleij et al., 2019). The widely used term ‘eHealth’ refers to ‘the use of information and communications technologies in support of health and health-related fields, including healthcare services, health surveillance, health literature, and health education, knowledge and research’, as defined by the World Health Organisation (WHO) (2021a). This broad concept encompasses all digital health-related services, including smartphone health applications (apps), digital healthcare visits, electronic medical records and health-related Internet information (HRII).

eHealth has been shown to provide various benefits, both in general and in PHC settings, including improved communication between patients and healthcare professionals, enhanced self-care capabilities, increased healthcare service availability, enhanced resource efficiency, enhanced self-management of chronic diseases and a heightened focus on person-centred care (Bashshur et al., 2016). To benefit from eHealth services, including HRII, individuals must be able to comprehend and utilise them effectively; in other words, they must possess sufficient eHealth literacy (eHL) (Norgaard et al., 2015; Norman and Skinner, 2006b). Little is known of the eHL of patients and patients’ acquisition of HRII in a Swedish context. This thesis addresses this knowledge gap from the perspectives of PHC patients and primary healthcare nurses (PHNs) in Sweden.

# Background

## Primary healthcare

Primary healthcare (PHC) is widely recognised as the cornerstone of the healthcare system (Nergårdh et al., 2018; World Health Organisation, 2018b). As a broad concept, PHC serves as the point of entry for individuals with various health issues. According to the WHO, PHC should meet people's health needs through promotive, protective, preventive, curative, rehabilitative and palliative care, at both the individual and population levels (Muldoon et al., 2006; World Health Organisation, 2018b). The importance of high-quality PHC cannot be overemphasised, as it has been demonstrated to result in increased access to healthcare services, reduced avoidable hospitalisations, enhanced diagnostic accuracy, improved health outcomes and, ultimately, higher life expectancy (World Health Organisation, 2018b). The mission of the Swedish PHC is to provide medical treatment, nursing, preventive care and rehabilitation to individuals. This mission does not exclude diseases, ages or patient groups, as long as hospitals' medical or technical resources are not required (National Board of Health and Welfare, 2016).

PHC, however, is currently confronted with substantial challenges in light of the world's demographic and epidemiological transition towards an aging population. Advancements in living conditions, medical breakthroughs and enhanced public health strategies has significantly increased global life expectancy. The 21st century is defined by a noteworthy demographic transition towards an increasingly older population, highlighted by a 23-year increase in average life expectancy from 1955 to 2020 (Robine, 2021). This rising life expectancy and expanding proportion of elderly individuals present significant challenges for healthcare delivery, both globally and in Sweden. Destructive habits (e.g. tobacco consumption, unhealthy dietary practices and physical inactivity) exacerbate these challenges, leading to an increased prevalence of multi-morbidity and noncommunicable diseases (NCDs). NCDs

are chronic illnesses that are non-transmissible; they encompass cardiovascular diseases, cancers, chronic respiratory diseases and diabetes. These diseases constitute the primary cause of global mortality and are a significant contributor to premature deaths (i.e. deaths occurring before the age of 70) (World Health Organisation, 2023a). In the Swedish context, NCDs are responsible for most deaths (89%) and comprise a significant portion (80%–85%) of healthcare expenditures. Moreover, people affected by NCDs use healthcare services at a rate four to six times higher than individuals without NCDs (Swedish Agency for Health and Care Services Analysis, 2014; World Health Organisation, 2023b).

Consequently, mitigating the negative impacts of NCDs on humans, society and the economy is a priority (World Health Organisation, 2014). Type 2 diabetes, an NCD that is rapidly increasing in prevalence, is typically treated in PHC. With its adverse effects on individuals, healthcare infrastructures and economies, this disease is considered to be one of the most pressing challenges confronting PHC systems worldwide (Rollo et al., 2016). The consequences and complications associated with type 2 diabetes – which include increased risk of cardiovascular diseases, obesity, retinopathy, neuropathy and impaired wound healing – can result in substantial patient suffering and necessitate PHC (World Health Organisation, 2016). Moreover, individuals with type 2 diabetes were found to be more vulnerable during the COVID-19 pandemic, with a higher risk of hospitalisation, more severe disease progression and increased mortality (Rawshani et al., 2021).

To address welfare challenges, there has been a global and national shift towards proactive healthcare through a transition from specialised hospital care to PHC. This shift offers various benefits, including cost effectiveness and enhanced accessibility and equity. Swedish PHC is currently undergoing a reform called ‘Close Care’, which started in 2017 and aligns with the WHO’s vision for Universal Health Coverage (Nergårdh et al., 2018; World Health Organisation, 2022). The Close Care reform aims to improve the efficiency

of Swedish PHC and transition it from a reactive model to a proactive, health-promoting approach that encourages active patient involvement in healthcare (Nergårdh et al., 2018; Swedish Association of Local Authorities and Regions (SALAR), 2022). Increased collaboration between healthcare instances is central to this reform, with PHC as the foundational element (Nergårdh et al., 2018). Here, ‘Close’ refers to the population’s perception of care, which is supported when care is accessible in a manner and at hours that suit peoples’ needs (National Board of Health and Welfare, 2022a). In Sweden’s transition to Close Care, eHealth is considered a prerequisite (National Board of Health and Welfare, 2022b).

## eHealth on the rise

Recognising the significance of eHealth, the WHO and governments worldwide have prioritised the development of eHealth systems (Government Offices of Sweden, 2016; World Health Organisation, 2021). In the Swedish context, eHealth is highly prioritised, as reflected in the collaboration between the government and regional authorities in 2016 to formulate the strategic framework known as ‘Vision eHealth’. By the year 2025, the framework aims to promote Sweden to be:

...the best in the world at utilising the opportunities presented by digitalisation and eHealth with the aim of facilitating the achievement of good and equitable health and well-being for individuals, as well as developing and reinforcing their own resources for increased independence and participation in societal life. (Government offices of Sweden, 2016, p. 5)

The report highlights the significance of ensuring the secure and safe management of digital information and the central role of the individual as a co-creator of eHealth services (Government Offices of Sweden, 2016; Swedish Association of Local Authorities and Regions (SALAR), 2020).

Internet accessibility in Sweden has surged from 2% in 1995 to near-universal availability in households today, with approximately 96% of the

population utilising the Internet (Swedish Internet Foundation, 2023). Even though Internet usage among individuals over 65 has historically been lower than usage among younger age groups, there has been a recent increase. In 2022, 90% of individuals aged 65–74 used the Internet, as did 80% of those aged 75–85 (Statistics Sweden, 2022). The rapid pace of digital advancement has culminated in the Internet becoming an integral part of daily life for many, serving multifarious purposes including entertainment (e.g. streaming and gaming), social interaction, information acquisition and involvement in various societal matters. The latter include shopping, financial transactions and healthcare management – such as HRII information acquisition (Swedish Internet Foundation, 2022).

During the COVID-19 pandemic, which required quarantine and social isolation, eHealth services were considered to be crucial for delivering healthcare and informational support (Øvretveit, 2021). Digital contacts became a common alternative to traditional face-to-face visits in PHC. Swedish reports have shown a massive increase in the use of digital services – including healthcare apps, digital appointments and log-ins to digital patient journals – during the first year of the pandemic (Inera, 2022; Swedish eHealth Agency, 2020b; Swedish Internet Foundation, 2021). The same pattern has been reported globally (Golinelli et al., 2020).

## Use of health-related Internet information

Information acquisition is one of the most common activities people engage in on the Internet, with health-related information retrieval being a predominant part of eHealth (Swedish Internet Foundation, 2017). Most people in Sweden, Europe and the United States use the Internet to access HRII, with younger individuals, those with higher education and those with better health literacy being more inclined to do so (Eurostat, 2021; Fox et al., 2013; Levine et al., 2016; Swedish Internet Foundation, 2021; Waring et al., 2018). In contrast, individuals who do not seek HRII are usually male, have poorer health, have lower socioeconomic status, belong to a minority group

or are elderly (Levin-Zamir and Bertschi, 2018; Waring et al., 2018). A Swedish report from 2022 disclosed that every other individual aged 65–74 and four out of ten individuals aged 75–85 had sought HRII within the past 3 months (Statistics Sweden, 2022).

HRII acquisition serves a myriad of purposes, including gaining insights into medical conditions (e.g. diabetes), assessing the need for healthcare visits, preparing for medical consultations and verifying information received during healthcare interactions (Ramsey et al., 2017; Wong and Cheung, 2019). By empowering individuals with health knowledge, HRII has the potential to improve their self-management skills, increase their engagement in healthcare and strengthen their capacity to make informed decisions. This may promote person-centred communication during healthcare encounters (Eysenbach and Jadad, 2001; Xiang and Stanley, 2017). During the COVID-19 pandemic, the importance of reliable HRII became particularly evident, as it was a vital way for many people to stay up-to-date with news and guidelines (Okan et al., 2023).

On the other hand, inaccurate HRII may pose health risks. For example, studies have revealed substantial disparities in the accuracy and comprehensibility of HRII, with only a limited portion of health-related websites presenting high-quality information (Corcelles et al., 2015; Hirsch et al., 2017). Studies in both Swedish and international contexts have indicated that most individuals seeking HRII start their information search through Google. In contrast, a minority of individuals initiate their information gathering on quality-assured health websites (European Commission, 2014; Swedish Internet Foundation, 2017). The most problematic aspect of a reliance on Google is that, when searching for a specific symptom (e.g. headache), the search results may highlight websites with unlikely results (e.g. a brain tumour), thereby sending the user to websites with unreliable information (White and Horvitz, 2009). Furthermore, social media platforms such as Facebook, Twitter and YouTube are common sources of HRII where



anyone – including private individuals and healthcare professionals – can disseminate information (Suarez-Lledo and Alvarez-Galvez, 2021). The news media is another common provider of HRII and is considered a crucial source for public health and policy information today (Mach et al., 2021). It can be challenging for individuals to evaluate the credibility of HRII, due to the abundance of available sources. Inaccurate HRII combined with an individual’s limited skill in critically evaluating information can lead to negative consequences such as heightened anxiety, improper self-care, delay in seeking medical help and tension in the patient-healthcare professional interaction (Ahmad et al., 2006; El Sherif et al., 2018). During the COVID-19 pandemic, challenges related to HRII became evident, as the overabundance of information and the dissemination of false information on social media contributed to the creation of an ‘infodemic’, resulting in confusion, fear and inappropriate health behaviours among many individuals (Zarocostas, 2020).

In Sweden, the national healthcare platform for residents to access publicly administered healthcare services is known as ‘1177’. Citizens can contact the 1177 telephone helpline for healthcare advice or visit the digital counterpart of this service at 1177.se, a website that serves as a centralised platform for both general and personalised health and medical information and services (Inera, 2023a). The number of visitors to 1177.se varies significantly in different months; however, it has had between 12 million and 30 million monthly visits in recent years (Inera, 2023b). The 1177 website offers personalised eHealth services, with an average of 20 logins per capita in 2022. The most frequently accessed personalised activities include reading medical journals, booking healthcare appointments, renewing pre-scriptions, accessing test results and contacting healthcare providers. A 2022 survey showed that 99.2% of the Swedish population was aware of 1177 (Directorate of eHealth, 2023). Another survey showed that more than 80% of Swedes had visited the 1177 website and logged in at least once, although usage among seniors was lower, with just over 60% having done the same (Swedish Inter-

net Foundation, 2021). Notably, younger and middle-aged women are the primary users of these services (Directorate of eHealth, 2023).

Among the visits to 1177.se, two-thirds are related to the website's search engine, which provides information about diseases, symptoms and treatments (Inera, 2023b). All content on 1177.se undergoes a meticulous quality-assurance process and is fact-checked by medical professionals, including physicians, nurses, dentists and other healthcare experts. The language used on 1177.se is designed to be clear and easily understandable for non-specialists and is often accompanied by illustrations, photos and videos to enhance content accessibility. The information can also be read aloud, and a selection of the information is available in languages other than Swedish (Inera, 2023a). The most common health-related searches in 2023 were related to cancer, dental care, pregnancy, fever, COVID-19, influenza, stomach flu and diabetes (Inera, 2023b). Alongside the public healthcare sector, many private digital healthcare providers exist that resemble 1177.se; these offer a range of informational resources and medical services (Swedish Agency for Health and Care Service Analysis, 2022).

## eHealth as a facilitator of person-centred care

Healthcare organisations and governments in Sweden and worldwide advocate for eHealth to promote person-centred care (PCC) (Swedish Agency for Health and Care Service Analysis, 2022; World Health Organisation, 2021a). The Close Care reform aims to establish an integrated healthcare system tailored to individuals' needs, for PCC (National Board of Health and Welfare, 2022b). The terms 'patient-centred care', 'people-centred care' and 'person-centred care' are often used interchangeably in research and healthcare without being clearly defined (Håkansson Eklund et al., 2019). In this thesis, I consistently use 'person-centred care', as I consider it a more comprehensive concept. Although PCC lacks a universally accepted definition, it generally involves shifting from a biomedical model to a biopsychosocial model that prioritises the person over the disease. PCC centres

on the individual in the care process, with a focus on understanding and addressing each patient's unique needs. This holistic approach provides respectful, compassionate care tailored to individual characteristics, including age, gender, ethnicity, culture and health. Furthermore, PCC acknowledges that each individual's experiences, beliefs, values and preferences influence that person's healthcare expectations and requirements (Ekman et al., 2011).

A fundamental aspect of PCC is establishing a partnership that is characterised by mutual respect for the distinct knowledge and expertise held by both patients and healthcare professionals. This approach actively involves patients, their families and their friends in the decision-making process, ensuring that their voices are heard (Ekman et al., 2011). Research has shown that PCC has various benefits, including improved patient satisfaction, better health outcomes, enhanced communication between patients and healthcare providers, and more efficient use of healthcare resources (Edvardsson et al., 2008; Ekman et al., 2011; Hamovitch et al., 2018). Research on eHealth in general and PHC settings in particular has underscored eHealth's capacity to enable key components of PCC. Examples include enhanced health knowledge through both personal and general HRII, which empowers individuals and enables them to actively engage in their own healthcare. Moreover, as eHealth includes features such as digital healthcare visits and 24/7 access to health information, it bolsters PCC by increasing patient access to healthcare services (Leonardsen et al., 2020, 2023; Swedish Association of Local Authorities and Regions (SALAR), 2022; World Health Organisation, 2018a).

From a Swedish governmental perspective, there has been an apparent effort to address PHC challenges by expecting patients to take increased responsibility for their own health and to engage in self-care. Engaged, empowered and autonomous individuals are more likely to experience improved health outcomes, utilise healthcare resources efficiently and reduce costs. In addition, the WHO recognises increased self-care utilisation as a promising approach for enhancing health outcomes at the individual and

health-system levels. The WHO defines self-care as the ability of individuals, families and communities to promote health, prevent disease, maintain health and cope with illness and disability, with or without the support of a health-care professional. Self-care includes activities such as nutrition, exercise, sleep, stress management, self-medication, self-treatment, self-monitoring and self-education (World Health Organisation, 2021b). HRII and other eHealth services are considered to be central tools in facilitating self-care for individuals with and without chronic conditions (Swedish Association of Local Authorities and Regions (SALAR), 2022). During the COVID-19 pandemic, the significance of reliable HRII and self-care became particularly evident, given measures such as social distancing, mask-wearing, hand-washing, self-testing and at-home treatment (Cuan-Baltazar et al., 2020).

While the concept of self-care pertains to the preservation of general health and well-being, the term ‘self-management’ is used more specifically to address the management of chronic diseases and health conditions. In diabetes care, effective self-management practices involving knowledge of and skills in blood glucose monitoring, medication adherence, dietary regulation and physical activity are crucial in avoiding long-term complications (Rollo et al., 2016). Barriers to self-management among patients with type 2 diabetes generally include a lack of knowledge and skills, limited access to healthcare, financial constraints, cultural and language barriers, competing priorities, and psychological and environmental factors. Addressing these barriers requires a multifaceted approach that includes person-centred education and support from healthcare professionals – most commonly diabetes nurses in PHC – and involves addressing the social determinants of health and creating supportive environments for self-care (Pennbrant et al., 2020).

Many patients with diabetes face challenges such as fear of complications, unpleasant blood glucose testing experiences, and difficulty balancing their diet and physical activity. These difficulties necessitate

guidance and support to enhance patients' comprehension and management of diabetes. Therefore, trustful communication with nurses is crucial in creating a sense of participation, responsibility and safety in self-management (Pennbrant et al., 2020). Overall, a collaborative and individualised approach between healthcare providers and patients is essential for the successful self-management of type 2 diabetes (Powers et al., 2016). Swedish primary health-care nurses (PHNs) are trained to provide advice and support for self-care, which includes educating patients on diabetes management, promoting self-efficacy and developing personalised care plans (Swenurse, 2019a). Various eHealth services, such as mobile apps, are continuously being developed to provide support to individuals with specific conditions, including depression (Cederberg et al., 2022), fall risk (Pettersson et al., 2021) and diabetes (Schimmer et al., 2019). Moreover, person-centred eHealth support has demonstrated promise in enhancing self-care practices and outcomes for patients with type 2 diabetes (Öberg et al., 2019; Schimmer et al., 2019).

## eHealth as a hurdle in person-centred care

Delivering PCC in PHC in the digital era may pose a hurdle, as digital interaction can be considered to contrast with the core principles of PCC. The primary concern is that the absence of face-to-face interaction can hinder the establishment of meaningful connections, particularly in meetings where emotional support is vital (Leonardsen et al., 2023).

Using HRII can be challenging for many individuals because of issues such as complexity, contradictions and information overload. However, studies have shown that only a minority of patients discuss the HRII they have obtained during healthcare consultations, due to a concern about being seen as confrontational or because of embarrassment and low confidence in the information's significance (Tan and Goonawardene, 2017; Waring et al., 2018). Although research highlights several benefits of Internet-informed patients, adverse outcomes – including tensions in the patient-healthcare professional relationship – have also been reported (McMullan, 2006;

Townsend et al., 2015). These tensions can complicate person-centred encounters, where an equal partnership is fundamental.

Prior research on healthcare professionals' attitudes towards patients who present HRII has yielded mixed findings. Some healthcare professionals view Internet-informed patients positively, anticipating increased patient engagement, more productive interactions and in-depth discussions (Lu et al., 2023; Murray et al., 2003; Sommerhalder et al., 2009). However, other professionals perceive this trend negatively, feeling undervalued, less competent or as if they have lost control of the consultation (Ahluwalia et al., 2010). Notably, a substantial knowledge gap remains – especially in the Swedish context – regarding nurses', including PHNs', attitudes towards Internet-informed patients.

## Bridging the digital divide

During a person-centred healthcare encounter, it is vital to acknowledge the various factors that can influence an individual's beliefs, preferences and needs (Byrne et al., 2020). Examples of such factors include age, health status, language and culture (Kringos et al., 2013). Despite relatively low socioeconomic disparities in Sweden compared to many other countries, there is a concerning trend of increasing health disparities – especially among immigrant populations, which make up a substantial portion (20%) of the country's total population (Statistics Sweden, 2021). Although eHealth services are often emphasised as enhancing healthcare availability and promoting healthcare equality, digitalisation can exacerbate disparities in individuals' healthcare utilisation due to varying capabilities, a phenomenon known as the 'digital divide' (Heponiemi et al., 2020; Neter and Brainin, 2012; Swedish eHealth Agency, 2020a). Initially, the term 'digital divide' referred to the gap between those with Internet access and those without; now, however, it is most often used to refer to disparities in the abilities needed to use eHealth effectively, which are collectively known as eHealth literacy (eHL) or digital health literacy (Azzopardi-Muscat and Sørensen, 2019; Wilson et al.,

2021). The digital divide can lead to individuals who lack the ability to use eHealth services being excluded from certain aspects of healthcare. This exclusion may appear in the form of challenges in appointment scheduling, a limited understanding of diseases and treatment, and reduced engagement in managing one's health. Digital alienation is linked to certain risk factors, including advanced age, low educational attainment and physical limitations such as visual impairment and hand tremors (Iacobaeus et al., 2019; Swedish eHealth Agency, 2020a). Other contributing factors include a lack of motivation, limited digital access, low self-confidence and inadequate knowledge and abilities (Iacobaeus et al., 2019).

One in every five people in Sweden does not use eHealth services. Among those aged 65–75, this proportion increases to one in four; among those aged 75 or older, it is one in two (Swedish Internet Foundation, 2023). To achieve digital inclusion for as many people as possible, it is necessary to first build a fundamental understanding of people's abilities in and experiences of using eHealth services – that is, to understand the Swedish population's eHL.

## Addressing eHealth literacy

The concept of eHL is rooted in health literacy, which pertains to the abilities that enable individuals to obtain, comprehend and apply health information when making informed decisions that affect their health status. Health literacy is an observable set of abilities that varies between individuals and between different contexts; it also depends on an individual's health status, source of health information and social support (Mårtensson and Hensing, 2012; Nutbeam et al., 2018). Hence, health literacy should not be considered a fixed state but should rather be viewed as a dynamic and complex phenomenon (Mårtensson and Hensing, 2012). Health literacy encompasses a range of abilities, from acquiring, comprehending and applying basic health information to critically evaluating health information from diverse sources (Nutbeam, 2008). The WHO emphasises health literacy as a fundamental

component of health promotion and a critical tool for reducing health inequities (World Health Organisation, 2022).

Norman and Skinner (2006) first introduced the concept of eHL and described it as encompassing various skills for seeking and applying health information from digital sources. Their original definition of eHL was ‘the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem’. However, this original definition of eHL has been subjected to criticism, including its failure to consider situational, cultural or social contexts or to encompass the interactive elements in the increasingly evolving Internet, including social media (Griebel et al., 2018). To address this issue, Norgaard and colleagues (2015) expanded the eHL concept by including both individual and eHealth-system-related factors. The researchers conducted workshops with patients, healthcare professionals, health informatics experts and researchers; this led to the development of the eHealth Literacy Framework (eHLF), which is taken as the definition of eHL in this thesis.

The eHLF includes seven domains of eHL: (1) using technology to process health information, (2) understanding health concepts and language, (3) being able to actively engage with digital services, (4) feeling safe and in control, (5) being motivated to engage with digital services, (6) having access to digital services that work, and (7) having access to digital services that suit individual needs. The first two domains primarily rely on the individual’s competency, while domains 6 and 7 depend on the characteristics of the eHealth systems. Meanwhile, domains 3, 4 and 5 are influenced by the dynamics that arise when the individual interacts with eHealth systems (Figure 1). Therefore, the eHLF provides an understanding of eHL that is not solely focused on individual abilities but is also highly dependent on contextual factors and the intricacies of the systems involved (Norgaard et al., 2015).



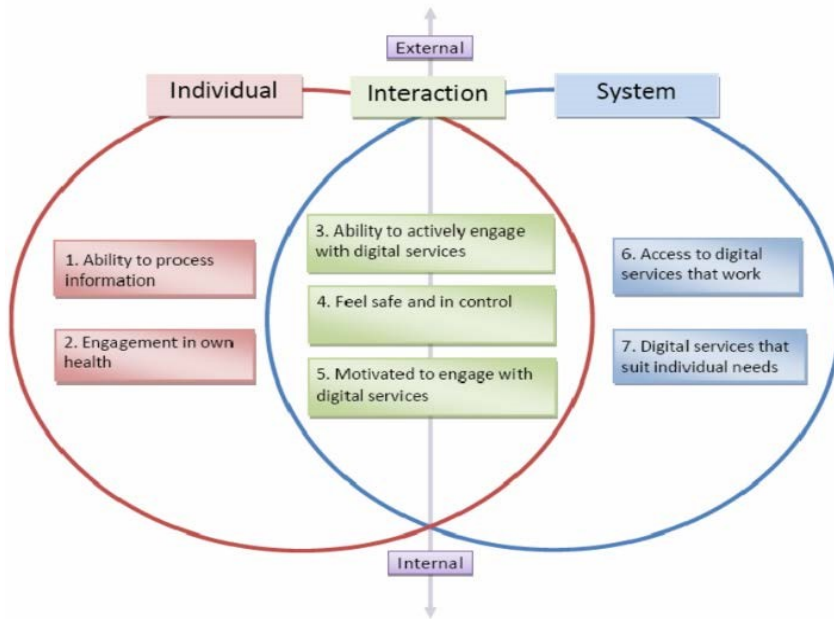


Figure 1. The eHealth Literacy Framework.

The eHLF includes all the skills described in Norman and Skinner’s original eHL definition in the first three domains, while the last four are unique to the eHLF (Norgaard et al., 2015; Norman and Skinner, 2006b). Nevertheless, factors such as communicative expertise, bodily experience, and cultural and social context are not included, and the researchers suggest that these factors should be covered by a dimension outside the eHLF model (Norgaard et al., 2015).

Similar to health literacy, eHL is not static but can evolve over time or vary according to the context; thus, it can be defined as both a process and an outcome (Norman and Skinner, 2006b). Healthcare professionals should be aware of the fluidity of patients’ health literacy and eHL, as professionals’ communication and actions can have a positive or negative impact on a patient’s health literacy in specific situations (Mårtensson and Hensing, 2012). Improving a patient’s eHL can be achieved through interventions and structured learning opportunities. However, interventions designed to en-

hance eHL should be person-centred and tailored to individual needs, taking into account factors such as age, education, technical skills, prior experiences and intentions for Internet usage (Chang et al., 2021; Levin-Zamir and Bertschi, 2018; Xie, 2009).

The benefits of sufficient eHL for individuals include increased access to health information, which can lead to an enhanced understanding of their medical condition, improved self-empowerment, more effective self-management, the adoption of healthier behaviours, enhanced communication with healthcare professionals and better health outcomes (Mitsutake et al., 2012, 2016; Neter and Brainin, 2012, 2019; Schulz et al., 2017). In individuals with diabetes, research has demonstrated a direct association between sufficient eHL and enhanced self-management behaviours, improved glycemic control and better self-rated health status (Guo et al., 2021). During the COVID-19 pandemic and the ‘infodemic’, health organisations and researchers emphasised the essential role of sufficient eHL in allowing individuals to critically evaluate online COVID-19 information, access eHealth services during social isolation and stay updated (Paakkari and Okan, 2020).

## Assessing eHealth literacy

As eHealth services become more popular, there is a need for instruments that can assess eHL at both the individual and population levels. Such instruments can be used to evaluate eHL education, assess its impact on health outcomes, and understand eHL in different groups (Karnoe et al., 2015). Understanding people’s eHL is vital in ensuring that eHealth services and HRII are accessible and understandable to those who require them (van der Vaart et al., 2011).

A systematic review from 2021 has identified seven available instruments for eHL measurement (Lee et al., 2021). The most commonly used tool is the eHealth Literacy Scale (eHEALS), an 8-item Likert scale self-report instrument. The eHEALS is widely regarded as an easy-to-administer

and valid tool, and is currently accessible in at least 18 languages (Lee et al., 2021; Norman and Skinner, 2006a). However, the eHEALS has been criticised for being outdated, given that the context for eHL has shifted from static online information to more dynamic platforms such as social media (Griebel et al., 2018). As a result, new tools have emerged, such as the eHealth Literacy Questionnaire (eHLQ) (Kayser et al., 2018).

The eHLQ is based on the eHLF. It has been implemented in more than 12 countries and validated in English, Danish, Spanish, Chinese and Dutch to date (Chen et al., 2022; García-García et al., 2022; Griebel et al., 2018; Kayser et al., 2018; Norgaard et al., 2015; Poot et al., 2023). With its seven eHL domains, the eHLQ is a valuable tool for various applications, such as population surveys, eHealth service implementation and intervention assessment. Due to its broad applicability, the eHLQ can inform eHealth service design, support research (both quantitative and qualitative) and aid in eHL education (Kayser et al., 2018).

The existing literature on eHL measurements suggests that higher eHL levels are more prevalent among younger individuals, those with higher levels of education and those who use the Internet more frequently (Chang et al., 2021; Neter and Brainin, 2012; Tennant et al., 2015). In a Swedish context, however, only a few studies have measured eHL, and these studies have focused on specific groups, such as parents, Arabic-speaking immigrants and the elderly (Bergman et al., 2021; Ghazi et al., 2023; Kristjánsdóttir et al., 2023). Hence, further research is required to explore eHL in Sweden – including within a PHC setting – using a comprehensive instrument that assesses strengths and challenges within the Swedish eHL context.

## Theoretical framework

As a theoretical framework, I have drawn upon eHL as contextualised within the previously described eHLF. Furthermore, from a theoretical nursing-based perspective, I have based my approach on the Umeå Model of Nursing Care. This model (Figure 2) can be employed as a framework to support the

organisation and description of nursing care in theory, research and clinical practice. The structure of the model is open and must be filled with content, such as theories developed to describe, comprehend and explain specific phenomena relevant to nursing. Nursing care aims to prevent disease and ill health, enhance and restore health, alleviate suffering, provide comfort and create conditions for a dignified end of life. 'Health' is described based on individuals' perception of their situation, which determines whether health or ill health is present. Furthermore, societal values and political governance influence nursing philosophy and ethics, which in turn affect nursing care. Political and economic conditions in society are also critical factors in healthcare organisation and prioritisation.

At the core of nursing lies the patient-healthcare professional interaction, in which a person-centred approach is pivotal. The nursing encounter comprises an interplay of tasks and relationships, with the occasional prioritisation of tasks (e.g. during acute illness) over the relationship aspect and vice versa. Family and friends are viewed as significant extensions of the patient. The extension of the caregiver is the care team of different professions, where teamwork is considered essential. Both the internal and external environments play a role in nursing and health. For example, the psychosocial care environment involves promoting privacy and establishing a secure healthcare setting. Lastly, a continuous thread of ethics runs through all aspects of the nursing model.



Figure 2. The Umeå Model of Nursing Care. Translation and figure based on the original version from the Department of Nursing, Umeå University.

## Rationale

The world's ageing population has increased the demand for healthcare services, posing challenges to PHC systems. The Close Care reform, which focuses on eHealth as a prerequisite, aims to improve the efficiency, effectiveness and outcomes of PHC by providing access to health information and services. eHealth has the potential to empower individuals, promote patient participation and enable personalised care.

In a digitalised healthcare landscape, services must be equitable and person-centred, while considering individuals' needs, prerequisites and resources. Adequate eHL among citizens is crucial, with the COVID-19 pandemic underscoring its significance. Assessing people's eHL is essential for developing interventions, guidelines and strategies, reducing health disparities, and ensuring eHealth accessibility. Previous eHL research has often used narrow instruments that cover limited aspects of the concept. The eHLQ provides a comprehensive assessment across seven domains but has lacked validation in the Swedish context. Moreover, there is a research gap in understanding and exploring eHL among Swedish PHC visitors.

PHNs are often the initial point of contact for the general population; they act as a consistent resource for individuals with chronic conditions such as type 2 diabetes and can play a pivotal role in promoting eHL. Successful person-centred interactions in the eHealth era require collaboration between patients and PHNs, fostering knowledgeable and active patients and enabling shared decision-making. However, research on nurses' experiences – particularly PHNs' experiences – with Internet-informed patients is limited. Furthermore, research on patients' experiences with acquiring HRII is scarce, making up-to-date research crucial.

# Aims

## Overall aim

The overall aim of this thesis was to explore eHL and the use of HRII in a Swedish PHC context.

## Specific aims

**Paper I** aimed to explore PHNs' experiences of consultations with patients who present HRII.

**Paper II** aimed to explore online COVID-19 information-acquisition experiences among persons with type 2 diabetes and varying eHL.

**Paper III** aimed to translate, culturally adapt and evaluate the psychometric properties of the Swedish version of the eHLQ.

**Paper IV** aimed to explore eHL and its association with health-related Internet use among PHC visitors.

# Materials and Methods

## Methodological assumptions

The primary objective of scientific activities is the production of knowledge. Therefore, it is imperative for researchers to consider two key aspects of knowledge: ontology, which concerns the nature of reality, and epistemology, which pertains to the means by which we acquire knowledge about reality (Hoeck and Delmar, 2018). The qualitative papers in this thesis are guided by the principles of constructivism, which presuppose that reality and knowledge are inherently subjective and socially constructed. In this perspective, there is no singular, objective reality or truth; instead, there exist multiple realities and truths, shaped by individual perceptions of situations and phenomena (Creswell and Poth, 2016; Polit and Beck, 2020). In accordance with this perspective and the assumptions of qualitative research, the world is viewed as complex, context-specific and open to interpretation, influenced by individuals' personal histories, situations and cultural backgrounds. Hence, I have striven to capture and convey knowledge about the various realities held by the study participants, myself, my co-researchers and readers in the qualitative studies of my thesis (Creswell and Poth, 2016).

In contrast, quantitative methodology is frequently associated with positivism, which emphasizes the objectivity of reality and the importance of measurement, quantitative data and statistical analysis in the pursuit of knowledge that should ideally be generalizable (Polit and Beck, 2020). In papers III and IV of this thesis, quantitative data from a psychometric questionnaire – the eHLQ – are used, along with statistical analysis methods, to explore participants' eHL. In these analyses, the participants' responses regarding eHL are treated as objective data points. However, the participants' responses pertain to self-assessed abilities and experiences, which are based on individual experiences, beliefs and perceptions, rendering them subjective and not in line with the positivist perspective. These studies are thus guided by pragmatism, which prioritizes practical outcomes and the real-world



applicability of ideas, while considering various perspectives, such as the viewpoints of researchers, participants and healthcare professionals. In this case, pragmatism involves striking a balance between objectivity in eHL measurements and an understanding of the subjective, individual experiences that have shaped these self-assessments (Dolan et al., 2022). The combination of methods and assumptions in this thesis is seen as an advantage, as it produces a richer and deeper insight into eHL and Internet usage among PHC visitors (Foss and Ellefsen, 2002).

## Study design

Qualitative and quantitative designs were used to address the aims of the four papers in this thesis (Table 1).

Table 1. Overview of the papers in this thesis

| Paper | Design                  | Data                          | Participants   | Analysis   |
|-------|-------------------------|-------------------------------|--|--|
| I     | Exploratory descriptive | Interviews                    | PHNs ( $n=9$ )   | Qualitative content analysis                     |
| II    | Exploratory descriptive | Interviews and questionnaires | Persons with type 2 diabetes ( $n=10+58$ )                       | Thematic analysis                                |
| III   | Cross-sectional         | Questionnaires                | PHC visitors and parents of hospitalised children ( $n=172+64$ ) | Psychometric analysis                            |
| IV    | Cross-sectional         | Questionnaires                | PHC visitors ( $n=172$ )   | Descriptive, comparative and regression analyses |

## Setting

The data for all four studies were gathered from patients and PHNs at PHC centres of varying sizes and locations within a county in northern Sweden. The data for paper III were also collected from the parents of hospitalised children at a hospital in southern Sweden.

### Swedish primary healthcare

Swedish PHC is mandated by both municipal and regional councils (National Board of Health and Welfare, 2016). PHC centres in Sweden have similarities

with PHC centres in other developed countries, such as being the point of entry to healthcare, and Sweden's PHC professionals have a similarly holistic approach to patient health. However, one difference is the extent to which Swedish PHC services are publicly driven and financed through taxation (Swedish Agency for Health and Care Services Analysis, 2017). Professionals working in Swedish PHC centres include physicians, specialist nurses (i.e. PHNs), midwives, undergraduate nurses, assistant nurses, physiotherapists, occupational therapists, psychologists, social workers and dietitians. Ideally, the healthcare professionals at PHC centres should hold specialised graduate degrees in their respective fields (National Health Competence Council & National Board of Health and Welfare, 2021). Common reasons for PHC visits in Sweden include infections, pain disorders, cough and mental health issues. Moreover, elderly patients with multiple chronic conditions such as high blood pressure, type-2 diabetes and asthma tend to visit PHC facilities regularly (National Board of Health and Welfare, 2022b).

### **Primary healthcare nurses' role**

PHNs are often the first point of contact for people seeking medical advice and services at PHC centres in Sweden. These nurses typically operate independently of general practitioners and are expected to possess general medical knowledge and the ability to evaluate, identify, diagnose and treat various health conditions—including the prescription of drugs, as necessary—in accordance with evidence-based methods (Swenurse, 2019a). The most frequent work duties for Swedish PHNs are outpatient clinic (i.e. assessments, blood pressure measurement, wound treatment and injections); nurse-led clinics for patients with conditions such as diabetes, asthma or COPD, and incontinence; and telephone guidance, documentation and pharmaceutical preparation (Boström et al., 2012). A PHN's work is also rooted in promoting health, emphasising the empowerment of people, and building a partnership between the patient and the nurse, including shared decision-making throughout treatment (Swenurse, 2019a). In 2021, nearly

14,000 PHNs were active in Swedish healthcare. Among them, 7,200 were employed in various forms of outpatient care. However, specific figures regarding the number of PHNs employed in PHC centres were unavailable (National Board of Health and Welfare, 2021).

## Participants and procedure

### **Paper I**

The inclusion criteria for paper I were registered nurses with a postgraduate specialisation diploma in PHC nursing that were employed at a PHC centre. Supervisors at three PHC centres were asked to identify potential PHNs – with an emphasis on a diverse representation of age and professional experience – for participation in an interview about eHealth. Nine PHNs voluntarily agreed to participate. The participants ranged in age from 27 to 64 years (median 42), with work experience of 4–39 years (median 18) as registered nurses and 1–23 years (median 5) as PHNs.

### **Paper II**

The participants in paper II were persons diagnosed with type 2 diabetes who consisted of a control group from an ongoing research project on patients with type 2 diabetes (Öberg et al., 2019). The inclusion criteria were: aged  $\geq 18$  years, diagnosed with type 2 diabetes within the last 5 years, Swedish-speaking and owning a smartphone.

In April 2020, 107 eligible persons were approached via postal mail and email, asking for their involvement in the study. In addition to being invited to complete a questionnaire, the potential participants were informed of the opportunity to contribute through an interview. A total of 10 persons agreed to participate in the interview – five males and five females, aged between 45 and 81 years (median age 66) – while 88 individuals, representing 82.5% of the eligible group, completed questionnaires. Of the latter, 58 (66%) responded to the open-ended questions in the questionnaires, which con-

stituted the data for this study. This sample comprised 30 females and 28 males, aged 41–82 years (median age 73).

### **Papers III and IV**

For the cognitive interviews in paper III, a convenience sample was selected, comprising nine adults (five females) aged 18–80 (median 50) years, with varying educational backgrounds and Internet experience. The questionnaire data for papers III and IV were derived from the same PHC visitor sample. Swedish-speaking adult ( $\geq 18$  years) The sample consisted of 172 individuals – 93 females and 77 males ranging in age from 20 to 93 years, with a median age of 60.5 (IQR=40–74).

In addition, to enhance the generalisability of the validation study, paper III incorporates 64 questionnaires completed by Swedish-speaking parents of children under the age of 4 who were receiving treatment at the paediatric surgery department and the neonatal department of a hospital in southern Sweden. The parental sample included 36 females and 28 males aged 24–55 years old, with a median age of 32 (IQR=30–36).

## **Instruments**

### **eHealth Literacy Scale**

In paper II, the eHEALS was employed to measure the eHL of the participants. This instrument encompasses eight items that address perceived competencies in locating, evaluating and applying HRII. The items are rated on a 4-point Likert scale from ‘strongly disagree’ to ‘strongly agree’. The aggregated score of all items ranges from 8 to 40, with higher scores indicating higher competencies (Norman and Skinner, 2006a). The eHEALS also includes two non-mandatory stand-alone items, which are not included in the total score, concerning the perceived usefulness and importance of HRII. The responses to these two items were used in paper IV.

## **eHealth Literacy Questionnaire**

The eHLQ which was used in papers III and IV, was developed based on the eHLF. The eHLQ comprises 35 items in seven domains that are relevant to the interaction between the individual and eHealth technology systems. The seven domains are: (1) using technology to process health information, (2) understanding health concepts and language, (3) being able to actively engage with digital services, (4) feeling safe and in control, (5) being motivated to engage with digital services, (6) having access to digital services that work and (7) having access to digital services that suit individual needs. The questionnaire includes a self-assessment of the respondent's abilities and experiences with eHealth services. Each domain consists of four to six items on a 4-point Likert scale ranging from 'strongly disagree' to 'strongly agree'. The domain scores range from 1 to 4, calculated on an index by averaging the item scores within each domain with equal weighting. Each domain is presented separately, and no overall eHLQ score is calculated. Higher scores indicate stronger abilities or agreement within the domain's focus (Kayser et al., 2018).

## **Translation and cultural adaptation of the eHLQ**

Prior to the translation of the eHLQ, permission was obtained from the developers of the instrument. During the process of translation and cultural adaptation from a Danish version of the eHLQ to a Swedish equivalent, the 'Translation Integrity Procedure' (TIP) guidelines were used, as required by the instrument developers (Hawkins et al., 2020). The TIP includes a step-by-step description of how the process should be conducted and a document – 'the Grid' (i.e. the Translation Management grid) – with detailed descriptions of the intent of each item, which is continuously cross-referenced during translation and cultural adaptation. The objective of the TIP is to maintain measurement consistency through a systematic and documented translation process, thereby ensuring the linguistic and cultural relevance of the Swedish version while using plain language to ensure that the ques-

tionnaire is easily comprehensible for individuals with low literacy (Hawkins et al., 2020).

One of the eHLQ's developers, Lars Kayser, oversaw the TIP process. The team responsible for the translation and cultural adaptation comprised two native Swedish forward translators, one native Danish back translator, a team of cognitive interviewers and two academic professionals. The original Danish eHLQ questionnaire was first translated into Swedish with the two independent forward translators. These translators utilised the Grid as a reference while synthesising their translations. Next, team discussions were conducted to select and merge the most suitable statements for each item, resulting in the initial Swedish eHLQ version. Subsequently, the initial Swedish eHLQ underwent back-translation into Danish by a native Danish-speaking translator unfamiliar with the original instrument. The back-translation was then compared with the Danish eHLQ version, and team discussions were held to reach a consensus on the Swedish eHLQ translation. Finally, cognitive interviews were conducted to test the pre-final Swedish eHLQ.

Cognitive interviewing involves asking initial survey questions and gathering spoken details about the responses. This method is beneficial when translating and validating a questionnaire for a different language and culture, as it ensures a more accurate interpretation of items and helps to assess response quality while determining whether the questions effectively convey the intended information (Beatty and Willis, 2007; Hawkins et al., 2020). Furthermore, this method allows for the identification and correction of questions that may not be interpreted as intended, which helps prevent biased data collection (Hawkins et al., 2020).

Consequently, I conducted nine cognitive interviews. First, the participants were carefully observed as they completed the questionnaire. I then reviewed each item with the participant, concentrating on items the participant found difficult. Questions such as: 'What were you considering when

responding to that item?', 'Could you explain why you selected that answer?', 'What do you think the intent of this question is?' and 'This question seemed challenging; could you explain why?' were posed (Beatty and Willis, 2007; Hawkins et al., 2018). The interviews were recorded and transcribed. These transcriptions were subsequently analysed and discussed repeatedly within the research group by aligning the findings with the original item-intent descriptions of the Grid.

Following the cognitive testing and subsequent discussions, the following wordings were revised to enhance the clarity of the items for the intended respondents: The Swedish term '*digitala hälsosystem*' (digital health systems) was consistently replaced by '*digitala vårdtjänster*' (digital healthcare services). Furthermore, the Swedish phrase '*Jag är säker på...*' (I am sure that...) was replaced by '*Jag känner mig trygg att...*' (I feel confident that...). When an agreement on all formulations was reached, the final version of the Swedish eHLQ was considered ready to be distributed to the participants (Figure 3).



Figure 3. The Swedish eHLQ translation process, in line with the Translation Integrity Procedure.

## Data collection

### **Paper I**

Nine individual, semi-structured interviews were conducted at the participants' workplaces, with eight being carried out in 2016 and a ninth in 2018. An interview guide with open-ended questions related to the PHNs' encounters with patients presenting HRII during consultations was utilised. Questions encompassed topics such as 'In your day-to-day professional duties, how do you perceive patients searching for HRII?', 'What issues do you identify?', 'What advantages of HRII do you perceive?' and 'How do patients' presentations of HRII impact your professional routine?'. In addition, follow-up questions were posed using the interview guide as a foundational structure, and the participants were prompted to give several examples of their experiences. The first interview, while not formally designated as a pilot interview, served as a pilot test of the interview protocol and was utilised to identify any issues that needed change. The first interview was conducted collaboratively by me and a co-author, after which we conducted the remaining interviews independently. The interviews, which lasted from 30 to 60 minutes (median: 50 minutes), were audio recorded and transcribed verbatim.

### **Paper II**

In April 2020, participants were asked to complete a paper or online questionnaire with several components: the eHEALS, demographic information (e.g. age, gender and educational attainment), questions on the respondent's Internet and HRII usage (both in general and specifically in connection to diabetes), and questions exploring the respondent's experiences with gathering HRII about COVID-19. The participants were also asked to provide open-ended responses to questions such as: 'Can you describe how you critically evaluate online information about COVID-19?', 'Can you describe if and how you are affected by posts about COVID-19 on social media?' and 'Can you describe your perceptions of online news reports



about COVID-19?'. In addition, the questionnaire asked participants whether they were willing to participate in an interview.

Following the social distancing guidelines enforced due to the COVID-19 pandemic, I conducted the interviews by telephone towards the end of May 2020. The interviews were guided by a semi-structured interview guide that broadly focused on the participants' perspectives and experiences regarding COVID-19-related online information, both in a general context and specifically in relation to diabetes. The questions incorporated into the guide included: 'Can you describe your everyday Internet usage before and after the outbreak of COVID-19?', 'Can you describe how you critically assess online facts and news about COVID-19?', 'Can you describe your perceptions about online information about COVID-19 and diabetes?' and 'What advantages/disadvantages do you see with using the Internet for information about COVID-19?'. The duration of these interviews varied between 11 and 52 minutes, with a median length of 29 minutes; all interviews were recorded and subsequently transcribed verbatim.

### **Papers III and IV**

Data collection from PHC visitors for papers III and IV was conducted in November 2020. Receptionists at the participating PHC centres were asked to distribute questionnaires to all patients who visited the PHC centre during 2 weeks in November 2020 and who met the inclusion criteria. The participants filled out the questionnaire either at the PHC centre or at home and returned it by mailing it back in a provided stamped and addressed envelope. Demographic data (e.g. age, gender and educational level), health-related queries (e.g. self-rated health and the presence of chronic disease) and inquiries about general and health-related Internet habits were included. As all questionnaires were answered anonymously, no follow-up reminders were distributed. Determining the precise response rate posed a challenge, since the receptionists could not account for the number of patients who opted not to participate in the study. Data collection for the parental sample in

paper III was executed by researchers affiliated with Lund University; nurses from the participating departments distributed questionnaires to parents in the spring of 2021.

## Analyses

### **Qualitative content analysis**

In paper I, the transcribed interviews with the PHNs were analysed inductively via qualitative content analysis, as described by Graneheim and Lundman (2004). This approach focuses on both the manifest, descriptive content and the latent, interpretative content of a text (Graneheim et al., 2017). Initially, the interview text was read thoroughly to acquire a basic understanding of and familiarisation with the content. The next step involved de-contextualising the data, wherein the interview data were separated from their context in an initial stage to shed light on all participants' experiences with Internet-informed patients. This was achieved by identifying the text relevant to the research objective, segmenting it into meaningful units, condensing it (i.e. shortening it while preserving the core message) and labelling it with codes. Subsequently, re-contextualisation was performed, as the codes were recombined into new patterns and reintegrated into their context, with the aim of gaining a deeper understanding of PHNs' experiences with Internet-informed patients. At this stage, I discussed the codes with all the other authors of the paper; based on similarities and differences, the codes were abstracted into nine subcategories, three categories and one overarching theme. We continuously discussed the coding and categorisation until consensus was achieved, thereby strengthening the study's trustworthiness (Lindgren et al., 2020). The qualitative content analysis process is described as nonlinear. Therefore, we repeatedly moved between the entire text and specific text segments during the analytical process (Graneheim and Lundman, 2004; Graneheim et al., 2017; Lindgren et al., 2020).

## **Thematic analysis**

The analysis in paper II was conducted using an inductive thematic approach, as described by Braun and Clarke (2006). Thematic analysis is a flexible method for identifying, analysing and reporting patterns (i.e. themes) within a dataset that answer the research question. During the analysis, I followed the six phases of the thematic approach as described by Braun and Clarke – namely, data familiarisation, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. Since thematic analysis is not a straightforward, linear approach but rather an iterative and reflective process that evolves over time, I continuously moved between phases (Braun and Clarke, 2006). To become acquainted with the data, I repeatedly read the transcribed texts from the interviews and free-text responses, while continuously making notes on emerging ideas. It quickly became evident that the data primarily revolved around challenges related to online COVID information and how participants were dealing with these challenges. Short data segments corresponding to the study's objectives were subsequently coded, and the codes were organised into initial themes. These themes were then reviewed and labelled by the entire research team. To support the analysis process, I kept an ongoing reflexive journal, used mind maps to explore and visualise relationships, and documented notes on initial interpretations and decisions before proceeding to establish the final themes. MAXQDA software (version 2020) was used to store, explore and organise the transcribed interviews.

Following the thematic analysis, in which all data were analysed as a whole, the participants were categorised into low/high eHL groups based on their eHEALS scores. The threshold for high eHL was established at a score of 26 or higher, in accordance with previous comparable research (Richtering et al., 2017). In the results section of paper II, this division is visible in the form of the participant's eHL group, which is indicated alongside the quotations. However, group differences are mentioned only in the discussion section of the paper.

## Statistical analyses

Data analyses of papers III and IV were conducted by employing SPSS (version 25) and JAMOVI (version 2.2.3). Cases presenting with  $\geq 50\%$  ( $n=18$ ) missing values were omitted from the studies ( $n=2$ ). Any remaining missing values were substituted using the expectation-maximisation algorithm imputation method in SPSS.

In paper III, demographic characteristics (i.e. gender, age, education and employment status) were conveyed via frequency and percentage (for categorical variables) or mean and standard deviation (for continuous variables). Descriptive statistics were also used to analyse and present the domain means, item medians, number and percentage of missing values, and each response option. The presence of floor and ceiling effects was established if more than 15% of the participants recorded either the lowest or the highest possible response for a given item (cf. Terwee et al., 2007).

Since this paper aimed to validate the Swedish version of an instrument with pre-established domains, a confirmatory factor analysis (CFA) was conducted. Each domain was analysed using Cronbach's  $\alpha$ , where good internal consistency was denoted by an  $\alpha$  value ranging from .70 to .95 (cf. Terwee et al., 2007). First, seven single-factor CFA models were fitted to the data in order to examine local independence by evaluating standardised factor loadings, modification indices and standardised expected parameter changes (Whittaker, 2012). Following this, a seven-factor CFA was implemented without cross-loadings or interrelated residuals. The diagonally weighted least squares (DWLS) estimator was utilised, sourced from the structural equation modelling (SEM) module in JAMOVI. The DWLS estimator is explicitly tailored for ordinal data, such as Likert scales, and does not impose any distributional assumptions on the observed variables. Instead, it implies a normal latent distribution for each categorical variable observed (Li, 2016). To evaluate model fit, the standardised root mean residual (SRMR) was used following Shi and Maydeu-Olivares' (2020) recommendation, as well as the comparative fit index (CFI), Tucker-Lewis Index (TLI), root mean square of

approximation (RMSEA) and chi-square/df values. A close fit was indicated by an SRMR < 0.09, a CFI > 0.95, a TLI < 0.95, an RMSEA < 0.05, and a chi-square/df value of <3 (Kline, 2023). Factor loadings >0.40 were considered satisfactory (Raykov and Marcoulides, 2011).

In paper IV, demographic characteristics, alongside Internet and HRII usage data, were reported as frequencies and percentages for categorical variables. To provide a comprehensive overview of the distribution of Internet usage and eHL within the sample and to facilitate comparative analyses, the participants were categorised into four age groups. This categorisation was guided by both statistical considerations – with each group representing a quartile of the total sample – and a theoretical rationale. Means, standard deviations (SDs), confidence intervals (CIs), and medians and interquartile ranges (IQR) were provided for continuous variables. A boxplot was also presented, illustrating the distribution of the collected data across the seven eHLQ domains.

The Shapiro-Wilk test indicated that the eHLQ and Internet habits data did not adhere to a normal distribution, so non-parametric tests were employed. In the univariate analyses, the Mann-Whitney U-test was used to compare the eHLQ mean scores between two variables, and the effect size was denoted using Cohen's *d*. According to Cohen, reference values for effect size are 0.2, 0.5 and 0.8 for small, medium and large effect sizes (Cohen, 1988). For comparisons between three or four groups, the Kruskal-Wallis test was employed, and the effect size was analysed using Epsilon squared ( $\epsilon^2$ ). The  $\epsilon^2$  effect sizes are categorised as follows: values between 0.00 and 0.01 are considered negligible, those between 0.01 and 0.04 are weak, those ranging from 0.04 to 0.16 are moderate, those between 0.16 and 0.36 are relatively strong, and values ranging from 0.36 to 0.64 are strong (Tomczak and Tomczak, 2014).

Before conducting the logistic regression analysis, the participants were separated into low or high eHL groups based on their mean scores for each

domain. The threshold for high eHL was set at a domain mean greater than 2.50, which suggested that the participants were predominantly in agreement with the items of that specific domain. A backward stepwise logistic regression was conducted for each of the seven domains, with low eHL as the dependent variable. The independent variables included gender, age, education, self-rated health, frequency of HRII acquisition, and perceived importance and usefulness of HRII acquisition.

A multicollinearity test was performed, which revealed no significant concern. More specifically, the variance inflation factors (VIFs) for all independent variables were under the generally recognised threshold of 10, indicating the absence of significant correlations among the variables (Hair, 1998). Furthermore, all variables were analysed for interaction effects (Nick & Campbell, 2007). A  $p$  value of less than 0.05 was designated as the criterion for statistical significance. The odds ratio (OR) and corresponding 95% CIs were reported. The Nagelkerke  $R^2$  was calculated to assess the variance of the model.

# Results

## Views of primary healthcare nurses

The PHNs interviewed in paper I described it as a common occurrence for patients to present HRII during consultations. They expressed ambivalent attitudes towards Internet-informed patients, recognising both advantages and disadvantages. The availability of HRII was perceived to have transformed the dynamics in PHC consultations by altering patient behaviour, reshaping conversation patterns and shifting the roles of both PHNs and patients, as described in the overarching theme of the analysis. The analysis also identified nine subcategories and three categories regarding the PHNs’ experiences of patients presenting HRII during consultations (see Table 2).

Table 2. Primary healthcare nurses’ experiences of consultations with Internet-informed patients

| Theme: Internet-informed patients change the rules of the game |  |
|--|--|
| Category   | Subcategory                            |
| Facing the downsides of Googling                               | Confusion due to contradictions        |
|  | Disputes related to differing opinions |
|  | Unfounded anxiety among patients       |
| Patients as main actors  | Patients as lay experts                |
|  | Self-care initiatives facilitated      |
|  | Patients as equal partners             |
| Nurse’s role challenged  | Being considered unnecessary           |
|  | Importance of keeping up to date       |
|  | Coaching instead of controlling        |

The category 'Facing the downsides of free Googling' describes the unfavourable consequences the PHNs believed patients' unrestricted online searching of symptoms and illnesses could have, both for patients and for the PHC system. Unrestricted online searches were considered to pose a risk of leading patients to unreliable sources or conflicting information, which were believed to cause confusion and unfounded anxiety for many patients.

...or when they call about a headache. Well, then they imagine it is a brain tumour. Since they read on the Internet that, for some people, it started with a headache, well then, it must be a brain tumour... (Interviewed PHN nurse)

According to the PHNs, anxiety and confusion often stemmed from the challenge many patients encountered in discriminating reliable from unreliable information. Individuals who already had a tendency towards health anxiety and the parents of toddlers were regarded as being the most disposed to express anxiety after acquiring HRII. The PHNs commented that unrestricted online searching and its effects on patients affected healthcare consultations because these patients tended to be more persistent and dissatisfied. The consultations took longer and were more energy draining due to disagreements that arose regarding diagnosis or treatment, for example.

The category 'Patients as main actors' covers the PHNs' experiences of patients becoming more active and confident in managing their health through the knowledge they obtained from HRII. According to the PHNs, reliable HRII was sourced from quality-reviewed outlets such as 1177.se – a website commonly cited by PHNs in patient interactions. The PHNs noted that a significant advantage of this credible HRII was its self-care advice, which was believed to assist patients and alleviate the PHC system. Another benefit was that the Internet-informed patients were better prepared for consultations, potentially leading to more efficient and structured discussions that reached the core issues more rapidly. However, challenges could arise



when, based on the acquired HRII, the patients saw themselves as medical experts who had already decided on a diagnosis and treatment, making them less receptive to advice from PHNs.

The third category, 'Nurse's role challenged', addresses the role transformation the PHNs experienced due to Internet-informed patients. With increasingly knowledgeable and active patients, the PHNs perceived their function to be shifting from a controlling role to a more coaching and supportive one. However, the PHNs felt that Internet-informed patients could sometimes view them as unnecessary, given these patients' strong opinions on matters such as diagnosis, medication prescribing and referrals. Moreover, well-informed patients had higher expectations for the PHNs' knowledge and skills, which motivated the PHNs to stay updated with the latest evidence. This was seen as a positive development for healthcare quality and the PHN role.

## Views of patients with type 2 diabetes

In the analysis of data on experiences of patients with type 2 diabetes concerning online COVID-19 information during the early stages of the pandemic (II), two domains were identified: perceived challenges with online information about COVID-19 and coping strategies to manage these challenges (Table 3).

Table 3. Experiences of online COVID-19 information acquisition among patients with type 2 diabetes

| Domains   | Themes                                |
|---|---------------------------------------|
| Perceived challenges with online information about COVID-19 | Being exposed to information overload |
|   | Encountering conflicting information  |
|   | Being heavily emotionally affected    |
| Coping strategies to manage the challenges                  | Protecting oneself                    |
|   | Trusting the authorities              |
|   | Taking command                        |
|   | Using common sense                    |

The participants in paper II expressed that the Internet was a crucial source of COVID-19 information that allowed them to stay updated and to limit the spread of the virus through self-care advice and guidelines. However, managing such online information presented numerous challenges, including the overwhelming volume of information that had taken over the Internet, on both news websites and social media. This could be experienced as a forced and passive information intake. The vast amount of information was perceived as confusing because it was challenging to sift through and identify the most critical information.

Another challenge stemmed from the confusion caused by contradictory information from experts and non-experts on news and social media. The participants experienced frustration due to the general knowledge gap at the start of the pandemic, which made it difficult to find straightforward answers to their questions. This particularly applied to answers about COVID-19 regarding individuals with diabetes, as this group has been reported to be at a higher risk of severe illness. News websites were deemed

to be significant sources of COVID-19 information for the participants, but these were perceived as being prone to exaggeration, presenting either overly optimistic cases or worst-case scenarios. News websites were also considered to play a significant role in evoking various emotions in participants. Negative news (e.g. high death rates) triggered anxiety, while positive news (e.g. reduced mortality rates) elicited feelings of hope. The participants considered that news – such as diabetes-related news – had a particular emotional impact when it applied to their own lives.

The participants developed strategies to address these challenges, including shielding themselves from distressing reactions such as confusion, anxiety and a sense of being fed up with online COVID-19 information. To protect themselves, the participants transitioned from reading nearly all available information to limiting their information intake to only the most essential or to avoiding COVID-19-related information altogether.

I have NOT searched about corona and diabetes, and I think it is out of fear. Fear of reading something that I don't want to know about myself. Because I also have trouble accepting that I have diabetes. It's a defence mechanism. I put my head in the sand. That's it. I can't handle it. (Interviewed participant with type 2 diabetes)

Another strategy, in cases of contradictory information, involved prioritising authoritative information, especially information from the Public Health Agency of Sweden, as the participants believed this to be the most reliable source. A different strategy was to evaluate the credibility of online COVID-19 information, which included maintaining a critical perspective, actively seeking online sources or discussing information with family or friends. Furthermore, the participants emphasised that they relied on common sense to assess the credibility of information. Common sense was described as a 'gut feeling', an inner sense of what is true or false, or something being in alignment with the knowledge and experiences acquired throughout their lives.

I trust my common sense. I use my experiences from life and contacts I have had with healthcare. And also from my educational background, like risk analyses and things like that. I immediately think along these lines. Given my life experience and knowledge acquisition, I feel somewhat in control of the situation. (Interviewed participant with type 2 diabetes)

## eHealth Literacy Questionnaire

The 35-item eHLQ instrument, which contains seven domains (Table 4), was translated, culturally adapted and validated in paper III. Cognitive interviews based on the initial translation revealed that most of the questions were perceived as intended. However, a few changes were necessary to clarify specific items to fit the Swedish eHealth context. The recurring and centrally important term '*digitala hälsosystem*' (digital health systems) was consistently changed to '*digitala vårdtjänster*' (digital healthcare services) in items 9, 13, 16 and 28.

The eHLQ mean scores ranged from 2.58 (SD 0.73) on domain 7 (Digital services that suit individual needs) to 3.04 (SD 0.55) on domain 2 (Understanding health concepts and language) (Table 4).

Table 4. Overview of eHLQ domains, number of items and means of validation sample

| DOMAIN  | No. of items | Mean (SD) [CI]          |
|---|--------------|-------------------------|
| 1. Using technology to process health information               | 5            | 2.65 (0.73) [2.56–2.75] |
| 2. Understanding health concepts and language                   | 5            | 3.04 (0.55) [2.97–3.11] |
| 3. Being able to actively engage with digital services          | 5            | 2.88 (0.82) [2.78–2.99] |
| 4. Feeling safe and in control                                  | 5            | 3.03 (0.54) [2.96–3.10] |
| 5. Being motivated to engage with digital services              | 5            | 2.62 (0.68) [2.53–2.71] |
| 6. Having access to digital services that work                  | 6            | 2.68 (0.59) [2.60–2.76] |
| 7. Having access to digital services that suit individual needs | 4            | 2.58 (0.73) [2.48–2.67] |

The range of unanswered items varied from 0.8% to 4.2%. No ceiling or floor effects were observed at the domain level. However, floor effects were identified in three items, while most items exhibited ceiling effects. In domains 2, 3 and 4, all items showed ceiling effects.

Cronbach's  $\alpha$  was satisfactory, ranging from 0.82 to 0.92. The single-factor confirmatory factor analysis (CFA) model demonstrated acceptable fit indices and satisfactory-to-high factor loadings for 34 of the 35 items, ranging from 0.55 to 0.90. However, item 3 in domain 6, which inquired whether information about the participant's health is always accessible to those who require it, had a low factor loading (0.35). Nonetheless, all factor loadings were statistically significant.

A seven-factor CFA model was applied to the 35 items. Despite the restricted model, which disallowed cross-loadings or residual covariances and included a substantial number of items, the model exhibited a satisfactory fit

(SRMR=0.06, CFI=1.00, TLI=1.00, RMSEA=0.00,  $\chi^2/df=0.6$ ). Similar to the single-factor CFA, all factor loadings were generally satisfactory to high, except for item 3 in domain 6. The inter-factor correlation coefficients within the seven-factor model ranged from 0.54 (between domains 2 and 7) to 0.99 (between domains 1 and 5). The next highest inter-factor correlation coefficient of 0.97 was observed between domains 6 and 7 (paper III).

## Internet use and eHealth literacy of primary healthcare visitors

The results showed that all individuals in the lowest age group (<40) used the Internet daily, compared with approximately half of those older than 75. About half of the participants accessed HRII at least monthly; the majority under 60 did so regularly, while the majority over 60 did so less often. Furthermore, 61% of participants 40 years and younger chose the Internet as the primary source of health information, compared with 5% of participants over 75 years old. When accessing HRII, the primary start source was equally divided between Google and 1177.se, without any clear age pattern (Table 5).

The proportion of participants who considered HRII useful decreased with age, from 86% of participants <40 to 30% of participants >75 years old. The same pattern was observed for the proportion of participants who considered HRII important, from 95% among participants <40 to 43% of participants >75 years old. (Table 5).

PHC visitors received the highest rating concerning their understanding of health concepts (2) and feeling safe and in control (4). At the same time, the lowest scores were found regarding using technology to process health information (1), being motivated to engage with digital services (5) and finding that digital services suited individual needs (7) (Figure 4).

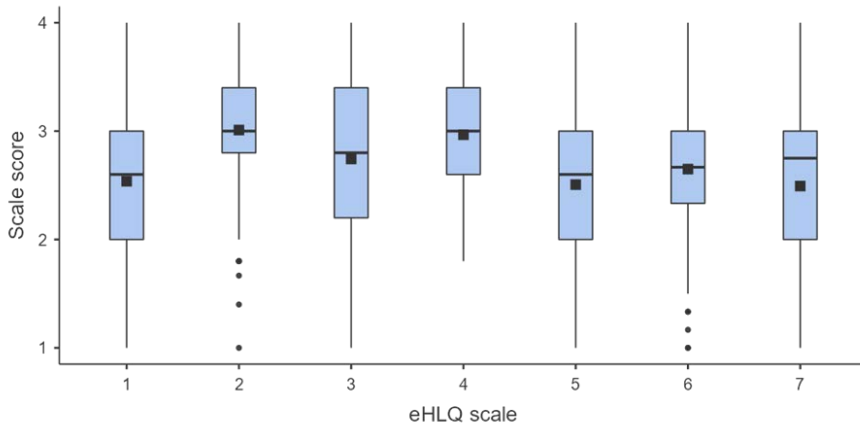
Women had significantly higher mean values than men in all domains except 3 and 5. Furthermore, younger people were rated as having higher eHL in all domains in comparison with older people, where the higher the

education level, the higher the eHL. Moreover, the higher the level of self-reported health, the higher the estimated eHL (data not shown).

Table 5. Internet/HRII use of the total sample and of different age groups n (%)

|   | <b>Total sample</b> | <b>≤40</b> | <b>41-60</b> | <b>61-74</b> | <b>≥75</b> |
|---|---------------------|------------|--------------|--------------|------------|
| <b>Frequency of Internet use</b>            |                     |            |              |              |            |
| Every day                                   | 142 (82.6)          | 44 (100.0) | 40 (97.6)    | 35 (81.4)    | 22 (52.4)  |
| Less often or never                         | 29 (17.4)           | -          | 1 (2.4)      | 8 (18.6)     | 20 (47.6)  |
| <b>Frequency of HRII acquisition</b>        |                     |            |              |              |            |
| Every week                                  | 27 (15.9)           | 10 (22.7)  | 8 (19.5)     | 5 (11.6)     | 3 (7.1)    |
| Every month                                 | 57 (33.5)           | 26 (59.1)  | 14 (34.1)    | 10 (23.3)    | 7 (16.7)   |
| Less often or never                         | 86 (50.6)           | 8 (18.2)   | 19 (46.3)    | 27 (62.8)    | 31 (73.8)  |
| Missing                                     | 2 (1.2)             | -          | -            | 1 (2.3)      | 1 (2.4)    |
| <b>Primary source of health information</b> |                     |            |              |              |            |
| Healthcare                                  | 84 (48.8)           | 7 (15.9)   | 17 (41.5)    | 24 (55.8)    | 34 (81.0)  |
| The Internet                                | 58 (33.7)           | 27 (61.4)  | 17 (41.5)    | 12 (27.9)    | 2 (4.8)    |
| Other                                       | 30 (17.4)           | 10 (22.7)  | 7 (17.0)     | 7 (16.3)     | 6 (14.3)   |
| <b>Primary source of HRII</b>               |                     |            |              |              |            |
| Google                                      | 70 (47.9)           | 23 (52.3)  | 17 (43.6)    | 19 (55.9)    | 10 (37.0)  |
| 1177  | 68 (46.6)           | 20 (45.5)  | 22 (56.4)    | 13 (38.2)    | 13 (48.1)  |
| Other                                       | 8 (5.5)             | 1 (2.3)    | -            | 2 (5.9)      | 4 (14.8)   |
| Missing                                     | 26 (15.1)           | -          | 2 (4.9)      | 9 (20.9)     | 15 (35.7)  |
| <b>Perceived HRII usefulness</b>            |                     |            |              |              |            |
| Not useful                                  | 28 (17.3)           | -          | 2 (5.0)      | 8 (20.0)     | 16 (43.2)  |
| Unsure                                      | 32 (19.8)           | 6 (14.0)   | 7 (17.5)     | 9 (22.5)     | 10 (27.0)  |
| Useful                                      | 102 (63.0)          | 37 (86.0)  | 31 (77.5)    | 23 (57.5)    | 11 (29.7)  |
| Missing                                     | 10 (5.8)            | 1 (2.3)    | 1 (2.4)      | 3 (7.0)      | 5 (11.9)   |
| <b>Perceived HRII importance</b>            |                     |            |              |              |            |
| Not important                               | 27 (16.7)           | -          | 5 (12.5)     | 5 (12.5)     | 16 (43.2)  |
| Unsure                                      | 15 (9.3)            | 2 (4.7)    | -            | 8 (20.0)     | 5 (13.5)   |
| Important                                   | 120 (74.1)          | 41 (95.3)  | 35 (87.5)    | 27 (67.5)    | 16 (43.2)  |
| Missing                                     | 10 (5.8)            | 1 (2.3)    | 1 (2.4)      | 3 (7.0)      | 5 (11.9)   |





eHLQ domains:

1. Using technology to process health information
2. Understanding of health concepts and language
3. Ability to actively engage with digital services
4. Feeling safe and in control
5. Motivated to engage with digital services
6. Access to digital services that work
7. Digital services that suit individual needs

Figure 4. Boxplot of the seven eHLQ domains.

Low perceived usefulness of HRII was associated with low eHL across all eHLQ domains, except for accessing digital services that work. Similarly, low perceived importance of HRII was associated with low ability in using technology to process health information (1), actively engaging with digital services (3) and low motivation to engage with digital services (5). Furthermore, higher age was associated with a lower ability to engage with digital services actively (3) and a feeling that digital services did not suit their individual needs (7). Moreover, lower self-rated health was associated with a lower motivation to use digital services (5). Gender, education and the frequency of accessing HRII were not significantly connected with low eHL in any of the domains (paper IV) (Table 6).

Table 6. Final logistic regression models for low eHealth literacy

| eHLQ domain   | Significant independent variables (OR, 95% CI, <i>p</i> value)   | <i>R</i> <sup>2</sup> |
|---|--|-----------------------|
| 1. Using technology to process health information   | Higher age (1.02, 1.00–1.05, 0.033)<br>HRII not useful (4.16, 1.64–10.56, 0.003)<br>HRII not important (9.50, 2.72–33.16, <0.001)              | 0.51                  |
| 2. Understanding of health concepts and language    | HRII not useful (7.41, 2.76–19.90, <0.001)   | 0.20                  |
| 3. Ability to actively engage with digital services | Higher age (1.05, 1.02–1.08, <0.001),<br>HRII not useful (12.32, 4.98–30.49, <0.001)   | 0.53                  |
| 4. Feel safe and in control                         | HRII not useful (3.12, 1.46–6.70, <0.001)  | 0.08                  |
| 5. Motivated to engage with digital services        | Poorer self-rated health (2.64, 1.15–6.01, 0.022)<br>HRII not useful (4.47, 1.81–10.74, 0.001)<br>HRII not important (6.72, 2.13–21.20, 0.001) | 0.43                  |
| 6. Access to digital services that work             | Higher age (1.02, 1.00–1.05, 0.025)<br>HRII not useful (3.85, 1.72–8.64, 0.001)  | 0.23                  |
| 7. Digital services that suit individual needs      | HRII not important (10.64, 3.12–36.32, <0.001)   | 0.18                  |

# Discussion

## Summary of the main results

Paper I found that PHNs considered correct HRII that was properly interpreted and utilised to be valuable for patients' engagement in self-care and person-centred encounters in healthcare. However, they noted that many patients lacked the competence to interpret and use HRII effectively, which could lead to patient distress, time-consuming and unnecessary visits, conflict and the PHNs feeling redundant.

Paper II found that patients with type 2 diabetes reported experiencing challenges related to COVID-19 Internet information, which included dealing with a large volume of information, encountering contradictory HRII, and associated anxiety. Strategies to manage these challenges included trusting the authorities and one's own common sense, double-checking information and limiting information intake.

To enhance patients' eHL abilities, it is essential to understand patients' strengths and difficulties. The Swedish eHLQ is a useful way to determine such information; in paper III, the eHLQ was found to demonstrate good validity and reliability. In paper IV, a multidimensional exploration of eHL among PHC visitors found low ratings in several eHL domains – particularly those regarding the motivation to use digital tools for eHealth purposes, and especially in older age groups (>60). The results also showed that the existing eHealth services were not tailored to their needs. Beyond age, perceptions that HRII was neither useful nor important were found to be associated with low eHL.

## eHealth as a valuable resource in primary healthcare

Given the challenges confronting PHC, eHealth – including HRII access – is considered to be crucial for facilitating Sweden's 'Close Care' reform. eHealth can help patients make informed decisions based on engagement, self-awareness and updated health knowledge, which aligns with PCC (Calvillo et

al., 2015; Ekman et al., 2011; Xiang and Stanley, 2017). Thus, eHealth is considered to have positive implications at various levels, benefiting both individuals and healthcare professionals and reducing costs (World Health Organisation, 2018a). In this research, people with type 2 diabetes were found to generally share this positive perception of eHealth, as they emphasised the Internet's role in providing general COVID-19 information and self-care advice during the pandemic (paper II). According to the interviewed PHNs in paper I, the most significant advantage of HRII was that it relieves the healthcare system by providing patients with self-care information and enables more efficient consultations for prepared patients – a finding that aligns with previous research (Ahluwalia et al., 2010; Barnoy et al., 2009, 2011; Sommerhalder et al., 2009; Walker and Sillence, 2023). The interviewed PHNs emphasised that, in order for HRII to be beneficial, it should come from reliable and evidence-based sources; the nurses put particular emphasis on the Swedish healthcare website 1177.se (Caiata-Zufferey and Schulz, 2012).

By considering eHL as a multidimensional concept in accordance with the eHLF, my objective was to utilise the eHLQ to identify the areas in which visitors to PHC demonstrated strengths and faced challenges (c.f. Norgaard et al., 2015; Kayser et al., 2018). Such knowledge may provide an opportunity to identify areas in Swedish PHC that work satisfactorily and, most importantly, areas where interventions are needed to facilitate eHealth utilisation for all who desire it. My findings largely align with those of studies conducted in other countries and contexts (Chen et al., 2022; Cheng et al., 2022; García-García et al., 2022; Holt et al., 2019).

In paper IV, the sample of PHC visitors demonstrated strengths in their perceived knowledge about and engagement in health and sense of security through the use of eHealth services, including the confidentiality of health data. It was notable that health knowledge and security were the only domains in which the mean scores were closer to 'agree' than 'disagree' across

all age groups. From a person-centred perspective, it is important that patients have knowledge about their health and a willingness to manage it effectively, as this may foster collaborative decision-making within the partnership between patients and healthcare providers (Byrne et al., 2020; Norgaard et al., 2015). Moreover, access to one's medical records is important to PCC, as it fosters patient knowledge, engagement and collaborative decision-making; thus, it is beneficial for patients to have confidence in the secure handling of electronic health records and online communication with healthcare professionals (Skär and Söderberg, 2018). A sense of security regarding privacy in eHealth is crucial, since its absence has been shown to be a significant obstacle to eHealth service utilisation, particularly among older individuals (Georgiou and Prgomet, 2019; Wilson et al., 2021). However, what is notable among PHC visitors regarding these two strong domains – that is, engagement in their health and feeling secure – is that these domains are not directly related to the use of digital technology and eHealth.

### Using health-related Internet information is challenging

PHNs and patients with type 2 diabetes agreed on two of the most significant negative consequences of excessive and contradictory HRII: namely, confusion and anxiety. This finding corroborates those of prior studies showing that inaccurate and unclear HRII – along with increased frequency and longer durations of seeking HRII – is linked to heightened health anxiety (McMullan et al., 2019; Starcevic et al., 2020; Tanis et al., 2016). In line with the patients' concerns reported in paper II, other research during the COVID-19 pandemic has shown increased health anxiety to be associated with constant and conflicting HRII updates, misinformation, reduced ability to filter out unnecessary HRII, and frustration (Starcevic et al., 2021).

The interviewed PHNs identified a problem in relying on search engines such as Google as the primary source of HRII, as such search results may lead to unreliable pages instead of going directly to a trustworthy online healthcare resource (paper I). In paper IV, many PHC visitors reported

initiating their searches on Google. The fact that search engines such as Google are the most common choice when initiating a search for HRII has also been reported by previous studies (Chu et al., 2017). The existing literature supports the PHNs' concerns associated with search engine usage, highlighting issues such as the overwhelming quantity of search results, which can lead to websites providing non-peer-reviewed HRII that is misleading and inaccurate (Rothrock et al., 2019). The hazards of any inaccurate HRII – regardless of source – include confusion, anxiety, wrongful self-diagnosis, wrongful treatment and postponement of healthcare consultations (Frey et al., 2022).

Both the PHNs and the patients described the important role of news media and social media in obtaining HRII – a role that was particularly pronounced during the pandemic. However, even in non-pandemic circumstances, news media and social media are becoming increasingly common sources of health information (Viviani and Pasi, 2017). In fact, many people prefer news or social media platforms over healthcare websites because they find the information to be easily accessible and presented in a more everyday, non-medical manner. As readers' and viewers' interest is substantial, news websites are also eager to publish health-related content (Sandberg and Möllerström, 2014).

The drawbacks of using social media platforms (e.g. Facebook or various health and parenting peer forums) to acquire HRII may include the prevalence of a dominant opinion that is perceived as the singular truth. This may result in inaccurate, conflicting and potentially harmful information that participants must navigate without guidance, potentially leading to confusion, anxiety, delayed healthcare seeking or harm from incorrect treatment (Bradshaw et al., 2021; Frey et al., 2022; Hanley et al., 2019). Nevertheless, peer forums are reported to fulfil needs other than information acquisition, such as convenience, anonymity and the opportunity for peer support – features that conventional healthcare often cannot provide (Chu et al., 2017).

Furthermore, peer forums facilitate connections between individuals with similar concerns or conditions, such as mental health issues, diabetes or the care of sick children, thereby offering emotional support, a platform for sharing personal thoughts and a sense of belonging (Elnaggar et al., 2020; Niela-Vilén et al., 2014; Prescott et al., 2017). These characteristics can assist individuals in coping with various situations (Hanley et al., 2019). For people with diabetes who make infrequent healthcare visits and often struggle with self-care, studies have shown that online peer-to-peer support is beneficial and may lead to enhanced knowledge, facilitated self-care and improved health behaviours (Elnaggar et al., 2020).

Another aspect of HRII from news media and social media is that such information retrieval is often passive, meaning that individuals come across information by chance through posts, headlines or advertisements. Different people have varying preferences and needs in this regard: while some actively seek health information, others prefer to have it delivered to them, in both healthcare contexts and other situations (Kelly et al., 2014). Research suggests that persons with type 2 diabetes tend to be passive recipients of information, meaning that they often rely on information that is delivered to them, such as through healthcare professionals, informational brochures in waiting rooms, or encounters with information online or on television, rather than actively seeking it (Longo et al., 2010; Milewski and Chen, 2010). It is important for healthcare professionals to be responsive to patients' various individual needs, behaviours and preferences concerning information retrieval. Considering the widespread passive information consumption in today's digital society, healthcare providers – including PHNs – have the task of promoting the acquisition of HRII from reputable sources, encouraging source criticality and facilitating open dialogues in healthcare settings regarding online findings.

The increasingly popular concept of 'organisational health literacy' pertains to healthcare organisations (e.g. PHC centres or healthcare

authorities) effectively delivering health information and services that are easily understandable and actionable for all patients. The objective is to attain equitable healthcare, ensuring that as many individuals as possible – including those with limited health literacy – can benefit from information. Organisational health literacy emphasises the importance of a person-centred approach and collaboration between patients and healthcare providers in the design of health information (Palumbo, 2021). Therefore, healthcare professionals and organisations should be highly interested in learning from and supporting effective strategies such as those the participants in paper II described using to mitigate the adverse effects of HRII during the pandemic’s challenging ‘infodemic’. One of these strategies was to choose information from credible, authoritative sources – a strategy that was also emphasised by the PHNs in paper I. It should be noted that Swedes are generally characterised by a relatively strong trust in the authorities, compared with the citizens of other countries (Kumlin and Haugsgjerd, 2017; Liobikienė and Bernatoniene, 2018; Sykes et al., 2022). Another strategy reported in paper II was to limit the time spent on news and social media, in order to reduce health-related anxiety (c.f. McMullan et al., 2019; Starcevic et al., 2020). Yet another important strategy was to critically examine information in various ways, such as by conducting web searches to determine the origin of information or by discussing the information with family members.

Social networks can be a significant factor in enhancing an individual’s health literacy through the combination of collective knowledge, in what is often referred to as ‘distributed health literacy’ (Papen, 2009). In individuals with type 2 diabetes, distributed health literacy has been reported to be important in the assessment of HRII, positively affecting self-management and glycaemic control (Abreu et al., 2018; Aponte and Nokes, 2017; Osborn et al., 2010). This finding underscores the importance of involving family members or friends in diabetes care and other healthcare contexts.



## Identifying and reducing obstacles to eHealth literacy

In a healthcare system that is progressively embracing digitalisation, it is essential to examine the factors that contribute to patients' perceived obstacles to utilising eHealth services, in terms of both adoption and effectiveness. As anticipated, and in line with prior research (Chang et al., 2021; Neter and Brainin, 2012), eHL decreased with age across all domains (paper IV). Individuals over 60 exhibit lower digital capabilities, lower motivation and less favourable experiences with eHealth services, which is unfortunate, given their greater medical needs (Heponiemi et al., 2020).

The domain in which the PHC visitors in paper IV obtained the lowest scores pertained to the suitability of eHealth services for their individual needs. In this context, 'individual needs' could be related to the perception that digital technology is too complicated or that information is presented in overly medical language or is not available in the language one is proficient in. It could also be the case that an individual has some form of disability that hinders the use of eHealth services. If such inability is attributed to physical issues, such as visual impairment, cognitive challenges or fine-motor-skill difficulties, there may be relatively simple potential solutions, such as implementing more suitable technical aids in the form of larger screens, increased text size or audio feedback (Nymberg et al., 2019; Wilson et al., 2021). In the broad conceptualisation of eHL used in this thesis, which not only focuses on individual capabilities but also includes interactions with and features of eHealth services, achieving good eHL requires eHealth services to adapt to meet individual needs. In the literature, an increasingly emphasised solution to this adaption is the expanded inclusion of the intended end-users of an eHealth service in its development (Calvillo-Arbizu et al., 2019; Wilson et al., 2021). The Swedish eHealth Agency (2020a) also emphasises that eHealth services should be universally designed and capable of individual or group customisation.

Based on the findings of this thesis, other areas in which PHC visitors encountered difficulties included their ability to utilise digital technology and to find, comprehend, critically assess and apply HRII. Most eHL initiatives and interventions occur within these domains. In Sweden, there are several initiatives under way to train digital skills, such as through senior organisations, libraries and various associations focusing on digital technology (Swedish eHealth Agency, 2020a).

The PHC visitors also exhibited low motivation to utilise eHealth services (paper IV). Lack of motivation is a common barrier to Internet use altogether (Iacobaeus et al., 2019; Basis Social & Good Things Foundation, 2022). Motivation is often regarded as the initial step towards and the cornerstone of digital inclusion (Iacobaeus et al., 2019; Swedish eHealth Agency, 2020; Van Dijk, 2012). A British survey demonstrated that the key factors influencing motivation to use eHealth services are perceived effectiveness, a sense of having one's needs understood and acknowledged, the perception of having increased control over one's healthcare, and the capabilities to use eHealth services (Basis Social & Good Things Foundation, 2022). Motivation to use digital services is often fostered through recurrent positive user experiences, which may be impeded by experiences that do not satisfy users' needs. To enhance motivation, potential strategies may involve presenting eHealth as something relatable (used by 'people like me') and providing opportunities for individuals to explore digital services without any pressure (e.g. in waiting rooms) (Basis Social & Good Things Foundation, 2022). However, as previously mentioned, most efforts to increase digital inclusion predominantly focus on digital training – an approach that is often insufficient if motivation is not concurrently addressed.

The perception that eHealth is not useful or important is closely related to a lack of motivation. According to the majority of the participants in all the papers in this thesis, HRII is fundamentally useful and important (papers I, II, IV), although this perception seems to diminish with age (paper IV).

The finding that older participants more frequently perceive eHealth/HRII as not useful is corroborated by prior research (Chu et al., 2017; Heponiemi et al., 2020; Swedish eHealth Agency, 2020a). Paper IV also revealed an association between perceiving HRII as not useful and low eHL in most domains. However, determining the causal relationship is complex: does a perceived lack of usefulness affect one's motivation to use eHealth, or does the inability to use eHealth make it challenging to view it as useful? These factors are likely to be intertwined, with the individual's perception of usefulness and level of eHL mutually reinforcing each other. Previous studies confirm that the perceived usefulness of eHealth utilisation is strongly correlated with eHealth service usage and eHL (Deshpande et al., 2023; Heponiemi et al., 2020; Jokisch et al., 2022; Van Deursen and Helsper, 2015; Wilson et al., 2021).

A substantial number of studies and interventions aimed at enhancing eHL have primarily focused on individual capabilities, such as the ability to use the Internet and digital technology, comprehend health information and critically analyse data. However, it is important to remember that, at the core of eHealth usage, a person must be motivated to engage with eHealth and must have a sense of its usefulness. Furthermore, eHL is not a static concept but fluctuates due to various concurrent factors such as life circumstances, health conditions, needs and motivation. If individuals experience multiple factors working against them, these factors will likely reinforce each other, creating significant barriers to digital inclusion (Basis Social & Good Things Foundation, 2022). Given today's rapidly evolving digital landscape, it is also essential to consider digital learning as a lifelong process (Swedish eHealth Agency, 2020a). As frontline healthcare professionals who frequently interact with patients, PHNs and other nurses can play a key role in motivating patients to adopt eHealth. This can be achieved by normalising eHealth ('people like me use it'), identifying barriers to usage and explaining how eHealth can benefit each patient's specific needs. However, it is important to remember that eHealth is not a replacement of but rather a complement to

traditional healthcare, and some individuals may choose not to utilise digital healthcare options. Therefore, eHealth should not be imposed on patients; instead, PHNs are suggested to facilitate the use of eHealth by those with genuine interest and need.

## New roles for patients and healthcare professionals in the digital era

The PHNs in paper I agreed with the societal vision of eHealth as a means of promoting more independent, active and informed patients and an expanded person-centred PHC. The benefits of patient engagement with HRII were illustrated by informative and efficient healthcare encounters, reduced PHN workload through increased patient self-care, and fewer unnecessary PHC visits. However, according to the PHNs, consultations with Internet-informed patients were not without challenges. Due to inaccurate HRII, misinterpretation of information, and patients often assuming an expert role, there were more unnecessary and time-consuming consultations, disagreements between patients and PHNs, and dissatisfied patients; moreover, the PHNs reported feeling potentially redundant. These experiences are shared by healthcare professionals in other studies (Caiata-Zufferey and Schulz, 2012; Tanis et al., 2016; Townsend et al., 2015; Walker and Sillence, 2023).

Nevertheless, the increasing knowledge and engagement of patients have undeniably led to a transformation of traditional roles and power dynamics within healthcare. It has been suggested that the previous model, in which professionals monopolised knowledge, is being replaced by a model in which they function more as partners in patient care (Ekman et al., 2011, Farnood et al., 2020; Skär and Söderberg, 2018). How this shift influenced the PHNs' attitudes in this thesis is challenging to assess. However, it is important to note that the literature indicates that patients primarily engage in HRII searches to foster a collaborative relationship with healthcare professionals, rather than seeking to challenge or contradict them (Farnood

et al., 2020). Moreover, research demonstrates that, while patients may seek HRII independently, healthcare professionals are still considered to be the most reliable and a highly valued source of information (Farnood et al., 2020; Townsend et al., 2015). Despite their perceived frustration, the PHNs in this thesis emphasised that they attempted to listen to the patient, while respectfully explaining their reasoning (paper I). The PHNs also described that – due to more informed and engaged patients – their professional roles had transitioned into a coaching role rather than solely focusing on controlling patients' compliance. This shift is in line with PCC. The nurses' coaching encompassed elements such as providing reassurance, emotional support and counselling; normalising experiences and dispelling fears; and guiding patients to trustworthy websites such as 1177.se (Ekman et al., 2011; Farnood et al., 2020; Skär and Söderberg, 2018).

Previous research has indicated that many patients refrain from sharing their HRII findings with PHNs out of fear that doing so may be perceived as questioning and may thus challenge the patient-nurse relationship (Gilmour et al., 2016). This is unfortunate, as it deprives PHNs of the opportunity to contextualise HRII within the patient's situation, correct inaccuracies when necessary, and guide the patient to more reliable sources. Instead of feeling challenged by Internet-informed patients, PHNs should actively encourage patients to share their gathered information and should express that eHealth and traditional healthcare can positively complement each other. The Swedish Nursing Association has established an eHealth strategy that emphasises the necessity for nurses to possess the competences required to offer patients professional guidance on HRII. This strategy report underlines the pivotal role nurses play in preventing digital exclusion (Swenurse, 2019b). As PHNs are often the patient's initial point of contact for healthcare needs, these nurses are in an excellent position to identify barriers to eHealth usage, promote source criticality and refer to credible HRII. Thus, it is crucial for PHNs themselves to possess adequate eHL. Patients' encounters with healthcare professionals that have limited eHL and a conventional, provider-

led approach can potentially lead to relationships that are not trusted by patients (Marston and Musselwhite, 2021). Furthermore, studies have demonstrated that nurses with greater confidence and competence in eHealth exhibit more positive attitudes towards Internet-informed patients (Barnoy et al., 2009, 2011)

In line with prior research, the PHNs in this thesis (paper I) perceived that Internet-informed patients had altered the nurses' role by placing high expectations on them; this gave the PHNs the opportunity to expand their knowledge and thereby avoid feeling incompetent. While this change in their role may positively motivate PHNs to stay updated with the latest evidence and reliable HRII sources, it may also contribute to heightened stress within an already demanding work environment (Ahluwalia et al., 2010; Lu & Schulz, 2023; Öberg et al., 2017; Townsend et al., 2015). In a PHC setting that is increasingly advocating for eHealth usage, finding a balance between digital and physical care is imperative. For example, older individuals may express a positive attitude towards eHealth but still highly value personal relationships with PHNs and the option of physical healthcare appointments – a preference associated with the practical and emotional support that is challenging to obtain digitally. Furthermore, a robust, trusting relationship between PHNs and patients has been shown to be important for patients to use eHealth services (Lindberg et al., 2021).

## Nurses' role as facilitators

Finally, I return here to the Umeå Model of Nursing Care and consider it in relation to the findings of this thesis, supported by relevant literature. With societal advancements, challenges, policies and economics, significant expectations have been placed on citizens' utilisation of eHealth. In their role as close and often initial contacts for many patients seeking care, PHNs are considered to be well-positioned to facilitate people's use of eHealth services, including HRII. In this thesis, the interviewed PHNs viewed patients from a person-centred and holistic perspective, acknowledging that different

patients have varying physical and mental health, needs, digital capabilities, motivation for eHealth use, confidence and so forth. These factors may change from one situation to another, so nothing in PHC can be regarded as static, and everything is context-bound to some extent. Through respectful interactions, patients should be encouraged to openly discuss their HRII findings and eHealth usage, in order to receive support, guidance and motivation tailored to their situation. Patients' relatives can act as an extension of the patient, as their abilities may compensate for the patient's low eHL or assist the patient in interpreting HRII. Along with patients and their relatives – and possibly other healthcare team members – PHNs must strive to help patients achieve good health, assist them to actively engage in their own health, and provide support with eHealth services if the patient desires it, all within a collaborative partnership. An ethical approach must guide every aspect of healthcare.

## Methodological considerations

The potential for selection bias was an important consideration throughout all four studies in this thesis; that is individuals with a positive inclination towards eHealth and health-related information acquisition may have been more likely to agree to participate in this research. Moreover, those with particularly strong opinions on the topic or high self-confidence in their abilities may have been overrepresented in the sample. Furthermore, the study includes only Swedish-speaking individuals, thereby excluding non-Swedish speakers who likely face even greater challenges in navigating the Swedish eHealth system.

It is also important to contextualize this thesis and its studies within the timeline of data collection and analysis. The research in paper I was conducted before the COVID-19 pandemic, while the data for the remaining three papers were collected during the first year of the pandemic. As previously discussed, the pandemic has accelerated and led to an increase in eHealth usage, likely resulting in improved abilities and heightened motivation for eHealth utilization. Furthermore, the substantial burden on PHC services during the pandemic posed data-collection challenges, particularly for papers III and IV, as two PHC centres withdrew their participation, receptionists could not document questionnaire distribution or refusals, and the data-collection period was limited to 2 weeks.

In the measurement of eHL in papers II, III and IV, it is important to recognize that the questionnaires assess individuals' *self-perceived* skills and self-confidence, rather than their *actual* demonstrated abilities in using eHealth services. Thus, there is potential for individuals to either underestimate or overestimate their abilities.

### **Paper I**

While the number of participants in paper I may be considered relatively low, most of the interviews were extensive, and their content was rich, profound and diverse – qualities often considered more important than the quantity of



data (Fusch and Ness, 2015; Malterud et al., 2016). Since the last two interviews did not provide essential additional information, it was determined that there was a sufficient amount of data to support meaningful and robust conclusions (Lincoln and Guba, 1985).

The participating PHNs exhibited diversity in terms of age and years of professional experience, which bolsters the credibility and transferability of our findings (Graneheim et al., 2017). One potential limitation to consider is that all participating PHNs were women. Nevertheless, it is important to note that the majority of Swedish PHNs are female, as reported by the National Board of Health and Welfare (2021). This demographic representation enhances the relevance and applicability of the study's findings within the specific context.

Four of the researchers, including myself, are PHNs. Thus, we entered the interviews in paper I with our own understanding of PHNs' thinking and situation. Interviewing fellow PHNs with this prior understanding had both advantages and disadvantages. One drawback was the potential lack of the distance needed to maintain objectivity (McEvoy, 2001). An interviewer who already has insight into the situation might unintentionally overlook the need to ask about what they consider to be self-evident; similarly, the interviewee may assume that the interviewer already knows the answers (McDermid et al., 2014; McEvoy, 2001). However, our insight as PHNs also offered advantages, such as a deeper understanding of the interviewee's experiences, which made it possible to pose relevant follow-up questions during the interview (McEvoy, 2001; Kvale and Brinkmann, 2014). One way to manage the impact of the researchers' preunderstanding was to continuously reflect upon and discuss it with my co-authors. In addition, after conducting the interviews, we listened to the recordings and transcribed them on the same day to carry over the reflections and lessons learned into the subsequent interviews.

## **Paper II**

In comparison with interviews, free-text data can yield less robust narratives from participants, which was a limitation of paper II. Nevertheless, likely due to the considerable interest surrounding information during the early stages of the COVID-19 pandemic, many participants provided responses that were extensive and highly detailed. One advantage of free-text responses over interviews can be the anonymity they afford, which may encourage individuals to participate and open up in a different manner. Since similar questions were posed in the questionnaires and interviews, even though the latter naturally allowed for more in-depth exploration and elaboration of responses, no issues were encountered in co-analysing the data.

Due to pandemic-related social distancing regulations, the interviews were conducted over the phone. The use of video calls was excluded because we aimed to maintain consistency in the interview format and did not want to exclude those who might have difficulty with video calls, particularly given the study's digital focus. A drawback of phone interviews is the potential loss of important non-verbal cues and body language from the interviewee (Garbett and McCormack, 2001). On the other hand, an advantage of phone interviews is that they can lead to increased disclosure and, consequently, richer data (Holt, 2010; Novick, 2008). Moreover, phone interviews can aid in participant accessibility, as this method is more flexible in terms of timing and location (Holt, 2010).

Utilizing quantitative data within qualitative studies is unconventional; nevertheless, due to our sample size and the depth of our data, we deemed it appropriate to incorporate this dimension, albeit solely in the discussion section of the article. Including information about the participants' eHL in the quotations and discussions on whether certain challenges or strategies were more common in one of the groups was regarded as a relevant complement in the article. Maxwell (2010) enumerates several advantages of incorporating quantitative data into qualitative research, such as enhancing

internal generalization, facilitating the identification of diversity within the study group, and providing supportive evidence for data interpretation.

The mean age of the participants was relatively high, and they were primarily of Swedish origin with high levels of education, which may have affected the results. However, a strength of this study was the even distribution between women and men.

### **Trustworthiness in qualitative analysis (papers I and II)**

Knowledge from interviews is co-created through the interaction between the interviewer and interviewee – a collaborative process of constructing meaning (Garton and Copland, 2010; Kvale and Brinkmann, 2014). Given the interpretive nature of qualitative research and the potential for biased interpretations, researchers must adopt a reflexive methodology. This approach emphasizes self-awareness, acknowledges the influence of the researchers' perspectives on knowledge creation, and rigorously monitors the impact of researchers' biases, beliefs and personal experiences on the research. I consistently considered my preunderstanding, values, presumptions and personal experiences at all stages of the research, especially as a nurse engaged in qualitative research, which necessitated mindfulness of my dual roles when conducting interviews (Sanjari et al., 2014). In paper I, four of the authors were PHNs, which necessitated a focus on reflexivity throughout the research process. While our familiarity with the participants' work situations could enhance our understanding, we took care not to impose our own assumptions and biases during the data collection and analysis (Berger, 2015).

As qualitative research gains recognition and importance, rigor in conducting it becomes essential for producing meaningful results. Trustworthiness, which relates to the credibility, reliability and validity of a study's results, interpretations and outcomes, is a fundamental concern across all phases of qualitative research, including preparation, data collection, analysis and reporting. This ensures that the findings accurately represent the

participants' experiences and the phenomena being studied. Utilizing well-defined analytical methods, such as qualitative content analysis (paper I) and thematic analysis (paper II), enhances trustworthiness by making the research process more transparent, consistent and reproducible (Clarke et al., 2015; Graneheim and Lundman, 2004). Important key terms when addressing trustworthiness are credibility, dependability, confirmability, transferability and authenticity (Lincoln and Guba, 1985). Credibility in qualitative research pertains to how faithfully the findings represent the participants' experiences and viewpoints, minimizing the potential for bias and misinterpretation (Polit and Beck, 2020). In this thesis, ensuring credibility involved having regular meetings during the analysis stages with the research team, which included members with extensive expertise in qualitative research methodology (Lincoln and Guba, 1985; Polit and Beck, 2020). Moreover, in the study reports, I offer a detailed description of the analysis methods, participants and data-collection context (Nowell et al., 2017). Including participant quotations in my qualitative findings reporting also enhances credibility (Elo et al., 2014).

To help readers assess the dependability and transferability of this research, I have explained the research processes, participants and contexts clearly, as suggested by Lincoln and Guba (1985). According to Lincoln and Guba (1985), confirmability – which ensures that the researcher's interpretations and findings are solely drawn from the data – is achieved when the criteria of credibility, transferability and dependability are met.

### **Paper III**

The strength of paper III, a validation study, lies in its use of both qualitative and quantitative methods to systematically assess evidence sources, thereby supporting validity (Hawkins et al., 2018). During the eHLQ translation and cultural adaptation phase, the systematic approach and explicit item intent descriptions (TIP) preserved equivalence with the source language. This increased the likelihood that the translated questionnaire effectively measures

the same constructs when used for the same purpose and in the same context. Continuous group discussions with eHealth and language experts, including an eHLQ developer, further strengthened the credibility of the results (Hawkins et al., 2018).

Due to the pandemic, this study suffered from a significantly lower number of participants than originally anticipated; moreover, it was not possible to calculate a response rate. These issues are limitations of the study. However, the number of participants was still considered to be entirely sufficient to conduct a factor analysis (MacCallum et al., 1999). Furthermore, since the instrument was built on a strong theoretical foundation and had been researched in various contexts, the number of participants was considered sufficient (Chen et al., 2022; Kayser et al., 2018; Norgaard et al., 2015).

Employing both Internet-based and paper-based questionnaires might have increased the sample size, but we chose to prioritize consistency and simplicity by exclusively using paper-based questionnaires. This decision aligns with our focus on Internet use and eHL abilities. Nonetheless, we recommend testing Internet-based versions of the eHLQ in the future. Another limitation was that, due to time constraints, we could not conduct a test-retest assessment.

#### **Paper IV**

In paper IV, the sample of PHC visitors displayed diversity across educational levels, genders, ages and work statuses. While this diversity may not precisely mirror the national average, it does reflect a generally diverse sample. However, it is important to note that this diversity primarily comprised Swedish-speaking individuals, inadvertently excluding a significant portion of the population that is not proficient in this language. This limitation poses challenges to the external validity of the findings, making their generalizability to non-Swedish speakers less straightforward.

Moreover, the dichotomization of eHL scores into 'low' and 'high' categories, using a threshold of 2.50, may have introduced subjectivity into

the analysis. The distinction between individuals with a score of 2.49 (categorized as “low”) and those with a score of 2.50 (categorized as ‘high’) may be statistically significant but is not necessarily clinically meaningful. This threshold simplifies analysis but may not fully capture the nuanced nature of eHL. Nevertheless, dichotomization streamlines data analysis, enhancing interpretability (Naggara, 2011).

An important consideration within the limitations of this study pertains to the significant  $p$  values observed in the comparative analyses, which were conducted to assess the relationships between eHL and various sociodemographic and Internet-related variables. While these significant findings provide valuable insights into potential associations, it is important to recognize the risk of Type I errors in multiple hypothesis testing, given the multitude of variables examined (Banerjee et al., 2009). To mitigate this risk, we subsequently included all relevant variables in a logistic regression model, retaining only those that remained statistically significant. The purpose of this step was to refine the analysis and focus on the most influential factors.

## Ethical considerations

All the research in this thesis adhered to the ethical principles for medical research involving human subjects as outlined in the Declaration of Helsinki (World Medical Association, 2013). Ethical approval was granted by The Regional Ethical Review Board at Umeå University (no. 2014-179-31M) and The Swedish Ethical Review Authority (no. 2019-0341), and included a complementary application regarding expanded data collection. Moreover, written consent was obtained from the healthcare director in the county and the head managers of all PHC centres prior to the questionnaire data collection. The participants in the four studies were informed about the study's background, methodology, objectives, publication and confidentiality. They were also informed about the voluntary nature of their participation and their ability to withdraw from the study at any time without providing a reason.

The core of the ethical principles of research is that research must be beneficial and do no harm (World Medical Association, 2013). I consider my research to be beneficial for both patients and healthcare in general, as the knowledge gained has the potential to facilitate widespread eHealth adoption. In terms of the principle of doing no harm, the research conducted for this thesis carries no serious risks. Nevertheless, the research involved sensitive data, including health-related inquiries such as medical history and diagnoses, and personal information such as names and voice recordings. Thus, it was important to prioritize data protection (European Union Parliament, 2016; Swedish Government, 2003; World Medical Association, 2013). To this end, I implemented several measures to ensure participant identity confidentiality, including replacing identifying information with separate codes. In addition, the audio recordings, transcribed interviews and code keys were stored in password-protected files and on locked in USB drives. The paper questionnaires were also securely stored. Confidentiality was also maintained

in the reporting phase of the papers by ensuring that no text – including the quotations – could be linked to a specific participant.

Another potential risk is that the interview context may induce emotional stress among participants. In the two qualitative studies (papers I and II), this stress may have been associated with the discomfort of discussing one's health, feelings of shame due to inadequate eHealth knowledge, or the fear of expressing negative healthcare experiences in the presence of an interviewing PHN. With this in mind, I put importance on creating a secure and relaxed atmosphere as an interviewer, providing the interviewees with the information that answering any of the questions was voluntary.



## Implications for practice

Based on the research conducted for this thesis, PHNs and other healthcare professionals with close patient contact are suggested to:

- Actively engage in dialogue about the patient's obtained HRII in order to gain the opportunity during consultations to refer patients to reliable websites and correct potential misconceptions;
- Encourage patients to apply critical thinking and to consult healthcare professionals regarding concerns arising from HRII, whether sourced from news media, social media or advertising;
- Always maintain respectful conversation, even in the presence of potential disagreement, and acknowledge patients' efforts to acquire and present HRII, with the aim of encouraging patients to continue sharing gathered information and to gain the opportunity to contextualise such information within the patient's situation, thereby avoiding confusion or unnecessary concern;
- Ensure that they themselves possess adequate eHL and stay updated on evidence-based websites from trusted sources in order to assist patients in increasing their eHL and be able to recommend reliable websites;
- Recognise that a patient's eHL may fluctuate based on various circumstances and engage in dialogue with patients about potential barriers to eHealth usage, with the awareness that these barriers may not only be practical but can also involve a lack of motivation. Based on existing barriers, appropriate actions can be taken, such as motivating appropriately, recommending easily accessible information or suggesting existing eHL training initiatives in the community;
- Encourage patients to seek support from their social network to assist them in using eHealth services and critically evaluating HRII;
- Maintain a balance between digital and traditional healthcare methods, while recognizing various patients' unique healthcare and information needs and preferences.

Moreover, healthcare authorities and eHealth-service developers are suggested to:

- Provide easily accessible HRII that is consistently updated with the latest findings and recommendations and is presented in a universally understandable manner to accommodate individuals with varying levels of eHL;
- Educate the public about the risks of misinformation and the importance of critical thinking;
- Involve end-users in the planning and development of new eHealth services and, when developing eHealth services, take a broad perspective on people's different circumstances, allowing for adaptations to various needs;
- Recognize that there will always be a group of individuals who prefer and can only manage traditional healthcare interactions and communication. Therefore, this option must be maintained alongside eHealth services.

## Future research

During the research in this thesis, new aspects that would be interesting to explore gradually emerged. To gain a broader understanding of eHL based on the seven domains of eHLQ, it would be valuable to conduct studies with a significantly larger sample of PHC visitors. Moreover, to enable digital inclusion for everyone, studies must be conducted that focus on groups that are particularly vulnerable to digital exclusion and that tend to have low eHL, such as older individuals, immigrants, people in rural areas and people with various types of disabilities. It would also be interesting to conduct studies comparing the eHLQ with other eHL instruments, such as the eHEALS, to see how well the results correlate and to discover differences and similarities regarding which aspects of eHL they assess. Finally, since PHNs play an important role in supporting patients to increase their eHL within the expanding digitisation of PHC, PHNs' eHL should also be explored. Using the customised eHLQ to assess health personnel can reveal domains in which PHNs may require support or development.

# Conclusions

This thesis contributes to the existing knowledge of what may facilitate society's pursuit of Close Care, increased person-centeredness and digitalisation in a PHC context. In this research, inaccurate and excessive HRII was described by PHNs and patients as the cause of confusion and anxiety on the part of patients and as leading to time-consuming, unnecessary and conflicted consultations. The findings from this thesis suggest that it would be beneficial for PHNs to actively discuss HRII findings and search behaviours with patients, identify potential barriers to eHealth usage and provide referrals to reliable websites.

The older PHC visitors in this study indicated that eHealth services did not suit their individual needs and that they had little motivation and low ability to use digital technology and to understand or utilise HRII. In light of this finding, this thesis proposes the increased inclusion of end-users in the development of eHealth services, the provision of opportunities for customisation based on HRII and eHealth service needs, and active efforts on the part of healthcare professionals to motivate patients while suggesting ways to facilitate individuals' ability to use digital technology and engage in eHealth utilisation.

## Acknowledgements

Jag vill rikta mitt varmaste tack till alla som hjälpt, stöttat och inspirerat mig under skrivandet av denna avhandling. Ett särskilt tack till:

**Samtliga deltagare** i mina studier som generöst har avsatt tid för intervjuer eller ifyllande av frågeformulär. Utan er hade denna avhandling inte varit möjlig.

Min huvudhandledare, **Ulf Isaksson**, för att du inspirerat med din egen entusiasm för forskning, statistik och undervisning. Tack för ovärderliga kunskaper, minnesvärda statistikliknelser, vänlighet, visat tålamod och för att din dörr alltid stått öppen. Jag har uppskattat den tydliga vägledning du gett, samtidigt som jag fått utrymme för frihet och egna idéer. Tack för att jag fick möjligheten att bli doktorand; det var lika fantastiskt som jag hade hoppats på!

Min bihandledare **Senada Hajdarevic**, för att du är en fantastisk förebild, både som forskare och människa! Den perfekta harmonin mellan din intelligens, klarsynthet och tydlighet, och din varma och uppmuntrande natur, har varit ovärderlig. Tack för allt du har lärt mig och för din genuina omtanke!

Min bihandledare **Åsa Hörnsten**, tack för att du var min inspirationskälla till att vilja forska och för att du trodde på mig! Tack för att jag har fått ta del av din briljanta hjärna, dina rappa kommentarer och dina omfattande kunskaper, särskilt inom kvalitativ metod. Din konstanta uppmuntran har varit väldigt värdefull.

**Ulrika Öberg**, för att jag fick vara en del av ditt projekt och att du tog mig under dina vingar när jag var ny doktorand. Ditt varma välkomnande gjorde att allt kändes extra tryggt och trevligt.

**Agneta Emmoth**; Du och jag, kaffe, lakrits och energidryck – mycket trevligare blir inte bibliotekshäng. Umeå saknar dig!

**Ólöf Kristjánsdóttir** and **Charlotte Castor**, thank you for the good and pleasant collaboration and conversations regarding the eHLQ study.

**Lars Kayser**, for din venlighed og ægte ønske om at hjælpe, samt din uvurderlige støtte under arbejdet med eHLQ.

**Britt-Marie Lindgren**, min examinator, för goda råd och stöd under hela doktorandtiden.

**Monica Krenchel**, för närvaro, stöd och omtanke. Du har verkligen varit den rätta personen på rätt plats.

**Rebecca Baxter**, för att du tog dig tid att hjälpa mig med akut språkgranskning. Du är oerhört omtänksam!

**Samtliga doktorandkollegor** från förr och nu, det börjar bli många. Ni har varit ovärderliga. Tack för alla skratt, tårar, och såväl forskningsmässiga som personliga samtal.

**Arbetskamrater** vid institutionen, för trevliga stunder, goda samtal och värdefull feedback vid seminarier.

**Mina fina vänner**, ni betyder så oerhört mycket. Tack för att ni har haft tålamod och fortsatt höra av er, även när jag tidvis gått i ide.

**Cecilia Hultstrand**, för att just Du fanns där i doktorandrummet för några år sedan! Tack för att jag har fått dela med- och motgångar med dig. Du är en fantastiskt omtänksam, klok och rolig vän samt ett stort stöd på alla plan!

**Ida Hedman**, syster of my soul, för din ovärderliga vänskap, din visdom, ditt ovillkorliga stöd, och ditt genuina intresse för *allt* jag berättar om.

**Ida Johansson** med det största hjärtat; för ändlösa mängder chokladkakor, blombuketter, skratt och samtal på låtsasdanska, samt för att jag vet ända in i hjärteroten att du alltid stöttar och finns vid min sida.

**Jenny Rudälv**, min allra äldsta vän; för att du i drygt 40 år bidragit med en massa värme, trygghet, äkthet, glädje, goda råd och inspiration i mitt liv. Du är verkligen en skatt!

**Maria Mistry**, min fantastiska vän, för din klokhet, saklighet, ditt smittande lugn och för trevliga luncher. Jag är så glad att du finns i mitt liv.

**Mamma**, för att du alltid finns där för mig och barnen med såväl kärlek som praktiskt stöd. Utan dig hade denna avhandling inte kunnat skrivas.

**Pappa och Anna**, för er varma omtanke i ord och handling. Jag kan inte sätta ord på hur värdefullt det har varit!

**Mina systrar: Linda**, tack för att du inspirerar mig med din kombination av klokhet, kreativitet och underfundiga humor. **Elin**, tack för allt som din oupphörliga omtanke och hjälpsamhet tillför i mitt liv samt för allt du lär mig. Er styrka inspirerar, och ni är jätteviktiga för mig!

**Alva**, för att du alltid peppat mig och för att du från första stunden vi möttes har berikat mitt liv med dina otaliga, alldeles fantastiska egenskaper. Du betyder massor för mig!

Mina barn **Nils** och **Maja**. Ni är viktigast i hela världen och mitt allt. Jag är SÅ tacksam för att jag fick gåvan att bli just er mamma. Jag älskar er så mycket!

Denna avhandling har finansierats med stöd från Svenska Diabetesförbundet, Strategiska Forskningsområdet–Vårdvetenskap (SFO-V), och Forskningsrådet för hälsa, arbetsliv och välfärd, (Forte). Dessutom har ytterligare medel erhållits från Stiftelsen J C Kempes Minnes Stipendiefond och Svensk Sjuksköterskeförening.

## References

- Abreu, L., Nunes, J. A., Taylor, P. & Silva, S. 2018. Distributed health literacy among people living with type 2 diabetes in Portugal: defining levels of awareness and support. *Health Soc Care Community*, 26, 90-101.
- Ahluwalia, S., Murray, E., Stevenson, F., Kerr, C. & Burns, J. 2010. 'A heartbeat moment': qualitative study of GP views of patients bringing health information from the Internet to a consultation. *Br J Gen Pract*, 60, 88-94.
- Ahmad, F., Hudak, P. L., Bercovitz, K., Hollenberg, E. & Levinson, W. 2006. Are physicians ready for patients with Internet-based health information? *J Med Internet Res*, 8, e22.
- Aponte, J. & Nokes, K. M. 2017. Electronic health literacy of older Hispanics with diabetes. *Health Promot Int*, 32, 482-489.
- Azzopardi-Muscat, N. & Sørensen, K. 2019. Towards an equitable digital public health era: promoting equity through a health literacy perspective. *Eur J Public Health*, 29, 13-17.
- Banerjee, A., Chitnis, U., Jadhav, S., Bhawalkar, J. & Chaudhury, S. 2009. Hypothesis testing, type I and type II errors. *Ind Psychiatry J*, 18, 127.
- Barnoy, S., Volfin-Pruss, D., Ehrenfeld, M. & Kushnir, T. 2009. Nurses' attitudes towards the informed patient. *Stud Health Technol Inform*, 146, 396-399.
- Barnoy, S., Volfin-pruss, D., Ehrenfeld, M. & Kushnir, T. 2011. Self-epistemic authority and nurses' reactions to medical information that is retrieved from Internet sites of different credibility. *Nurs Health Sci*, 13, 366-370.
- Bashshur, R. L., Howell, J. D., Krupinski, E. A., Harms, K. M., Bashshur, N. & Doarn, C. R. 2016. The empirical foundations of telemedicine interventions in primary care. *Telemed e-Health*, 22, 342-375.
- Basis Social & Good Things Foundation. 2022. *Increasing Motivation to use Digital Health and Social Care Services: A Behavioural Science Perspective* [Online]. Available: <https://www.basisresearch.com/nhs-england-digital-inclusion> [Accessed 25 Nov 2023]
- Beatty, P. C. & Willis, G. B. 2007. Research synthesis: the practice of cognitive interviewing. *Public Opin Q*, 71, 287-311.
- Berger, R. 2015. Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qual Res*, 15, 219-234.
- Bergman, L., Nilsson, U., Dahlberg, K., Jaansson, M. & Wångdahl, J. 2021. Health literacy and e-health literacy among Arabic-speaking migrants in Sweden: a cross-sectional study. *BMC Public Health*, 21, 1-12.
- Boström, E., Hörnsten, Å., Persson, C., Rising, I., Fischer, R. S. 2012. Clinical challenges and ongoing role changes for primary health-care nurses. *Br J Community Nurs*, 17, 68-74.
- Bradshaw, A. S., Shelton, S. S., Wollney, E., Treise, D. & Auguste, K. 2021. Pro-vaxxers get out: anti-vaccination advocates influence undecided first-time, pregnant, and new mothers on Facebook. *Health Commun*, 36, 693-702.



- Braun, V. & Clarke, V. 2006. Using thematic analysis in psychology. *Qual Res Psychol*, 3, 77-101.
- Byrne, A.-L., Baldwin, A. & Harvey, C. 2020. Whose centre is it anyway? Defining person-centred care in nursing: an integrative review. *PLoS One*, 15, e0229923.
- Caiata-Zufferey, M. & Schulz, P. 2012. Physicians' communicative strategies in interacting with Internet-informed patients: results from a qualitative study. *Health Commun*, 27, 738-749.
- Calvillo-Arbizu, J., Roa-Romero, L. M., Estudillo-Valderrama, M. A., Salgueira-Lazo, M., Aresté-Fosalba, N., Del-Castillo-Rodríguez, N. L., González-Cabrera, F., Marrero-Robayna, S., López-De-La-Manzana, V. & Román-Martínez, I. 2019. User-centred design for developing e-Health system for renal patients at home (AppNephro). *Int J Med Inform*, 125, 47-54.
- Calvillo, J., Roman, I. & Roa, L. M. 2015. How technology is empowering patients? A literature review. *Health Expect*, 18, 643-652.
- Cederberg, M., Alsén, S., Ali, L., Ekman, I., Glise, K., Jonsdottir, I. H., Gyllensten, H., Swedberg, K. & Fors, A. 2022. Effects of a person-centered eHealth intervention for patients on sick leave due to common mental disorders (PROMISE Study): open randomized controlled trial. *JMIR Ment Health*, 9, e30966.
- Chang, S. J., Jang, S. J., Lee, H. & Kim, H. 2021. Building on evidence to improve eHealth literacy in older adults: a systematic review. *Comput Inform Nurs*, 39, 241-247.
- Chen, Y.-C., Cheng, C., Osborne, R. H., Kayser, L., Liu, C.-Y. & Chang, L.-C. 2022. Validity testing and cultural adaptation of the eHealth literacy questionnaire (eHLQ) among people with chronic diseases in Taiwan: mixed methods study. *J Med Internet Res*, 24, e32855.
- Cheng, C., Gearon, E., Hawkins, M., McPhee, C., Hanna, L., Batterham, R. & Osborne, R. H. 2022. Digital health literacy as a predictor of awareness, engagement, and use of a national web-based personal health record: population-based survey study. *J Med Internet Res*, 24, e35772.
- Chu, J. T., Wang, M. P., Shen, C., Viswanath, K., Lam, T. H. & Chan, S. S. C. 2017. How, when and why people seek health information online: qualitative study in Hong Kong. *Interact Med*, 6, e7000.
- Clarke, V., Braun, V. & Hayfield, N. 2015. Thematic Analysis. In: Smith, J. A. (ed.), *Qualitative Psychology: A Practical Guide to Research Methods* (222-248). London: Sage Publications.
- Cohen, J. 1988. *Statistical Power Analysis for the Behavioral Science*. New York: Taylor & Francis Group.
- Corcelles, R., Daigle, C. R., Talamas, H. R., Brethauer, S. A. & Schauer, P. R. 2015. Assessment of the quality of Internet information on sleeve gastrectomy. *Surg Obes Relat Dis*, 11, 539-544.
- Creswell, J. W. & Poth, C. N. 2016. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches*. Thousand Oaks CA: Sage Publications.

- Cuan-Baltazar, J. Y., Muñoz-Perez, M. J., Robledo-Vega, C., Pérez-Zepeda, M. F. & Soto-Vega, E. 2020. Misinformation of COVID-19 on the Internet: infodemiology study. *JMIR Public Health Surveill*, 6, e18444.
- Deshpande, N., Arora, V. M., Vollbrecht, H., Meltzer, D. O. & PRESS, V. 2023. eHealth literacy and patient portal use and attitudes: cross-sectional observational study. *JMIR Hum Factors*, 10, e40105.
- Directorate Of eHealth. 2023. *Comparative Analysis 2023: National Health Portals in the Nordics* [Online]. Directorate of eHealth. Available: <https://www.ehelse.no> [Accessed 15 Nov 2023].
- Dolan, S., Nowell, L. & McCaffrey, G. 2022. Pragmatism as a philosophical foundation to integrate education, practice, research and policy across the nursing profession. *J Adv Nurs*, 78, e118-e129.
- Edvardsson, D., Winblad, B. & Sandman, P. O. 2008. Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurol*, 7, 362-367.
- Ekman, I., Swedberg, K., Taft, C., Lindseth, A., Norberg, A., Brink, E., Carlsson, J., Dahlin-Ivanoff, S., Johansson, I.-L. & Kjellgren, K. 2011. Person-centered care – ready for prime time. *Eur J Cardiovasc Nurs*, 10, 248-251.
- El Sherif, R., Pluye, P., Thoer, C. & Rodriguez, C. 2018. Reducing negative outcomes of online consumer health information: qualitative interpretive study with clinicians, librarians, and consumers. *J Med Internet Res*, 20, e169.
- Elnaggar, A., Ta Park, V., Lee, S. J., Bender, M., Siegmund, L. A. & Park, L. G. 2020. Patients' use of social media for diabetes self-care: systematic review. *J Med Internet Res*, 22, e14209.
- Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K. & Kyngäs, H. 2014. Qualitative content analysis: a focus on trustworthiness. *SAGE Open*, 4.
- European Commission. 2014. *European Citizens' Digital Health Literacy – Report* [Online]. European Commission. Available: <https://op.europa.eu/en/publication-detail/-/publication/fd42f9e7-937c-41f3-bf03-4221b2db712b> [Accessed 20 Nov 2023].
- European Union Parliament. 2016. *General Data Protection Regulation* (EU 2016/679).
- Eurostat. 2021. *One in Two EU Citizens Look for Health Information Online* [Online]. European Commission. Available: <https://ec.europa.eu/eurostat/web/products-eurostat-news/-/edn-20210406-1> [Accessed 1 Nov, 2023].
- Eysenbach, G., & Jadad, A. R. 2001. Evidence-based patient choice and consumer health informatics in the Internet age. *J Med Internet Res*, 3(2), e841.
- Farnood, A., Johnston, B. & Mair, F. S. 2020. A mixed methods systematic review of the effects of patient online self-diagnosing in the 'smart-phone society' on the healthcare professional-patient relationship and medical authority. *BMC Medical Inform Decis Mak*, 20, 1-14.
- Foss, C. & Ellefsen, B. 2002. The value of combining qualitative and quantitative approaches in nursing research by means of method triangulation. *J Adv Nurs*, 40, 242-248.

- Fox, S., Duggan, M. 2013. *Health Online 2013* [Online]. Pew Research Center. <https://www.pewresearch.org/internet/2013/01/15/health-online-2013/> [Accessed May 10, 2018].
- Frey, E., Bonfiglioli, C., Brunner, M. & Frawley, J. 2022. Parents' use of social media as a health information source for their children: a scoping review. *Acad Pediatr*, 22, 526-539.
- Fusch, P. I. & Ness, L. 2015. Are we there yet? Data saturation in qualitative research. *Qual Rep*, 20, 1408-1416.
- Garbett, R. & McCormack, B. 2001. The experience of practice development: an exploratory telephone interview study. *J Clin Nurs*, 10, 94-102.
- García-García, D., Ajejas Bazán, M. J. & Pérez-Rivas, F. J. 2022. Factors influencing eHealth literacy among Spanish primary healthcare users: cross-sectional study. *Int J Environ Res Public Health*, 19, 15497.
- Garton, S. & Copland, F. 2010. 'I like this interview; I get cakes and cats!': The effect of prior relationships on interview talk. *Qual Res*, 10, 533-551.
- Georgiou, A. & Prgomet, M. 2019. *E-health: Developing Trust, Confidence, Quality and Sustainability*. London: SAGE Publications.
- Ghazi, S. N., Berner, J., Anderberg, P. & Sanmartin Berglund, J. 2023. The prevalence of eHealth literacy and its relationship with perceived health status and psychological distress during Covid-19: a cross-sectional study of older adults in Blekinge, Sweden. *BMC Geriatr*, 23, 5.
- Gilmour, J., Strong, A., Chan, H., Hanna, S. & Huntington, A. 2016. Primary healthcare nurses and Internet health information-seeking: Access, barriers and quality checks. *Int J Nurs Pract*, 22, 53-60.
- Golinelli, D., Boetto, E., Carullo, G., Nuzzolese, A. G., Landini, M. P. & Fantini, M. P. 2020. Adoption of digital technologies in health care during the COVID-19 pandemic: systematic review of early scientific literature. *J Med Internet Res*, 22, e22280.
- Government Offices of Sweden. 2016. *Vision eHälsa 2025 – gemensamma utgångspunkter för digitalisering i socialtjänst och hälso- och sjukvård* [Online]. Available: <https://www.regeringen.se/contentassets/79df147f5b194554bf401dd88e89b791/vision-e-halsa-2025.pdf> [Accessed 26 Sep 2020].
- Graneheim, U. H. & Lundman, B. 2004. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today*, 24, 105-112.
- Graneheim, U. H., Lindgren, B.-M. & Lundman, B. 2017. Methodological challenges in qualitative content analysis: a discussion paper. *Nurse Educ Today*, 56, 29-34.
- Griebel, L., Enwald, H., Gilstad, H., Pohl, A. L., Moreland, J. & Sedlmayr, M. 2018. eHealth literacy research – quo vadis? *Inform Health Soc Care*, 43, 427-442.

- Guo, S. H.-M., Hsing, H.-C., Lin, J.-L. & Lee, C.-C. 2021. Relationships between mobile eHealth literacy, diabetes self-care, and glycemic outcomes in Taiwanese patients with type 2 diabetes: cross-sectional study. *JMIR mHealth uHealth*, 9, e18404.
- Hair, J. F., Anderson, R. E., Tatham, R. L. & Black, W. C. 1998. *Multivariate Data Analysis*. New Jersey: Prentice Hall.
- Hamovitch, E. K., Choy-Brown, M. & Stanhope, V. 2018. Person-centered care and the therapeutic alliance. *Community Ment Health J*, 54, 951-958.
- Hanley, T., Prescott, J. & Gomez, K. U. 2019. A systematic review exploring how young people use online forums for support around mental health issues. *J Ment Health*, 28, 566-576.
- Hawkins, M., Cheng, C., Elsworth, G. R. & Osborne, R. H. 2020. Translation method is validity evidence for construct equivalence: analysis of secondary data routinely collected during translations of the Health Literacy Questionnaire (HLQ). *BMC Med Res Methodol*, 20, 1-13.
- Hawkins, M., Elsworth, G. R. & Osborne, R. H. 2018. Application of validity theory and methodology to patient-reported outcome measures (PROMs): building an argument for validity. *Qual Life Res*, 27, 1695-1710.
- Heponiemi, T., Jormanainen, V., Leemann, L., Manderbacka, K., Aalto, A.-M. & Hyppönen, H. 2020. Digital divide in perceived benefits of online health care and social welfare services: national cross-sectional survey study. *J Med Internet Res*, 22, e17616.
- Hirsch, M., Aggarwal, S., Barker, C., Davis, C. J. & Duffy, J. M. N. 2017. Googling endometriosis: a systematic review of information available on the Internet. *Am J Obstet Gynecol*, 216, 451-458.e1.
- Hoeck, B. & Delmar, C. 2018. Theoretical development in the context of nursing – The hidden epistemology of nursing theory. *Nurs Philos*, 19.
- Holt, A. 2010. Using the telephone for narrative interviewing: a research note. *Qual Res*, 10, 113-121.
- Holt, K. A., Karnoe, A., Overgaard, D., Nielsen, S. E., Kayser, L., Roder, M. E. & From, G. 2019. Differences in the level of electronic health literacy between users and nonusers of digital health services: an exploratory survey of a group of medical outpatients. *Interact J Med Res*, 8, e8423.
- Håkansson Eklund, J., Holmström, I. K., Kumlin, T., Kaminsky, E., Skoglund, K., Högländer, J., Sundler, A. J., Condén, E. & Summer Merenius, M. 2019. 'Same same or different?' A review of reviews of person-centred and patient-centred care. *Patient Educ Couns*, 102, 3-11.
- Iacobaeus, H., Francisco, M., Nordqvist, C., Sefyrin, J., Skill, K. & Wihlborg, E. 2019. *Digitalt utanförskap: en forskningsöversikt*. Linköping: Linköping University Electronic Press.
- Inera. 2022. 1177 *Vårdguidens utveckling mot nära vård– rapport för programmet Första linjens digitala vård 2019–2021*. Stockholm: Inera.
- Inera. 2023a. 1177.se [Online]. Available: <https://www.inera.se/tjanster/1177/1177.se/> [Accessed Oct 1 2023].

- Inera. 2023b. *Statistik för Ineras tjänster* [Online]. Available: <https://www.inera.se/tjanster/statistik-for-ineras-tjanster/statistik-for-1177.se/anvandarbetaende/> [Accessed Oct 1 2023].
- Jokisch, M. R., Schmidt, L. I. & Doh, M. 2022. Acceptance of digital health services among older adults: findings on perceived usefulness, self-efficacy, privacy concerns, ICT knowledge, and support seeking. *Public Health Front*, 10, 1073756.
- Karnoe, A., Kayser, L. 2015. How is eHealth literacy measured and what do the measurements tell us? A systematic review. *Knowl Manag E-Learn*, 7, 576-600.
- Kayser, L., Karnoe, A., Furstrand, D., Batterham, R., Christensen, K. B., Elsworth, G. & Osborne, R. H. 2018. A multidimensional tool based on the eHealth Literacy Framework: development and initial validity testing of the eHealth Literacy Questionnaire (eHLQ). *J Med Internet Res*, 20, e36.
- Kelly, S., Eldredge, S. A., Dalton, E. D. & Miller, L. E. 2014. Health-information behavior: an initial validity portfolio for active and passive measures. *Commun Res Rep*, 31, 171-182.
- Kline, R. B. 2023. *Principles and Practice of Structural Equation Modeling*. Location: Guilford Publications.
- Kringos, D., Boerma, W., Bourgueil, Y., Cartier, T., Dedeu, T., Hasvold, T., Hutchinson, A., Lember, M., Oleszczyk, M., Rotar Pavlic, D., Svab, I., Tedeschi, P., Wilm, S., Wilson, A., Windak, A., Van Der Zee, J. & Groenewegen, P. 2013. The strength of primary care in Europe: an international comparative study. *Br J Gen Pract*, 63, e742-50.
- Kristjánsdóttir, Ó., Welander Tärneberg, A., Stenström, P., Castor, C. & Kristensson Hallström, I. 2023. eHealth literacy and socioeconomic and demographic characteristics of parents of children needing paediatric surgery in Sweden. *Nurs Open*, 10, 509-524.
- Kumlin, S. & Haugsgjerd, A. 2017. The welfare state and political trust: bringing performance back. In Zmerli, S. and van der Meer, T. W. G. (eds.), *Handbook on Political Trust* (pp. 285-301). Cheltenham, UK: Edward Elgar Publishing.
- Kvale, S. & Brinkmann, S. 2014. *Den kvalitativa forskningsintervjun*. Lund: Studentlitteratur.
- Lee, J., Lee, E.-H. & Chae, D. 2021. eHealth literacy instruments: systematic review of measurement properties. *J Med Internet Res*, 23, e30644.
- Leonardsen, A.-C. L., Bååth, C., Helgesen, A. K., Grøndahl, V. A. & Hardeland, C. 2023. Person-centeredness in digital primary healthcare services – a scoping review. *Healthc (Basel)*, 11, 1296.
- Leonardsen, A.-C. L., Hardeland, C., Helgesen, A. K. & Grøndahl, V. A. 2020. Patient experiences with technology enabled care across healthcare settings – a systematic review. *BMC Health Serv Res*, 20, 1-17.
- Levin-Zamir, D. & Bertschi, I. 2018. Media health literacy, eHealth literacy, and the role of the social environment in context. *Int J Environ Res Public Health*, 15, 1643.

- Levine, D. M., Lipsitz, S. R. & Linder, J. A. 2016. Trends in seniors' use of digital health technology in the United States, 2011–2014. *JAMA*, 316, 538-540.
- Li, C.-H. 2016. Confirmatory factor analysis with ordinal data: comparing robust maximum likelihood and diagonally weighted least squares. *Behav Res Methods*, 48, 936-949.
- Lincoln, Y. S. & Guba, E. G. 1985. *Naturalistic Inquiry*. Beverly Hills CA: Sage.
- Lindberg, J., Bhatt, R. & Ferm, A. 2021. Older people and rural eHealth: perceptions of caring relations and their effects on engagement in digital primary health care. *Scand J Caring Sci*, 35, 1322-1331.
- Lindgren, B.-M., Lundman, B. & Graneheim, U. H. 2020. Abstraction and interpretation during the qualitative content analysis process. *Int J Nurs Stud*, 108, 103632.
- Liobikienė, G. & Bernatoniene, J. 2018. The determinants of access to information on the Internet and knowledge of health related topics in European countries. *Health Policy*, 122, 1348-1355.
- Longo, D. R., Schubert, S. L., Wright, B. A., Lemaster, J., Williams, C. D. & Clore, J. N. 2010. Health information seeking, receipt, and use in diabetes self-management. *Ann Fam Med*, 8, 334-340.
- Lu, Q. & Schulz, P. 2023. Physicians' perspectives on Internet-informed patients: a systematic review. *J Medical Internet Res (Preprints)*, 47620.
- MacCallum, R. C., Widaman, K. F., Zhang, S. & Hong, S. 1999. Sample size in factor analysis. *Psychol Methods*, 4, 84.
- Mach, K. J., Salas Reyes, R., Pentz, B., Taylor, J., Costa, C. A., Cruz, S. G., Thomas, K. E., Arnott, J. C., Donald, R. & Jagannathan, K. 2021. News media coverage of COVID-19 public health and policy information. *Humanit and Soc Sciences Commun*, 8.
- Malterud, K., Siersma, V. D. & Guassora, A. D. 2016. Sample size in qualitative interview studies: guided by information power. *Qual Health Res*, 26, 1753-1760.
- Marston, H. R. & Musselwhite, C. B. 2021. *Improving Older People's Lives Through Digital Technology and Practices*. Los Angeles, CA: SAGE Publications.
- Maxwell, J. A. 2010. Using numbers in qualitative research. *Qual Inq*, 16, 475-482.
- McDermid, F., Peters, K., Jackson, D. & Daly, J. 2014. Conducting qualitative research in the context of pre-existing peer and collegial relationships. *Nurse Res*, 21, 28-33.
- McEvoy, P. 2001. Interviewing colleagues: addressing the issues of perspective, inquiry and representation. *Nurse Res (through 2013)*, 9, 49.
- McMullan, M. 2006. Patients using the Internet to obtain health information: how this affects the patient-health professional relationship. *Patient Educ Couns*, 63, 24-28.
- McMullan, R. D., Berle, D., Arnáez, S. & Starcevic, V. 2019. The relationships between health anxiety, online health information seeking, and cyberchondria: systematic review and meta-analysis. *J Affect Disord*, 245, 270-278.

- Milewski, J. & Chen, Y. 2010. Barriers of obtaining health information among diabetes patients. *Stud Health Technol Inform*, 160, 18-22.
- Mitsutake, S., Shibata, A., Ishii, K. & Oka, K. 2012. Association of eHealth literacy with colorectal cancer knowledge and screening practice among internet users in Japan. *J Med Internet Res*, 14, e153.
- Mitsutake, S., Shibata, A., Ishii, K. & Oka, K. 2016. Associations of eHealth literacy with health behavior among adult internet users. *J Med Internet Res*, 18, e192.
- Muldoon, L. K., Hogg, W. E. & Levitt, M. 2006. Primary care (PC) and primary health care (PHC). What is the difference? *Can J Public Health*, 97, 409-411.
- Murray, E., Lo, B., Pollack, L., Donelan, K., Catania, J., Lee, K., Zapert, K. & Turner, R. 2003. The impact of health information on the Internet on health care and the physician-patient relationship: national U.S. survey among 1050 U.S. physicians. *J Med Internet Res*, 5, e17.
- Mårtensson, L. & Hensing, G. 2012. Health literacy – a heterogeneous phenomenon: a literature review. *Scand J Caring Sci*, 26, 151-160.
- Naggara, O., Raymond, J., Guilbert, F., Roy, D., Weill, A., & Altman, D. G. 2011. Analysis by categorizing or dichotomizing continuous variables is inadvisable: an example from the natural history of unruptured aneurysms. *Am. J. Neuroradiol.* 32(3), 437-440.
- National Board of Health and Welfare. 2016. *Primärvårdens uppdrag*. Available: <https://www.socialstyrelsen.se/globalassets/sharepoint-dokument/artikelkatalog/ovrigt/2016-3-2.pdf> [Accessed October 20 2023].
- National Board of Health and Welfare. 2021. *Statistik om hälso- och sjukvårdspersonal* [Online]. Available: <https://www.socialstyrelsen.se/statistik-och-data/statistik/alla-statistikamnen/halso-och-sjukvardspersonal/> [Accessed 1 Nov 2023].
- National Board of Health and Welfare. 2022a. *Insatser under 2021 för att främja omställningen till en god och nära vård*. Stockholm: National Board of Health and Welfare.
- National Board of Health and Welfare. 2022b. *Uppföljning Nära vård. Deluppdrag II. Nationella Indikationer, slutrapport*. Stockholm: National Board of Health and Welfare.
- National Health Competence Council & National Board of Health and Welfare. 2021. *Kompetensförsörjning inom primärvården*. Stockholm: National Health Competence Council & National Board of Health and Welfare.
- Nergårdh, A., Andersson, L., Eriksson, J., Lundberg, M., Nordström, K. & Lindevall, M. 2018. *God och nära vård—En primärvårdsreform*. Stockholm: Ministry of Health and Social Affairs.
- Neter, E. & Brainin, E. 2012. eHealth literacy: extending the digital divide to the realm of health information. *J Med Internet Res*, 14, e19.
- Neter, E. & Brainin, E. J. 2019. Association between health literacy, eHealth literacy, and health outcomes among patients with long-term conditions. *Eur Psychol*, 24, 68-81.

- Nick, T. G. & Campbell, K. M. 2007. Logistic regression. *Topics in biostatistics*, 273-301.
- Niela-Vilén, H., Axelin, A., Salanterä, S. & Melender, H.-L. 2014. Internet-based peer support for parents: a systematic integrative review. *Int J Nurs Stud*, 51, 1524-1537.
- Norgaard, O., Furstrand, D., Klokke, L., Karnoe, A., Batterham, R., Kayser, L., Osborne, R. H. 2015. The e-Health Literacy Framework: a conceptual framework for characterizing e-health users and their interaction with e-Health systems. *Knowl Manag E-Learn*, 7, 522-540.
- Norman, C. D. & Skinner, H. A. 2006a. eHEALS: The eHealth Literacy Scale. *J Med Internet Res*, 8, e27.
- Norman, C. D. & Skinner, H. A. 2006b. eHealth literacy: essential skills for consumer health in a networked world. *J Med Internet Res*, 8, e9.
- Novick, G. 2008. Is there a bias against telephone interviews in qualitative research? *Res Nurs Health*, 31, 391-398.
- Nowell, L. S., Norris, J. M., White, D. E. & Moules, N. J. 2017. Thematic analysis: striving to meet the trustworthiness criteria. *Int J Qual Methods*, 16, 1609406917733847.
- Nutbeam, D. 2008. The evolving concept of health literacy. *Soc Sci Med*, 67, 2072-2078.
- Nutbeam, D., McGill, B. & Premkumar, P. 2018. Improving health literacy in community populations: a review of progress. *Health Promot Int*, 33, 901-911.
- Nymberg, V. M., Bolmsjö, B. B., Wolff, M., Calling, S., Gerward, S. & Sandberg, M. 2019. 'Having to learn this so late in our lives...' Swedish elderly patients' beliefs, experiences, attitudes and expectations of e-Health in primary health care. *Scand J Prim Health Care*, 37, 41-52.
- Okan, O., Messer, M., Levin-Zamir, D., Paakkari, L., & Sørensen, K. 2023. Health literacy as a social vaccine in the COVID-19 pandemic. *Health Promot Int*, 38(4), daab197.
- Osborn, C. Y., Bains, S. S. & Egede, L. E. 2010. Health literacy, diabetes self-care, and glycemic control in adults with type 2 diabetes. *Diabetes Technol Ther*, 12, 913-919.
- Paakkari, L. & Okan, O. 2020. COVID-19: health literacy is an underestimated problem. *Lancet Public Health*, 5, e249-e250.
- Palumbo, R. 2021. Leveraging organisational health literacy to enhance health promotion and risk prevention: a narrative and interpretive literature review. *Yale J Biol Med*, 94, 115-128.
- Papen, U. 2009. Literacy, learning and health: a social practices view of health literacy. *Lit Numeracy Stud*, 16, 19-34.
- Pennbrant, S., Berg, A. & Fohlin Johansson, L. 2020. Self-care experiences of older patients with diabetes mellitus: a qualitative systematic literature review. *Nord J Nurs Res*, 40, 64-72.



- Pettersson, B., Janols, R., Wiklund, M., Lundin-Olsson, L. & Sandlund, M. 2021. Older adults' experiences of behavior change support in a digital fall prevention exercise program: qualitative study framed by the self-determination theory. *J Med Internet Res*, 23, e26235.
- Polit, D. & Beck, C. 2020. *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. Philadelphia, PA: Wolters Kluwer Health/ Lippincott Williams & Wilkins.
- Poot C. C., Meijer, E., Fokkema, M., Chavannes, N. H., Osborne, R. H. & Kayser, L. 2023. Translation, cultural adaptation and validity assessment of the Dutch version of the eHealth Literacy Questionnaire: a mixed-method approach. *BMC Public Health*, 23, 1-17.
- Powers, M. A., Bardsley, J., Cypress, M., Duker, P., Funnell, M. M., Fischl, A. H., Maryniuk, M. D., Siminerio, L. & Vivian, E. 2016. Diabetes self-management education and support in type 2 diabetes: a joint position statement of the American Diabetes Association, the American Association of Diabetes Educators, and the Academy of Nutrition and Dietetics. *Clin Diabetes*, 34, 70-80.
- Prescott, J., Hanley, T. & Ujhelyi, K. 2017. Peer communication in online mental health forums for young people: directional and nondirectional support. *JMIR Mental Health*, 4, e6921.
- Ramsey, I., Corsini, N., Peters, M. D. J. & Eckert, M. 2017. A rapid review of consumer health information needs and preferences. *Patient Educ Couns*, 100, 1634-1642.
- Rawshani, A., Kjölhede, E. A., Rawshani, A., Sattar, N., Eeg-Olofsson, K., Adiels, M., Ludvigsson, J., Lindh, M., Gisslén, M. & Hagberg, E. 2021. Severe COVID-19 in people with type 1 and type 2 diabetes in Sweden: a nationwide retrospective cohort study. *Lancet Reg Health Eur*, 4, 100105.
- Raykov, T. & Marcoulides, G. A. 2011. *Introduction to Psychometric Theory*. New York: Routledge.
- Richtering, S. S., Hyun, K., Neubeck, L., Coorey, G., Chalmers, J., Usherwood, T., Peiris, D., Chow, C. K. & Redfern, J. 2017. eHealth literacy: predictors in a population with moderate-to-high cardiovascular risk. *JMIR Hum Factors*, 4, e4.
- Robine, J.-M. 2021. *Ageing Populations: We Are Living Longer Lives, but Are We Healthier?* Geneva: United Nations DESA Publications.
- Rollo, M. E., Aguiar, E. J., Williams, R. L., Wynne, K., Kriss, M., Callister, R. & Collins, C. E. 2016. eHealth technologies to support nutrition and physical activity behaviors in diabetes self-management. *Diabetes Metab Syndr Obes Targets Ther*, 9, 381-390.
- Rothrock, S. G., Rothrock, A. N., Swetland, S. B., Pagane, M., Isaak, S. A., Romney, J., Chavez, V. & Chavez, S. H. 2019. Quality, trustworthiness, readability, and accuracy of medical information regarding common pediatric emergency medicine-related complaints on the web. *J Emerg Med*, 57, 469-477.

- Sandberg, H. & Möllerström, V. 2014. Hälsomedvetenhet och medier. In: Ringsberg, K., Olander, E. & Tillgren, P. (eds.), *Health literacy: teori och praktik i hälsofrämjande arbete* (pp. 99-120). Lund: Studentlitteratur AB.
- Sanjari, M., Bahramnezhad, F., Fomani, F. K., Shoghi, M. & Cheraghi, M. A. 2014. Ethical challenges of researchers in qualitative studies: the necessity to develop a specific guideline. *J Med Ethics Hist Med*, 7, 14.
- Schimmer, R., Orre, C., Öberg, U., Danielsson, K. & Hörnsten, Å. 2019. Digital person-centered self-management support for people with type 2 diabetes: qualitative study exploring design challenges. *JMIR Diabetes*, 4, e10702.
- Schulz, P. J., Fitzpatrick, M. A., Hess, A., Sudbury-Riley, L. & Hartung, U. 2017. Effects of eHealth literacy on general practitioner consultations: a mediation analysis. *J Med Internet Res*, 19, e166.
- Shi, D. & Maydeu-Olivares, A. 2020. The effect of estimation methods on SEM fit indices. *Educ Psychol Meas*, 80, 421-445.
- Skär, L. & Söderberg, S. 2018. The importance of ethical aspects when implementing eHealth services in healthcare: a discussion paper. *J Adv Nurs*, 74, 1043-1050.
- Sommerhalder, K., Abraham, A., Zufferey, M. C., Barth, J. & Abel, T. 2009. Internet information and medical consultations: experiences from patients' and physicians' perspectives. *Patient Educ Couns*, 77, 266-271.
- Starcevic, V., Berle, D. & Arnáez, S. 2020. Recent insights into cyberchondria. *Current Psychiatry Reports*, 22, 1-8.
- Starcevic, V., Schimmenti, A., Billieux, J. & Berle, D. 2021. Cyberchondria in the time of the COVID-19 pandemic. *Hum Behav Emerg Technol*, 3, 53-62.
- Statistics Sweden. 2021. *Utrikes födda i Sverige* [Online]. <https://www.scb.se/hitta-statistik/sverige-i-siffror/manniskorna-i-sverige/utrikes-fodda-i-sverige/> [accessed 1 nov 2023].
- Statistics Sweden. 2022. *Befolkningens IT-användning - Sakernas internet, Grön IT*. Stockholm: Statistics Sweden.
- Suarez-Lledo, V. & Alvarez-Galvez, J. 2021. Prevalence of health misinformation on social media: systematic review. *J Med Internet Res*, 23, e17187.
- Swedish Agency for Health and Care Service Analysis. 2014. *Vip i vården – Om utmaningar i vården av personer med kronisk sjukdom*. Stockholm: Swedish Agency for Health and Care Service Analysis.
- Swedish Agency for Health and Care Service Analysis. 2017. *Primärvården i Europa. En översikt av finansiering, struktur och måluppfyllelse*. Stockholm: Swedish Association of Local Authorities and Regions.
- Swedish Agency for Health and Care Service Analysis. 2018. *Från mottagare till medskapare. Ett kunskapsunderlag för en mer personcentrerad hälso- och sjukvård*. Stockholm: Swedish Agency for Health and Care Service Analysis.
- Swedish Agency for Health and Care Service Analysis. 2022. *Besök via nätet*. Stockholm: Swedish Agency for Health and Care Service Analysis.
- Swedish Association of Local Authorities and Regions (SALAR). 2020. *Strategi för genomförande av Vision eHälsa 2025 (2020–2022)*. Stockholm: Swedish Association of Local Authorities and Regions.

- Swedish Association of Local Authorities and Regions (SALAR). 2022. *Omställning till Nära vård*. Stockholm: Swedish Association of Local Authorities and Regions.
- Swedish eHealth Agency. 2020a. *Jämlik e-hälsa Tillgång, fördelning och användning av e-hälsotjänster och välfärdsteknik -Fokusrapport*. Stockholm: Swedish eHealth Agency.
- Swedish eHealth Agency. 2020b. *Årsrapport 2020 – Pandemi och e-hälsa*. Stockholm: Swedish eHealth Agency.
- Swedish Government. 2003. *Ethics Act* 2003:460.
- Swedish Internet Foundation. 2017. *Svenskarna och internet 2017 - Undersökning om svenskarnas internetvanor*. Stockholm: Swedish Internet Foundation.
- Swedish Internet Foundation. 2021. *Svenskarna och internet 2021*. Stockholm: Swedish Internet Foundation.
- Swedish Internet Foundation. 2022. *Svenskarna och internet 2022*. Stockholm: Swedish Internet Foundation.
- Swedish Internet Foundation. 2023. *Svenskarna och internet 2023*. Stockholm: Swedish Internet Foundation.
- Swenurse. 2019a. *Kompetensbeskrivning för distriktssköterska* Stockholm: Svensk sjuksköterskeförening.
- Swenurse. 2019b. *Strategi för sjuksköterskors arbete med eHälsa*. Stockholm: Svensk sjuksköterskeförening.
- Sykes, S., Wills, J., Trasolini, A., Wood, K. & FRINGS, D. 2022. eHealth literacy during the COVID-19 pandemic: seeking, sharing, suspicion amongst older and younger UK populations. *Health Promot Int*, 37, daab103.
- Tan, S. S. & Goonawardene, N. 2017. Internet health information seeking and the patient-physician relationship: a systematic review. *J Med Internet Res*, 19, e9.
- Tanis, M., Hartmann, T. & Te Poel, F. 2016. Online health anxiety and consultation satisfaction: a quantitative exploratory study on their relations. *Patient Educ Couns*, 99, 1227-1232.
- Tennant, B., Stellefson, M., Dodd, V., Chaney, B., Chaney, D., Paige, S. & Alber, J. 2015. eHealth literacy and Web 2.0 health information seeking behaviors among baby boomers and older adults. *J Med Internet Res*, 17, e70.
- Terwee, C. B., Bot, S. D., De Boer, M. R., Van Der Windt, D. A., Knol, D. L., Dekker, J., Bouter, L. M. & De Vet, H. C. 2007. Quality criteria were proposed for measurement properties of health status questionnaires. *J Clin Epidemiol*, 60, 34-42.
- Tomczak, M. & Tomczak, E. 2014. The need to report effect size estimates revisited. An overview of some recommended measures of effect size. *Trends Sport Sci*, 1, 19-25.
- Townsend, A., Leese, J., Adam, P., McDonald, M., LI, L. C., Kerr, S. & Backman, C. L. 2015. eHealth, participatory medicine, and ethical care: a focus group study of patients' and health care providers' use of health-related Internet information. *J Med Internet Res*, 17, e155.

- Van der kleij, R. M., Kasteleyn, M. J., Meijer, E., Bonten, T. N., Houwink, E. J., Teichert, M., van Luenen, S., Vedanthan, R., Evers, A. & Car, J. 2019. Series: eHealth in primary care. Part 1: Concepts, conditions and challenges. *Eur J Gen Pract*, 25, 179-189.
- Van Der Vaart, R., Van Deursen, A. J., Drossaert, C. H., Taal, E., Van Dijk, J. A. & Van De Laar, M. A. 2011. Does the eHealth Literacy Scale (eHEALS) measure what it intends to measure? Validation of a Dutch version of the eHEALS in two adult populations. *J Med Internet Res*, 13, e86.
- Van Deursen, A. J. & Helsper, E. J. 2015. *The Third-Level Digital Divide: Who Benefits Most from Being Online?* Leeds: Emerald Group Publishing Limited.
- Van Dijk, J. A. G. M. 2012. The evolution of the digital divide – the digital divide turns to inequality of skills and usage. In: Bus, J. et al. (eds.), *Digital Enlightenment Yearbook 2012* (pp. 57-75). Amsterdam: IOS Press.
- Viviani, M. & Pasi, G. 2017. Credibility in social media: opinions, news, and health information – a survey. *Wiley Interdiscip Rev Data Min Knowl Discov*, 7, e1209.
- Walker, L. & Silience, E. 2023. Examining healthcare professionals' communication around decision-making with Internet-informed patients. *Health Commun*, 1-8.
- Waring, M. E., Mcmanus, D. D., Amante, D. J., Darling, C. E. & Kiefe, C. I. 2018. Online health information seeking by adults hospitalized for acute coronary syndromes: who looks for information, and who discusses it with healthcare providers? *Patient Educ Couns*, 101, 1973-1981.
- White, R. W. & Horvitz, E. 2009. Cyberchondria: studies of the escalation of medical concerns in Web search. *ACM Trans Inf Syst*, 27, 1-37.
- Whittaker, T. A. 2012. Using the modification index and standardized expected parameter change for model modification. *J Exp Educ*, 80, 26-44.
- Wilson, J., Heinsch, M., Betts, D., Booth, D. & Kay-Lambkin, F. 2021. Barriers and facilitators to the use of e-health by older adults: a scoping review. *BMC Public Health*, 21, 1-12.
- Wong, D. K. & Cheung, M. K. 2019. Online health information seeking and eHealth literacy among patients attending a primary care clinic in Hong Kong: a cross-sectional survey. *J Med Internet Res*, 21, e10831.
- World Health Organisation. 2014. *Global Status Report on Noncommunicable Diseases 2014*. Geneva: World Health Organisation.
- World Health Organisation. 2016. *Global Report on Diabetes*. Geneva: World Health Organisation.
- World Health Organisation. 2018a. *Digital Technologies: Shaping the Future of Primary Health Care. Technical Series on Primary Health Care*. Geneva: World Health Organisation.
- World Health Organisation. 2018b. *A Vision for Primary Health Care in the 21st Century: Towards Universal Health Coverage and the Sustainable Development Goals*. Geneva: World Health Organisation.
- World Health Organisation. 2021a. *Global Strategy on Digital Health 2020–2025*. Geneva: World Health Organisation.

- World Health Organisation. 2021b. *WHO Guideline on Self-care Interventions for Health and Well-being*. Geneva: World Health Organisation.
- World Health Organisation. 2022a. *Health Literacy Development for the Prevention and Control of Noncommunicable Diseases. Overview*. Geneva: World Health Organisation.
- World Health Organisation. 2022. *Primary Health Care Measurement Framework and Indicators: Monitoring Health Systems Through a Primary Health Care Lens*. Geneva: World Health Organisation.
- World Health Organisation. 2023a. *Noncommunicable Diseases* [Online]. Available: <https://www.who.int/news-room/fact-sheets/detail/noncommunicable-diseases> [Accessed November 20 2023].
- World Health Organisation. 2023b. *Noncommunicable Diseases Data Portal, Sweden* [Online]. Available: <https://ncdportal.org/CountryProfile/GHE110/SWE> [Accessed 20 November 2023].
- World Medical Association 2013. World Medical Association Declaration of Helsinki: Ethical principles for medical research involving human subjects. *Jama*, 310, 2191-2194.
- Xiang, J. & Stanley, S. J. 2017. From online to offline: Exploring the role of e-health consumption, patient involvement, and patient-centered communication on perceptions of health care quality. *Comput Hum Behav*, 70, 446-452.
- Xie, B. 2009. Older adults' health information wants in the internet age: implications for patient-provider relationships. *J Health Commun*, 14, 510-524.
- Zarocostas, J. 2020. How to fight an infodemic. *Lancet*, 395, 676.
- Öberg, U., Isaksson, U., Jutterström, L., Orre, C. & Hörnsten, Å. 2019. Person-centered interactive self-management support in primary health care for people with type 2 diabetes: protocol for a randomized controlled trial. *JMIR Res Protoc*, 8, e10250.
- Öberg, U., Orre, C. J., Isaksson, U., Schimmer, R., Larsson, H. & Hörnsten, A. 2017. Swedish primary healthcare nurses' perceptions of using digital eHealth services in support of patient self-management. *Scand J Caring Sci.*, 32, 961-970.
- Øvretveit, J. 2021. Innovations in self-care and close care made during COVID 19 pandemic: a narrative review. *Int J Health Gov*, 26, 88-99.

