Degree Project in Medical Engineering

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Health Data Exchange during Transfer of Multi-morbid Elderly

HANAN HADI

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Abstract

This project aimed to enhance communication and collaboration among care providers in Stockholm Region and Stockholm Municipality by analyzing health data in various medical record systems and identifying the data that needs to be shared to support elderly individuals with multi-morbidity. Interviews with health experts, caregivers, and policymakers, as well as a literature review, were conducted to gather data.

The findings indicated that caring for multi-morbid elderly individuals poses many challenges, including managing multiple chronic conditions, the risk of adverse drug interactions, physical and emotional burden, reduced functional ability, social isolation, and economic consequences. A holistic approach to care is needed, including coordinating care across multiple specialities, addressing social and psychological factors, and providing support for caregivers. Additionally, health data sharing could help with the challenges of ageing and multi-morbidity, but barriers to accessing relevant health data exist. The barriers include a lack of measurement values, different systems used in different healthcare facilities, outdated systems and a large amount of health data existing as free-text notes which make it difficult to extract useful information.

Therefore, new HIE solutions are needed to improve patient safety and better integrate existing systems. Future work should focus on improving the accessibility and usability of health data, addressing security and privacy issues, and promoting standardization and interoperability.

Keywords

Ageing, Multi-morbidity, Health data, Health Information Exchange, Cooperation between region and municipality.

Sammanfattning

Målet med detta projekt var att förbättra kommunikationen och samarbetet mellan vårdgivare i Stockholmsregionen och Stockholm kommun genom att analysera hälsodata i olika medicinska journalsystem och identifiera de data som behöver delas för att stödja multi-sjuka äldre. Intervjuer med hälsoexperter, vårdgivare och beslutsfattare samt en litteraturstudie genomfördes för att samla in data.

Resultaten visade att vården för äldre personer med flera sjukdomar innebär många utmaningar, inklusive hantering av flera kroniska tillstånd, risken för biverkningar från läkemedel, fysisk och emotionell belastning, minskad funktionell förmåga, social isolering och ekonomiska konsekvenser. En helhetssyn på vården krävs, inklusive samordning av vården över olika specialiteter, beaktande av sociala och psykologiska faktorer och stöd till vårdgivare. Dessutom kan delning av hälsodata hjälpa till med utmaningarna med åldrande och flera sjukdomar, men det finns hinder för att få tillgång till relevant hälsodata. Hindren inkluderar brist på mätvärden, olika system som används i olika vårdinrättningar, föråldrade system och en stor mängd hälsodata som finns som anteckningar, vilket gör det svårt att extrahera användbar information.

Därav, behövs nya lösningar för hälsodata-utbyte för att förbättra patientens säkerhet och bättre integrera befintliga system. Framtida arbete bör fokusera på att förbättra tillgängligheten och användbarheten hos hälsodata, hantera säkerhets- och integritetsfrågor och främja standardisering och interoperabilitet.

Nyckelord

Äldre, Multisjuka, Hälsodata, Utbyte av hälsoinformation, Samarbete mellan region och kommun.

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Contents

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Acronyms

ADL Activities of Daily Life

ApoDos Pre-packaged dosages of medicines

BMI Body Mass Index

CFS Clinical Frailty Scale

COPD Chronic Obstructive Pulmonary Disease

DISRA Digital innovation in collaboration between city, region and academy

DISVO Digitalisation in Health and Social Care

EHR Electronic Health Record

eFI Electronic Frailty Index

GS Geriatric Syndrome

HIE Health Information Exchange

HL7 Health Level Seven

ICT Information and Communication Technology

NML National Medicines List

NPO National Patient Overview

SIP Coordinated Individual Plan

Chapter 1

Introduction

The population of the world is ageing. Individuals and families, as well as social, economic, and healthcare systems, are all challenged by ageing and age-related disorders. The number of individuals that are 60 years and older in the world is predicted to increase from 900 million in 2015 to over 2 billion by 2050 [1]. Hence, more and more advanced care is provided nowadays outside of hospitals, such as in home care and home services.

An ageing population where many suffer from multiple illnesses, a desire for more patient-oriented care, an increased involvement of patients and relatives, and competition between private and public actors, are all reasons for the increased involvement of care providers around elderly people [2].

In order to manage health and medical care more effectively, there ought to be an effective exchange of information between the involved health and social care providers [2]. A major challenge is the care providers' inability to get relevant and up-to-date information [3]. This may cause multiple re-admissions for inpatient care and inappropriate treatments, and in turn, lower quality of care [2, 3].

In Sweden, this challenge is especially true for multi-morbid elderly patients, who are frequently shuffled between the health and social care providers in the municipalities and the specialists in the regions. Consequently, there is a need to enhance communication between the care providers in the regions and municipalities.

The indicated need is the focus of Digital innovation in collaboration between city, region and academy (DISRA); a city, region, and higher education collaboration project for digital innovation concerning multi-morbid elderly patients [3, 4]. This thesis project was conducted to help DISRA at the ontological level and the practical level to define their future demonstrator.

1.1   Purpose

The purpose of this study was to identify the data that needs to be exchanged between the care providers in Stockholm Region and Stockholm Municipality, in order to improve their cooperation and to better support multi-morbid elderly patients.

1.2   Research questions

The following research questions were addressed in this study:

1. What health data is collected and exchanged around multi-morbid elderly individuals, with a need for both health care and home care, in Stockholm?

2. How does the exchanged health data represent the reality of the multi-morbid elderly individuals?

3. What health data should be exchanged to more effectively support elderly individuals with multi-morbidity?

1.3   Delimitation

Multi-morbid elderly is defined in this report as people aged 65 and over, with two or more diseases at the same time.

Chapter 2

Background

This chapter provides background information about the ageing population, the health profile of multi-morbid elderly and the health actors involved in their care of them. Additionally, this chapter describes the role of digital health in elderly care and the health information exchange systems used in Stockholm. The chapter also describes health data, related work and existing gaps.

2.1 Ageing population

Ageing population refers to a demographic trend in which the proportion of older individuals in a society increases as a result of declining fertility rates and increasing life expectancy. Between 2020 and 2050, the world's population of people aged 60 years and older is excepted to double and the number of people aged 80 years or older is expected to triple [1]. In Sweden, life expectancy was one of the highest in the EU in 2020; 80.6 years for men and 84.3 years for women [5]. Except for the sharp temporary reduction of 0.8 years due to the high number of deaths from COVID-19, life expectancy has steadily increased since 1970 and is expected to keep increasing [5, 6]. This trend has many consequences, including for the individual, their caregivers, and the healthcare system.

2.1.1 Ageing-associated physical and mental changes

At the physical level, ageing is associated with the buildup of numerous types of cellular and molecular damage over time [1]. This results in the deterioration of physical and mental abilities, an increased risk of developing diseases and eventually death.

These changes are not linear nor consistent, and they only tangentially correspond to an individual's age [1]. Hence, age-related diversity is not a coincidence. Some of the elderly are suffering from functions declining such as movement, sensory, or cognitive ability; some others of the same age may be in excellent condition of health [7].

Moreover, older age is commonly characterized by the emergence of Geriatric Syndromes (GSs) [1]. GSs describes a group of common health conditions in older people that do not fit into discrete disease categories [8]. That includes frailty, functional limitation, falls, depression, polypharmacy, malnutrition, and cognitive impairment. These conditions are complex because they are often the consequence of multiple underlying factors [1].

Beyond physical changes, ageing is frequently linked to other life transitions, such as retirement, moving, and loss of companions[1]. For instance, loneliness in old age has adverse consequences for well-being, physical and mental health, and mortality. While many studies have examined correlates of loneliness, fewer have explored risk factors for loneliness prospectively [9]. Thus, in developing a comprehensive healthcare system for the elderly, it is essential to look after the needs of their declining body functions and consider their psychological and social needs [7].

2.1.2 Multi-morbidity

Multi-morbidity, or the presence of two or more concurrent diseases, is a common condition among older individuals. According to a study [10], more than half of the population aged 65 years and older are affected by multi-morbidity and the reality of elderly individuals with multi-morbidity is complex and has many impacts.

Presence of multiple chronic conditions

Multi-morbid elderly people often have multiple chronic conditions, which can be complex and difficult to manage. Of people who are 85 years and older, almost 60 percent have two or more chronic diseases [10]. A chronic disease has a long-term and persistent course or is incurable [1]. Common diagnoses in elderly individuals with multimorbidity include cardiovascular disease (*e.g.* hypertension, coronary artery disease), diabetes, chronic respiratory disease (*e.g.* asthma, Chronic Obstructive Pulmonary Disease (COPD)), arthritis, cancer and mental health conditions (*e.g.* depression, anxiety) [11].

Furthermore, dementia is also a chronic condition that is commonly seen in multi-morbid elderly individuals [11]. It is a progressive condition that

affects cognitive function, including memory, thinking, and problem-solving. Because this condition can significantly impact an individual's ability to carry out everyday activities, it requires ongoing management and support. Several studies on the ageing population have focused on dementia as it has been shown that dementia has physical, psychological, social and economic impacts, not only for people living with dementia but also for their care-providers, families and society at large [12]. Consequently, several technological devices for living independently and fostering social health and social participation in people with dementia have been developed in the last years [12].

Most critically, chronic conditions can often have overlapping symptoms and treatment regimens, which can be confusing and difficult to navigate. For instance, many of these diseases lead to functional impairments [1]. This applies to both the ability to move and the heart and lung function, which results in reduced energy and fitness. In addition, age-related deterioration of sight and hearing are often added [10].

High health care utilization

A major consequence of multi-morbidity in elderly people is high healthcare utilization. Register-based analysis by the National Board of Health and Welfare showed that the proportion of episodes of unplanned readmission within 30 days is about twice as high for the multi-morbid elderly compared to all patients aged 65 years and over [13].

Mentioned in this analysis is that the five most common diagnoses among the care episodes preceding readmission are the same in 2019 as in 2010. These diagnoses are Chronic Obstructive Pulmonary Disease (COPD), heart failure, other diseases of the urinary organs, pneumonia and fracture of the femur. On the other hand, some diagnoses have increased or decreased in incidence.

In particular, COPD and femur fracture has decreased, while acute renal failure, acute tubulointerstitial nephritis, and mental and behavioural disorders caused by alcohol have increased. The cost of treating and managing these conditions can be high, which can put a strain on both the individual and the healthcare system [13].

Increased risk for adverse drug interactions

Individuals with multi-morbidity are at an increased risk for adverse drug interactions because they are often taking multiple medications to manage

their various health conditions. This can lead to a higher likelihood of drug-drug interactions, where the presence of one drug can alter the effectiveness of another drug. These interactions can either increase or decrease the efficacy of the drugs involved and may result in adverse effects, such as increased side effects or reduced effectiveness of one or more of the medications. [14]

Furthermore, multi-morbidity can also increase the risk of drug-disease interactions, where the presence of a certain disease or condition can affect a drug's effectiveness. This can further complicate treatment and management, as it may require additional adjustments to the medications or dosage regimens to ensure optimal therapeutic benefits and minimize the risk of adverse effects.[14]

Increased risk of social isolation and loneliness

Social isolation is a common problem among elderly people with multi-morbidity, as well as among elderly people, in general, [15]. Many older adults experience social isolation due to factors such as the loss of a spouse or close friends, physical disabilities that limit their ability to participate in social activities, and limited access to transportation.

These factors can contribute to feelings of loneliness, especially for elderly people with multi-morbidity and dementia due to the combination of physical and cognitive challenges they may face. Loneliness can exacerbate these challenges and make it more difficult for elderly people with multi-morbidity to manage their health conditions and maintain an active and fulfilling life [16]. Moreover, research has shown that loneliness and social isolation are associated with an increased risk of morbidity and mortality, as well as other negative outcomes such as cognitive decline, depression, and reduced quality of life [15].

There are various strategies that can be used to address loneliness and improve the quality of life of elderly people with multi-morbidity. These may include providing social support, engaging in social activities, providing access to transportation, and using technology to stay connected with loved ones [16]. By addressing loneliness and promoting social connection, it may be possible to improve the quality of life of elderly people with multi-morbidity [15].

In a study [9], a total of 120 unique risk factors for loneliness were examined. Risk factors with relatively consistent associations with loneliness were identified to be: not being partnered and partner loss; a limited social network; a low level of social activity; poor self-perceived health; and

depression. Thereby, the same study concludes that future research should explore longitudinal risk factors for emotional and social loneliness.

Other risk factors

A review of the literature on ageing with multi-morbidity [13], shows that the identified risk factors for multi-morbidity are increasing age, a higher number of previous diseases, and lower education, whereas a large social network seemed to play a protective role. However, the same review shows that little is known about other risk factors such as genetic background, biological factors (such as cholesterol, blood pressure, obesity), lifestyles (smoking, drinking, nutrition, physical activity), or environmental factors (air pollution, social environment) in relation to the development of multi-morbidity.

2.2 Elderly healthcare system

As a result of the growing number of elderly people with multiple and complex illnesses, many different healthcare providers are involved today in the health and social care of the elderly [2]. The different providers may have different specialities, be public or private, and have regional or municipality authorities. Overall, the elderly healthcare system refers to the range of services and facilities that are available to support the healthcare needs of elderly individuals. These services may be provided in a variety of settings, including hospitals, homes, and residential facilities. In general, the elderly healthcare system can be divided into short-term care and long-term care.

2.2.1 Short-term and long-term care

Short-term care typically refers to services that are needed for a relatively brief period of time, often in response to a medical emergency or acute illness [7]. This may include emergency medical care, trauma care, disease diagnosis and treatment, and surgery, and is typically provided in a hospital setting.

Long-term care, on the other hand, refers to a range of services that are needed over an extended period of time, often to support individuals with chronic or complex health conditions [7]. These services can be tailored to the individual's needs and may include personal care, such as meal preparation and bathing, as well as nursing care, such as convalescence, rehabilitation, and physiotherapy. Long-term care may be provided in a variety of settings.

In Sweden, the goal for elderly care is "to enable older persons to live in their homes under good circumstances" [17]. For this aim, there are both municipal and private home services ("hemtjänst" in Swedish) and home care ("Hemsjukvård" in Swedish) that makes it possible for the elderly to receive help in the comfort of their own home. In 2021, a total of 45,795 people have had a decision on home service in ordinary housing in Stockholm County [18]. Compared with previous decades, there are a higher number of older persons in Sweden with functional limitations who live at home with support from home care services [19, 20].

Home service is assistance in the form of service and personal care in the individual's home or equivalent [21]. Municipalities fund home care services for eligible applicants but the older persons must personally apply for needed support [16]. Local municipality assessors evaluate applicants' needs and decide the support to be provided after obtaining necessary information from the applicant and sometimes via family members and in consultation with health professionals [16].

Local municipality assessor ("biståndshandläggare" in Swedish) investigates the person's need for home care and makes an assistance decision about what help the applicant is entitled to [21].

Services offered by home service include:

- Daily chores such as showering, shopping and cleaning.

- Following any nutritional solutions prescribed by a doctor.

- Accompanying patients on errands such as visits to the health centre.

In parallel with home service, the elderly may need home care where more complex care can be received. Home care can be provided in ordinary residences or in special housing, such as nursing or dementia homes. The assessment of who can be cared for at home care is made, for example, in a hospital or health centre. To be eligible for home care, one must have regular contact at least once every two weeks [21].

Home care can include medical interventions, rehabilitation and nursing. Because of this, more actors are usually involved in home care than home service [21]. Nurses, on-call physicians and rehabilitation specialists are usually involved. Services provided by home care include wound dressing, giving insulin or other injections, administrating medication, management of catheter, insertion/replacement of stomi, testing, drip and measuring blood pressure, blood sugar or other clinical values depending on the patient's needs.

2.2.2 Ageing at home

As the global population ages and the demand for healthcare resources increases, the healthcare industry is facing significant strain, which can impact the quality of care provided to the elderly. One solution to this strain is the promotion of "ageing at home," or allowing elderly individuals to remain in their own homes or communities rather than receiving care in a hospital or residential facility [22]. This approach is often more cost-effective and allows elderly individuals to maintain independence and receive care in a familiar and comfortable environment.

Many elderly people prefer to age at home as it allows them to stay close to family and friends and provides a sense of familiarity [7]. Home healthcare can offer a range of benefits, including specialized services tailored to the individual's needs, reduced hospital visits and stays, and more rapid recovery in a comfortable home setting [23]. This can also provide peace of mind for both the patient and their family and make it easier for friends and family to visit.

The multi-morbid elderly are more likely to require hospital care and may have more admissions to hospitals and longer stays than other age groups [1]. This is often due to the fact that the elderly tend to have more chronic and complex health conditions that require ongoing medical attention. However, hospitals may have limited resources, leading to long wait times for treatment and low satisfaction with care [7]. As a result, there has been a shift towards promoting long-term care in the community to relieve pressure on hospitals and improve the quality of care for elderly individuals [7].

2.2.3 Needs

Based on the results of interview surveys conducted by the National Board of Health and Welfare [24], a continuing need is to support both municipal and regional services in their work with elderly with multiple illnesses. They argue that older people with multiple illnesses have complex needs that need to be taken into account in order to provide good care and in turn reduce the incidence of unplanned re-admissions. The following needs have been identified [24]:

1. Home health care procedures need to be ensured in order to treat diseases and conditions in the elderly person's home in a timely manner before they worsen and require hospitalisation. This requires good cooperation between the municipality's home care services and the

region's home care services.

2. Procedures need to be put in place to enable medical assessments to be carried out at home every day of the week and at all times of the day, in order to prevent emergency visits to the hospital.

3. In order to offer older people a holistic approach, there is a need to ensure that risk prevention is included in the responsibilities of their health- and social care providers.

4. Health care needs to ensure procedures for evaluating and reassessing the use of medicines in older people with renal impairment, particularly in the event of acute deterioration of renal function.

5. All those working with older people need to be able to assess alcohol overuse as a cause or contributory factor to the current health condition when older people are admitted to inpatient care.

6. Conditions that enable the health and social providers to use health data for monitoring and risk prevention purposes more effectively in their routines need to be created.

2.3 The role of digital health in elderly care

Digital health encompasses a wide range of technologies that could meet the healthcare challenges of the present consumer-driven era. The integration of digital health technologies, such as Information and Communication Technology (ICT) and Health Information Exchange (HIE) systems, into healthcare systems is no longer a trend, but a necessity [7, 22]. These technologies have been shown to enable the delivery of healthcare services, enhance the quality and efficiency of healthcare delivery, and empower patients to manage their own health and wellness [7]. Hence why they are widely used in the healthcare sector and are constantly being developed to improve healthcare delivery and patient outcomes. While technology cannot stop the ageing process, it can make elderly healthcare more manageable, accessible, and affordable [7].

2.3.1 Information and communication technology

ICT have the potential to improve the care of elderly people by enabling the delivery of healthcare services remotely, facilitating communication and socialization, and promoting independence and autonomy [7, 22]. ICTs can

also support caregivers by providing them with access to relevant information and tools, and by reducing their workload and stress [23].

Telecare

One of the main applications of ICTs in the care of elderly people is telecare, which refers to the use of ICTs to monitor and support the well-being of elderly people remotely [25]. Telecare can be used for continuous or periodic measurement and tracking of various health data, such as vital signs, physical activity, and diet [25]. This can be done using various types of devices, such as sensors, wearable devices, and videoconferencing, and can be used to track a patient's health status over time or to alert healthcare providers to potential health issues [7]. Hence, this kind of technology does not only have the potential to help elderly people maintain their independence and autonomy, but also reduce the burden on caregivers and the need for institutional care.

Related to telecare is the Internet of Things (IoT). IoT in healthcare refers to the use of connected devices, such as sensors and wearable devices, to collect and transmit data about a patient's health [7]. Wearable devices, such as fitness trackers, smartwatches, and wearable sensors, are gaining popularity in the digital health space [7]. These devices can monitor various health metrics, such as heart rate, sleep quality, and physical activity, and provide feedback and coaching to users to help them improve their health and wellness [26]. Wearable devices can also collect data that can be used by healthcare providers to inform treatment decisions and monitor the progress of care [26].

Moreover, mobile health applications can provide a wide range of services, such as tracking health metrics, connecting with healthcare providers, accessing health information, and managing chronic conditions [23]. Mobile health apps can empower patients to take an active role in their health and wellness and can also support the delivery of care by providing healthcare providers with access to relevant patient data [23].

Telemedicine

Another important aspect of using ICTs for the care of elderly people is telemedicine, which refers to the use of ICTs to deliver healthcare services remotely [23]. Telemedicine can enable healthcare providers to offer consultations, diagnoses, and treatments to elderly patients over the phone or through videoconferencing, which can improve access to care and reduce the need for in-person visits. Telemedicine can also support the management of chronic conditions and the coordination of care among different healthcare providers

[23]. In Sweden, various apps such as "Kry", "Min Doktor" and "Doktor.se" have been highly popular, especially after the COVID-19 outbreak [27].

Overall, ICTs have the potential to transform the care of elderly people by enabling the delivery of more efficient healthcare services, facilitating communication and socialization, and promoting independence and autonomy [28, 7]. While ICTs have numerous benefits, it is important to consider the challenges and barriers to their adoption and use, such as access to technology, digital literacy, and data security and privacy [23, 28]. These issues need to be carefully addressed to ensure that ICTs are used responsibly and ethically to support the care of elderly people [23].

2.3.2 Health information exchange systems

Health information exchange (HIE) systems are digital platforms that allow healthcare providers to securely share and access patient health information, such as medical records, lab results, and medication lists, among different healthcare organizations [29]. HIE systems aim to improve the quality, efficiency, and safety of healthcare by providing access to comprehensive and up-to-date patient information, which can facilitate diagnoses, treatment decisions, and coordination of care [30].

In recent years, there has been a significant increase in the adoption of HIE systems globally, driven by the growing demand for efficient and coordinated care and the advancement of digital health technologies [30]. HIE systems can provide numerous benefits to healthcare providers, patients, and payers, such as [31]:

- Improved patient care: HIE systems can help healthcare providers access comprehensive and up-to-date patient information, which can facilitate diagnoses, treatment decisions, and coordination of care.

- Reduced healthcare costs: HIE systems can help reduce unnecessary tests and procedures by providing access to relevant patient information, which can result in cost savings for healthcare providers and payers.

- Enhanced patient safety: HIE systems can help reduce medical errors by providing access to accurate and complete patient information, such as medication lists, allergies, and medical history.

- Improved population health: HIE systems can help track and analyze population health data, which can support public health efforts and inform decision-making.

Overall, HIE systems have the potential to transform healthcare by enabling the exchange of patient information among different healthcare organizations, which can improve the quality, efficiency, and safety of care [7, 31].

One of the main drivers of the digital health revolution is the increasing adoption of Electronic Health Records (EHRs), which are digital versions of paper-based medical records that enable the storage, management, and exchange of patient health information. EHRs have the potential to improve the quality and efficiency of care by providing healthcare providers with access to comprehensive and up-to-date patient information, which can facilitate diagnoses, treatment decisions, and coordination of care [32]. EHRs can also reduce administrative burden and costs, and improve patient safety by reducing medical errors [31].

There are however many challenges in implementing HIE systems in health- and social care. A main challenge is ensuring the security and privacy of patient health information [31]. To address this issue, HIE systems typically use various technologies and protocols, such as encryption, authentication, and access controls, to protect the confidentiality, integrity, and availability of patient data [31]. Another challenge is the interoperability of HIE systems, which refers to the ability of different systems to communicate and exchange information with each other [31]. To improve interoperability, various national and international standards and guidelines have been developed, such as the Health Level Seven (HL7) [32].

2.4 Utilised health information exchange systems in Stockholm

As mentioned in the previous section, HIE refers to the electronic sharing of healthcare information between or within healthcare organizations. There are many different systems used for HIE and this section provides information about the different HIE systems that are utilised in Stockholm.

2.4.1 Region Stockholm

Within the Stockholm region, about 1300 different systems are used. For care provided within the Stockholm Region or on the region's behalf, the medical record system "TakeCare" is used for the most part. TakeCare is a system for coherent record keeping in accordance with the Patient Data Act, which states that a healthcare provider can, under certain conditions, give direct access to

certain data to other healthcare providers. This is used by many different actors and is important for preventing, investigating and treating diseases [2].

Integration is an important aspect when talking about health information systems. It can be explained as the ability to "housing big data and using it in a meaningful way while addressing data accessibility, ownership, and privacy" [33]. Hence, integrated systems enable the flow of data to where they can be used [34]. The region's systems are partially integrated, partly through the widespread use of TakeCare, but also through the region's own integration platform and the regional service platform. The regional service platform is based on the national service platform developed by Inera, and is therefore also used for integration at the national level [4].

2.4.2 Stockholm Municipality

In the social care for the elderly, provided by Stockholm Municipality, there is a set of systems under the so-called "Paraply family". The Paraply family was developed by the municipality itself and consists of the communication systems Paraply, ParaSoL, SchemOS and ParaGå [4].

In addition, the municipality also uses the medical record system Vodok. To integrate the municipality's systems, the municipality has its own integration platform. Furthermore, the integration takes form through the widespread use of the systems in the Paraply family [2].

2.4.3 Cooperation between the municipality and the region

Coherent medical record keeping ("Sammanhållen journalföring" in Swedish) is one of the most central concepts in HIE systems. It means that a healthcare provider has the possibility to access a patient's medical record that has been established in another healthcare facility and in another computer system. The idea is to facilitate the work with a patient in terms of avoiding duplication of effort and making it easier for healthcare providers to access information about the patient's medical history. However, patients need to give their consent and have the right to block parts of their medical records that they do not wish to be seen or exchanged by specific healthcare providers. [2].

In order to coordinate patients' discharge from inpatient health care to ensure a safe homecoming in accordance with the act on discharge from inpatient care ("lagen om utskrivning från slutenvård" in Swedish), the WebCare system is used. WebCare exists as a link which is used to

convey information between the region and the municipality when patients are discharged. It contains a directory of the healthcare units that have an agreement with Region Stockholm, as well as current units in the county's municipalities. The system is owned by Stockholm Region and can be used by organisations that have an agreement with the region. Authorisation to use the systems is granted only to the extent necessary to carry out tasks under the act on discharge from inpatient care. However, WebCare is not a traditional system for system integration but is used by the region to manually document information that can then be manually retrieved by users in the municipality [2].

Nationally, there are several service platforms and systems that can be used by both regions and municipalities. In particular, the national service platform enables the exchange of information through a number of nationally standardised calls between systems. There are also systems that can be used relatively independently to access information within and between regions and cities, such as National Patient Overview (NPO), which uses the national service platform, and National Medicines List (NML). A difference here is that the national service platform is used by system developers to link systems, whereas NPO and NML can also be used directly by end-users in regions and municipalities [4].

To ensure efficiency, there are both voluntary and mandatory cooperation provisions. However, this is not always sufficient to determine whether the information exchange is possible between these actors since there might be confidentiality and secrecy issues [2].

2.5 Health data

Health data refers to information about a person's health. The information can be about their medical conditions, causes of death or even their overall quality of life. This information can be found in medical records, studies on the health of populations, data from blood or tissue samples, imaging data, and data from fitness and health-related devices. Large amounts of data pertaining to health are produced daily, by institutions of health and care as well as other sources like academic research and studies [35].

Other examples of health data, categorized, are [36]:

1. Biology: Age, height, gender, genetics, blood pressure and blood sugar.

2. Lifestyle: Tobacco habits, physical activity, alcohol use, eating habits and drug use.

3. Social network: Family situation, social support and network.

4. Housing, education, work environment, healthcare and social care: Risk factors, screening, diagnoses, treatments and interventions/measures.

5. Culture, environment, socioeconomic factors: Air pollution, segregation and discrimination.

2.5.1 General content of a medical record

A medical record is a source of information on the different stages of the care process for a patient, that is assessment, planning, implementation, outcome and evaluation. Hence the general content of a medical record is the following [37]:

- Identification of the patient.

- The patient's contact information.

- The name and position of the staff responsible for a particular medical record.

- The date of each contact the patient has had or is scheduled to have with a care provider.

- Current health status and medical assessments.

- Investigations and therapeutic measures.

- Prescriptions and their reason.

- Results of investigations and therapeutic measures

- Final notes and other summaries of the provided care.

- Hypersensitivity to medicinal products or certain substances.

- Complications of care and treatment.

- Healthcare-associated infections.

- Consents and withdrawn consents.

- The patient's wishes regarding care and treatment.

- Prescribed/ dispensed medical devices.

- Certificates, referrals and other incoming and outgoing information relevant to care and care planning.

- The information provided to the patient, his/her guardians and other close relatives and the considerations made regarding the choice of treatment.

- If the patient has decided not to receive certain care or treatment.

2.5.2   General content of a SIP

Coordinated Individual Plan (SIP) is a part of the law for cooperation in the event of discharge from inpatient health care (Act 2017:612) [38]. It states that coordinated individual planning must be carried out by representatives of the units responsible for the interventions after the patient has been discharged and is in need of interventions from both region and municipality in the form of health care or social services [39].

SIP is done at home 14 days after discharge. Invited to the meeting are [40]:

- Local municipality assessor

- Nurse

- Occupational therapist

- Physiotherapist

- Contact person from the home service

- Doctor (attends by phone)

- Possible diabetes nurse from the health centre

- Relatives

During the SIP meeting, the following emerges [40]:

1. When the SIP is created, the municipality and the healthcare centre that the patient is listed in automatically become participants. If there are participants from the closed care, they are added to the case manually.

2. A coordination officer for SIP is appointed and registered.

3. Participants, including the patient, are enrolled. The following information is then entered about each individual:

   Unit/ relationship

   Name

   Contact information

4. The patient's current situation and main goals

5. Risk assessment/ risk management and measures/ crisis plan is included

6. Early signs of relapse and medical/psychiatric support needs are entered

7. For each sub-goal, the following information is entered:

   Description of the sub-goal

   Responsible actor

   The patient's responsibility and participation to achieve the sub-goal

8. Activities, including:

   Status

   Activity type

   Description

   Follow-up (date and description)

   Responsible actor

9. The SIP is saved and all the participants need to approve it

2.6   Related work area

The lack of data exchange between health care and social care of elderly people in Sweden is a long-standing issue. Financed by Sweden's innovation agency "Vinnova", the project group DISRA is currently working on tackling this problem in Stockholm. Their aim is to design and develop a system demonstrator for elderly people in the Stockholm region who have clinical, nursing, and social care needs, and for whom access to relevant health data by different entities would enable a fundamental change to the quality of care [36].

The demonstrator is meant to enable care providers and elderly people needs to share their data with consent and under legal frameworks, in a way that bridges different organisational boundaries between health care and social care and includes patient-generated data and the role of informal caregivers. This demonstrator will be implemented in the complex context of the Stockholm municipality and region and integrated with actual services provided in operational work processes [36].

2.6.1 Gap

Increased involvement of health care providers requires increased collaboration between all actors involved, which in turn requires an effective exchange of information between them. As mentioned earlier, many different systems already exist for this very purpose, and many ways to integrate these systems. However, there is a gap and that is the lack of information on what health data is important to exchange.

Chapter 3

Methods

In this chapter, the methodology of the study is presented. First, disclosure of the research design is presented where the data collection, data analysis, validity and reliability and ethical considerations are explained. Following this, the research process is presented.

3.1 Research design

Overall, the methodology employed in this study was designed to provide a comprehensive and robust understanding of the challenges and barriers to health data exchange around multi-morbid elderly in Sweden and to identify strategies and approaches for improving data sharing in this context. An overview of this study's research design can be seen in 3.1.

3.1.1 Data collection

To gather data for the study, eight open interviews were conducted with health experts, healthcare providers, caregivers and policymakers. A semi-structured approach was deemed sufficient as the purpose of the interviews was not only to identify the collected and exchanged health data but also to get insights on the perceived issues and needs with health data exchange around multi-morbid elderly. This approach enabled the interviewees to speak openly and bring in their different experiences.

The inclusion criteria for the interviews were:

- Expert in the previous and current work of the DISRA project.

- Expert in the previous work of the DISVO project.

- Home care granted to clients aged 65+.

- Home services granted to clients aged 65+.

- Clinical care granted to clients aged 65+.

- Expert in the research around the care of multi-morbid elderly patients/ clients.

The interviews were conducted in Swedish and were transcribed verbatim for analysis. The transcriptions provided a more reliable context of the findings and allowed for the interviewees to be quoted exactly.

In addition, a review of several different papers and public documents was conducted, including academic articles, reports, and guidelines. The papers and documents were selected based on their relevance to the study topic and their timeliness. The purpose of the literature review was to be informative, rather than all-encompassing. Therefore, a non-systematic approach was deemed sufficient. This approach was largely based on a knowledgeable selection of current, high-quality publications and documentation to collect information about ageing, multi-morbidity, and health information exchange systems.

More specifically, the literature search included the following international databases: Web of Science, PubMed, World Health Organization, and the Swedish National Board of Health and Welfare. It was necessary to use multiple databases to thoroughly research this topic, as the literature on this subject spans various disciplines including geriatric medicine, nursing, behavioural and social sciences, health telematics, and ageing research.

Moreover, the following search terms were employed: Clinical information, health data, digital health, multi-morbid elderly, geriatric and health informatics in Sweden. A variety of combinations of the search terms were used, both as controlled vocabulary and as free-text searches, in order to comprehensively search the literature on this topic. A snowballing technique was also used, in which the reference lists of key articles were reviewed to identify additional relevant materials, including book chapters and reports. The author mainly searched for work by prominent researchers in this field, using a snowballing technique to identify relevant papers.

The author began by searching through titles and abstracts of articles in a database to find those relevant to the literature review on ageing with multi-morbidity and the use of information and communication technology interventions for older people and their healthcare providers. After carefully reading through the full abstracts, the author selected the articles that focused

on support in the home and were most relevant to the review. The selected literature was then thoroughly read and written summary critiques were created, including author, year, title, journal, pages, publisher, place of publication, literature type/category, summary, main themes, theoretical frameworks, main findings, and critique. This involved a thorough content analysis of each piece of literature. The summary critiques were then refined and finalized. Finally, the author re-examined the summary critiques and identified the key themes present across the literature, which formed the background for the study.

3.1.2   Data analysis

The collected data were analyzed using qualitative content analysis, which involves the systematic and inductive analysis of text data to identify themes and patterns. Guided by the research questions, the data were coded and organized into categories based on their content, and the categories were then grouped into broader themes. This approach was chosen because the focus was to find barriers and solutions when it comes to the collection and exchange of health data around multi-morbid elderly people that receive care from both the region and the municipality.

3.1.3   Validity and reliability

To ensure the validity and reliability of the study, several steps were taken. The interviews were conducted by trained and experienced researchers, and the interview transcripts were checked for accuracy. The review of papers and documents was conducted using a standardized search strategy and inclusion criteria, and the papers and documents were critically appraised for quality and relevance. In addition, after the data analysis was conducted, the results were verified by a second researcher.

3.1.4   Ethical considerations

To ensure the privacy of the participants, their names were kept anonymous. Furthermore, verbal informed consent to use their statements in this report was declared by all participants. Additionally, the interviewees were presented with information regarding the project's purpose and accessibility. Furthermore, fabrication, falsification, and plagiarism were avoided at all costs. There were no excepted outcomes of the research and the findings were reported as accurately as possible.
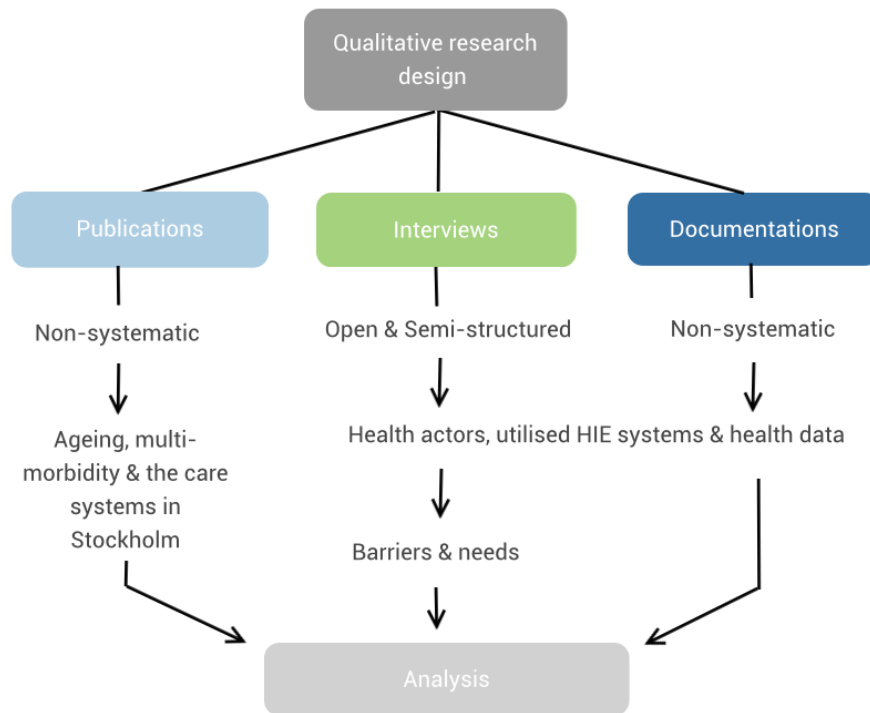
Figure 3.1: An overview of the research design that was used in this study.

3.2 Research process

The used methodology can be divided into the following six phases, conducted in chronological order:

1. Information collection on the current work of the DISRA project, to gain knowledge of what the project group has done and what was left undone. This knowledge was gained by interviewing an expert that is currently involved in the DISRA project. This helped define the problem and the goal of this research.

2. Information collection on the existing information systems of the health- and social care systems in Stockholm, to build the background section 2. This was done by interviewing an expert, that was part of the DISVO project, and by reading the report of the DISVO project.

3. Information collection on the ageing population and the health profile of multi-morbid elderly, through a literature review.

4. Information collection on health collection and exchange of data of multi-morbid elderly patients, through semi-structured open interviews.

5. To fill in gaps in knowledge about the existing HIE systems and the health data exchange, both "Valhandboken" and educational sources found through "Stockholms stads utbildningsplattform" were used.

6. Qualitative content data analysis.

Chapter 4

Results

In this chapter, the results that were gathered from the interviews and documentations are presented.

4.1   Interview 1 - Home Care

Respondent 1: Assistant nurse at home healthcare in Region Stockholm.

4.1.1   Involved actors

In home care, elderly individuals are cared for by doctors, nurses, assistant nurses or care assistants. The most common are assistant nurses. Other actors involved in the care of the elderly that receive care at home are:

- Local municipality assessors - They make the decision on whether or not a person is entitled to home service. They also investigate, assess and often also decide on interventions in home service and home care.

- "Planners" - The care plan is received from health centres but the planning is done by specific employees in home care.

- "Prescribers" - The regions and municipalities are obliged to offer necessary aids that help the elderly cope with their daily life. These are prescribed by different health actors, depending on the need.

4.1.2   Utilised HIE systems

In home care, the assistant nurses use the record system TakeCare at the beginning of the work shift, before setting out on their work assignments in

the patients' homes. When they are then out on assignment, they use work phones with an app that opens with their username and password.

4.1.3 Health data collection

In the work phone's app, home health care nurses can find the following information about their clients:

- Social security number

- Name

- Address

- Telephone number of

    the client or/and

    the client's relatives or/and

    the client's care providers from home service.

- Diagnosis

- Planned visitation time

- Planned care activities

In the record system TakeCare, an abundance of information can be found. However, the respondent stated that they primarily look for the following data under "Notes":

- If the patient has been sent to inpatient care.

- If the death of the patient has occurred.

At the end of a work shift, the assistant nurses may need to document the following data in TakeCare:

- In case of a concern, a message is written on TakeCare which reaches the health centre directly, which then carries out an investigation.

If a patient has been discharged from inpatient care, a new medication list is often received as a paper and brought with them home.

4.1.4 Barriers

The following barriers were mentioned during the interview:

- The home care's assistant nurses call the nurses if, for instance, they see the need to give more medicine than what is prescribed. This usually means a long waiting time, which is perceived as a shortcoming, especially in acute cases.

- Assistant nurses do not have access to Pascal, but nurses do. The medication list is sometimes updated in Pascal without the assistant nurses being informed about it.

- In case of death of the patient, the assistant nurses need to call nurses who in turn call the on-call doctor and the ambulance. This can result in a long waiting time.

- Before leaving for a visit, there is a protocol for the assistant nurses that implies that they have to review TakeCare for all patients they will be visiting during their work shifts. The assistant nurses mainly look at the free text notes, where there is often an abundance of information. Doing this for about 15 patients is perceived to be time-consuming by the assistant nurses, which leads to them either ignoring the protocol or looking very cursorily and may be missing critical information. The interviewed assistant stated that she "can't predict what the critical information might be. It takes time to read all the medical records for each patient."

- The work phones are updated when changes occur, but sometimes the updates are obtained too late.

4.1.5 Needs

The free text notes in the TakeCare system are often numerous. Because the assistant nurses at home care are required to look through them for several patients before leaving on a mission, it can be time-consuming. Hence, it is desirable, for the interviewed assistant nurse, to sort the notes by a caregiver. For example, as follows:

- Home care and home assistance

    Morning staff

    Night staff

- Inpatient care

- Open care

- Medical consultations

- Physiotherapists/ rehab

4.1.6   Further remarks

Firstly, patients with home care and/ or home services, are usually living alone. Secondly, when a patient has dementia, both the patient and the health actors usually want them to be receiving care from home, but the interviewed nurse stated that they often can't cope. They might fall several times without anyone noticing until they are badly injured and sometimes even die as a result. Lastly, it is usually preferred that the patients receive care from the same health actors because it results in a better quality of care. However, it is not unusual that the patient gets different staff from different areas all the time. Limiting the same home care staff visiting the patient at home increases patient safety as they know the patient's medical history and can more easily assess any changes in health.

4.2   Interview 2 - Social care

Respondent 2: Coordinator of Social systems at Stockholm Municipality.

4.2.1   Involved actors

In social services, the involved actors are clients, providers and assessors. Clients are defined as the people that are enrolled in home care services, while providers are defined as those who carry out the services of the clients according to the decisions taken by the assessors.

4.2.2   Utilised HIE systems

Social Systems, also often referred to as Paraply, is used for documentation in the care of the elderly, the disabled and families. Social Systems contain information on all steps in the process; from application to investigation to decision-making and finally to orders.

The providers mainly use ParaGå Web and ParaSol. The main difference between ParaGå and ParaSol is that ParaGå is a mobile documentation system that can be taken along by the providers when they visit the clients and contains only information that is important for the services, while ParaSol is located in the office and contains more information.

The assessors also use ParaSol, but for a different aim than the providers. The assessors use ParaSol to document assessments and decided interventions, in accordance with the Social Services Act.

In home care, SchemOS, which is also a part of the Social Systems, is used by the coordinators to plan home care visits.

There are also many other systems than what has been mentioned, that are part of the Social Systems.

Furthermore, Pascal is used for clients that are in need of prepackaged medicines. Pascal is governmental and not part of the Social Systems.

4.2.3 Health data collection

Social Systems contain many data-points, that could not be obtained in this interview. However, an overview of some of the collected data can be seen in 4.1. Furthermore, it is important to note that the collected data in the Social Systems is not transferred to the region.
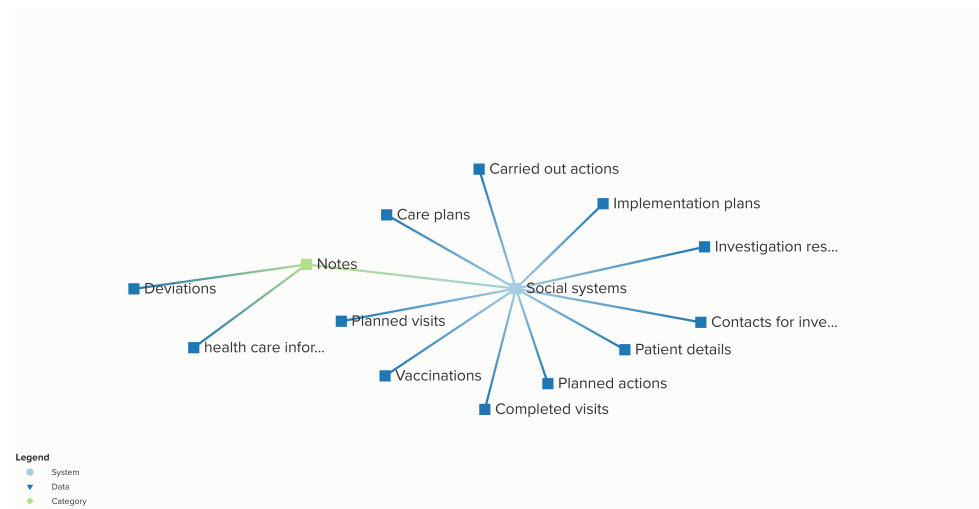

Figure 4.1: An overview of some of the health data that can be collected in the Social Systems.

4.2.4 Barriers and needs

Giving access to the involved actors was stated to be a long and difficult process. Therefore, the respondent also stated that a way to give access without having to use several different systems would help with this issue.

4.2.5 Further remarks

WebCare is currently (November 2022) being replaced with LifeCare in Stockholm, because WebCare was too old and could not be updated. No further information was given about LifeCare.

4.3 Interview 3 - Hospital

Respondent 3: Anaesthesiologist and intensive care head physician at Karolinska Hospital.

4.3.1 Involved actors

Within the region, there are several different care providers that can be found in facilities for inpatient care, primary care, rehabilitation and dental care.

4.3.2 Utilised HIE systems

All authorised health actors in Karolinska Hospital have access to the medical record system TakeCare.

4.3.3 Health data collection

In TakeCare you can find an overflow of health data, especially as a note in free text. The data that is generally included in TakeCare can be seen in 4.2.

Please note that the health data is not categorized in TakeCare as shown in 4.2, they're only categorized here for a better overview of what is being collected.

4.3.4 Barriers

Firstly, there is the perception that most health data that is needed to provide the care of an elderly patient is available. However, a barrier to getting the necessary health data seem to be that TakeCare feels outdated. The
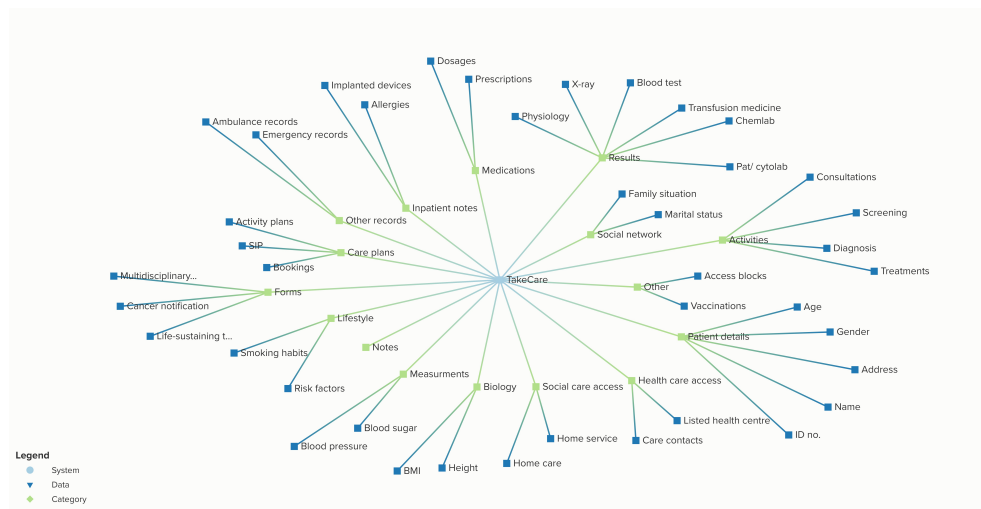
Figure 4.2: An overview of some of the health data that can be collected in TakeCare.

interviewed physician states that, for complicated cases, relevant health data can only be collected with experience, time and ambition.

Secondly, different hospitals and care centres use different medical record systems. For instance, S:t Görans Hospital uses "Cosmic". Furthermore, different departments use different templates for documenting in TakeCare. Hence, there is a large variety in the documentation of the health data

Thirdly, there are many issues with the list of medicines that lead to the information not always being trustworthy. For example, the medication list is often not updated; the doctor is responsible for updating it, but as there are many other actors involved and the patient may not always take his/her medication, this is difficult. Since the Pascal system in home care takes this information from TakeCare, it can lead to many complications.

Finally, there are also concerns about the reliability of the information on dose dispensing. For example, when the patient is at home, it becomes difficult to record this information in TakeCare.

4.3.5 Further remarks

Because there is a redundancy of data that is collected around multi-morbid elderly, the categorisations are helpful. The most commonly viewed headings are: "Patientuppgifter", "Att göra", "Mätvärden/ Laboratielista", "Arbete", "Översikter" and "Journaltext".

Under "Journaltext", the title "New visits" is perceived as important, as it

often contains a lot of information. However, this information is in free text, making it difficult to find.

Furthermore, there are patient records that can be found in 1177. This however is only a reading window in TakeCare and other systems, meaning that no data is actually stored there.

4.4 Webcare

Source: Educational version of Webcare [41] and Valhandboken [42].

4.4.1 Health data

The health data shown in 4.3 can be documented in Webcare during care transitions between hospitals, primary care and municipalities.
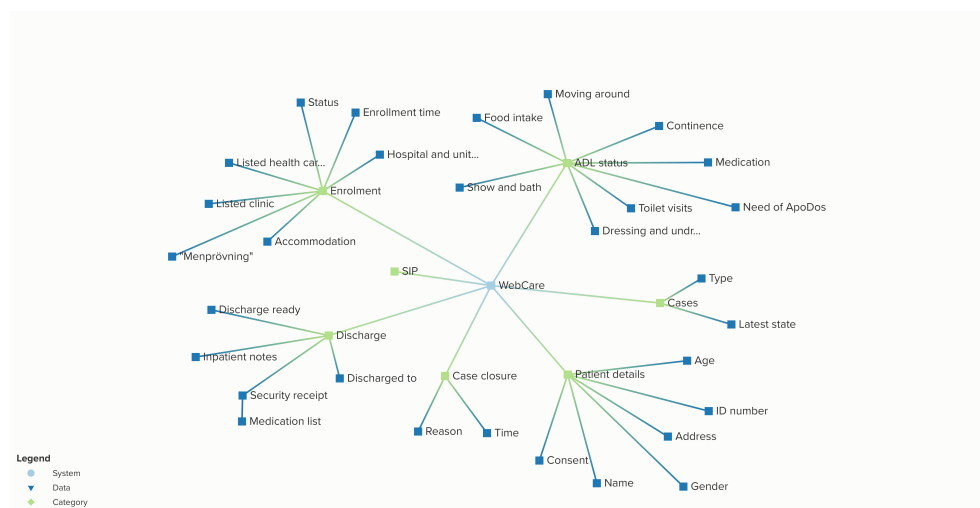
Figure 4.3: An overview of some of the health data that can be exchanged through WebCare.

When a patient has a SIP documented in WebCare, the data that can be found as part of the plan is shown in 4.4.

Figure 4.4: An overview of the health data that can be found as part of a SIP.

4.5 1177's patient record system

Source: The medical records in 1177.se [43].

4.5.1 Health data

Using a personal Bank-ID to sign in 1177.se, the categories and their under-categories that are shown in 4.5 could be found as part of the medical records. These categories and under-categories exist as part of the website, meaning anyone who signs in can see them. However, not all categories were documented with health data. Only if a physician has documented health data in a medical record system such as TakeCare, will it show up in 1177.
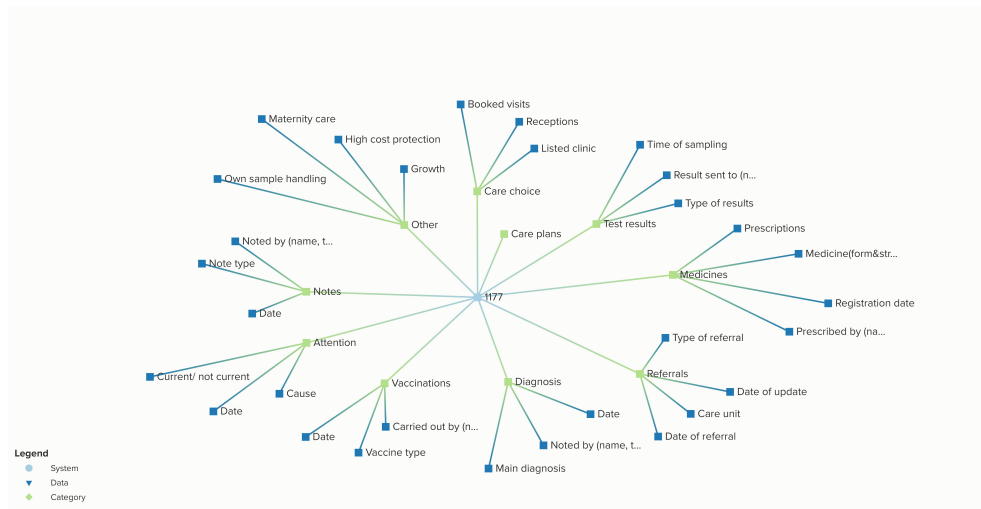
Figure 4.5: An overview of the health data that can be found in 1177.se

4.6 Interview 4 - The issues around obtaining information about a medication list

Respondent 4: Health informatics expert at The Swedish Association of Local Authorities and Regions (SKR).

4.6.1 Barriers

The following barriers were identified during the interview:

1. Many hospitals have their own medical record systems and hence different ways of documenting medicines. The information about which medicines a patient is taking or has taken is different; most medicines are available on prescription and are thus documented in the medicine list, but there are also so-called "rekvisition" medicines. Rekvisition medicines are normally ordered for ward or clinic supplies in inpatient settings. This means that there is no record at the distribution stage of which patient has received which medicine, in what quantity or when. This poses a number of problems in the monitoring of medicines.

2. A common and serious case is that a patient with osteoporosis is treated with a "rekvisition" of Aclasta, which the patient might already have access to. This information is not entered and it is then usually missed that the patient has already received it and thus gives it again. In this

way, the problem is perceived to be that the information in the medical record systems is not comprehensive, rather than accurate.

3. There is a new law on the national list of medicines (2018:1212) which is estimated to be very helpful, but it has not been implemented yet. There are studies that show that there are many patients that do not adhere to treatments well. The problem then becomes, the health care system has difficulty accessing the "real" medication list with the medications that are actually taken.

4. Prescriptions to patients with packaged medicines ("dose patients") within the Stockholm Region are primarily created on Pascal. When it is not possible to use Pascal, paper or fax is used. This means that there is a good overview of these patients' medicines. However, not all patients are dose patients.

5. The problem with home care is that patients are often given very many medicines, which can be difficult to keep track of. ApoDos has appeared to be a solution to this; it is pre-dosed medicines in dose packs that increase patient safety. But not all medicines are available in ApoDos. For example, prescribed patients may be given a bag of medicines to take home. Sometimes the home-care staff may also need to administer other medicines as needed, which is often not documented.

6. Laws regulate what can be transmitted that is transmitted and hence not much information is transmitted out of what is collected.

7. Data from home monitoring, of for instance blood sugar, does not get to the health care system but can be important to exchange.

4.6.2 Needs

There is a perceived need to link the information in the medical record systems and make it more structured and searchable. One problem is that the medical record systems currently do not show the links that exist between symptoms and diagnosis. Hence, whether the symptom or the diagnosis is being treated cannot usually be seen either. Moreover, the diagnoses have different conditions and are linked in different ways, which may be important to include in order to prevent more unwanted health conditions.

In addition, it may be important to have "smarter" data in the record systems. For example, one may need to know how long a patient has had a

catheter, but because the data is often stored as free text, this information is inaccessible.

4.6.3   Further remarks

Laboratory answers (done in regional care) are highly important. The results are received by the care provider but if the patient is also in another system, information can be missed. Within a care provider, it is easy to get information but between care providers, it is more difficult. Coherent medical record keeping and NPÖ are available to help with this issue.

4.7   Interview 5 - The issues around obtaining information about cognitive impairments

Respondent 5: Docent and licensed psychologist.

4.7.1   Memory assessment

Memory problems are common among elderly people. To find out the causes of memory problems, primary care providers can carry out a so-called "basic dementia assessment", which is mainly a test to rule out the presence of deficiency diseases or other medical conditions. The basic dementia assessment consists of several different examinations and tests. It is based on interviews with the person and their relatives, their physical and mental state, cognitive tests and functional and activity capacity. Even brain imaging might be needed. The scope of the basic dementia assessment may vary between different health centres and cases. Sometimes the assessment is carried out entirely by primary care, but it may also be done in collaboration with specialists.

It is common for a diagnosis not to be made, as the problems may be mild cognitive impairments; impairments that happen as a result of ageing and do not meet the criteria for dementia. The criteria for dementia include impairment that affects everyday activities or the performance of tasks given by professionals. In the case of mild cognitive impairments, the person usually has to return several times until a worsening in cognitive ability is seen and a diagnosis of dementia can be made.

A person with dementia has various difficulties remembering and interpreting their surroundings, as a result of damage to the brain. There are

several different types of dementia but the most common type is Alzheimer's disease. There is no cure for dementia, but there is a lot of support available.

Risk factors for dementia include both genetic and environmental factors. Furthermore, high blood pressure can increase the risk of dementia.

4.7.2 Barriers

The identified barriers during the interview were the following:

1. Much of the information in medical record systems has no measurement value or number, and can only be documented in free text. The problem with this is that there are many different ways of documenting text, and with so much information needed to be documented, it becomes difficult to find important data when needed.

2. Investigating cognitive changes usually involves longer investigations because the deterioration over time needs to be followed and the deterioration can take several years. Hence, it is common for many re-visits.

4.7.3 Need

The need identified during the interview was to standardise the medical records, by using new data-driven methods that can find patterns in the collected data. The patterns should be able to help find, for example, what the risk factors are for different diagnoses and thereby help with the prevention of various diseases.

Some risk factors, that can be valuable information for early diagnosis, are smoking habits, alcohol use, physical activity, eating habits, genetics and social networks. Information on whether the person has a habit of stimulating their cognition in different ways can also be a contributing risk factor, although it is usually not the whole explanation for a diagnosis. Furthermore, socioeconomic factors can also be contributory. For example, a person with poor finances might eat less healthily or even end up outside the healthcare system because they cannot afford to receive help. In addition, if a person has problems getting a job, they may become depressed and not be able to exercise.

4.7.4   Important health data to exchange

Changes in a person's motor skills, eating habits and cognitive status can be valuable information for early diagnosis.

4.8   Interview 6 - The issues around frailty

Respondent 6: Associate Professor and Nurse.

4.8.1   Barriers

Ageing is often associated with complicated care at home, multi-morbidity, congestive heart failure, muscle mass decrease, malnutrition and impaired cognition.

The older persons must personally apply for needed support. Local municipality assessors decide the support to be provided after obtaining necessary information from the applicant and sometimes via family members and in consultation with health professionals. Because no medical records (including possible medical diagnoses) need to be included in the evaluation, the assessor has to rely on the information provided by the applicant. This becomes an issue especially when the applicant has dementia and no family members to provide the necessary information.

4.8.2   Needs

The respondent stated that it can be helpful to exchange the following health data, about a multi-morbid elderly person, between the region and the municipality:

- Health status

- Utilised resources

- Contact information of relatives

- Social network, such as neighbours with whom the person has contact with

4.8.3 Previous research

A study that the respondent was part of [16] showed that clients with cognitive impairment were granted more services in personal care and more hours per month than clients without cognitive impairment. However, the same study also showed that no differences were observed between clients with and without cognitive impairment regarding social support services even though clients with cognitive impairment might have a greater need for social support. Cognitive impairment may have a strong impact on daily life, for example, for persons with dementia. Daily-living activities (e.g., shopping, moving outdoors) might be difficult to do in- dependently. Dementia involves reduced cognitive capacity such as impaired memory and often also the ability to communicate. It can, therefore, be problematic for persons with cognitive impairment to express their needs and wishes when applying for home care services. This might be the reason no differences were observed between clients with and without cognitive impairment regarding social support services.

Another study that was mentioned during the interview is about the clinical frailty scale [44]. This study states that frailty is a clinical syndrome associated with decreasing physiological reserves and increased vulnerability to stress. Frailty may be used as a marker of biological age. The Clinical Frailty Scale (CFS) is one of the most commonly used assessment instruments for frailty. It is a 9-level scale, derived from the accumulated deficit model of frailty, which combines comorbidity, disability, and cognitive impairment. CFS estimation is based on clinical assessment of the individual patient. Both the patient's story, medical records and other sources, such as home care, relatives or other close contacts, can be used in the assessment.

CFS can be used for, inter alia:

- Aid risk stratification, so that it can be one of the supports for clinical decision-making in consultation with patients and their families. Thereby, a more individualised treatment can be provided.

- Identification of chronologically aged individuals (80+) who are not biologically aged and therefore should not be excluded from prognosis-enhancing interventions. Thereby, one can ensure that individuals with high chronological age are not casually given low priority for different interventions.

- Making an initial selection of people who may benefit from comprehensive geriatric assessment, that is personalised, needs-based and inter-disciplinary

care.

Finally, a third study [45] was mentioned during the interview. This study states that, even though frailty assessment in the Swedish health system relies on the CFS, it is often missing in medical records. Therefore, an electronic frailty index (eFI) from routinely collected electronic health records was developed and assessed. The study concludes that eFI can be used in risk stratification in hospitalized older adults.

4.8.4 Further remarks

Stockholm Region is currently responsible for home health care. Previously, the home care service in Stockholm was able to distribute medicine (*i.e.* delegation), but the city decided not so long ago to hand the delegation back to the region.

4.8.5 Relevant sources for research about multi-morbid elderly

"Valdatabasen" is an administrative database that contains information on various medical records. It is used as a basis for finance and planning, and can also be used to conduct research. It is used by health actors in Stockholm to follow up on diagnoses, co-diagnoses and medicines, among other aspects.

Because the municipalities are obliged to report to the National Board of Health and Welfare, an overflow of information can be found there for research.

Furthermore, "Äldreguiden" and the unit surveys that can be found there can be used to find information about what the individuals think about their care and service.

4.9 Summary

The following tables summarize the obtained results of the collected and exchanged health data around multi-morbid elderly. The health data were categorized and linked with a colour based on how accessible they are: Green represents high accessibility, yellow represents medium accessibility and red represents low accessibility.

Health data	Collected in the region (by TakeCare)	Transferred between the region and the municipality (by Webcare)	Collected in the municipality (by Social Systems)
Patient/client details	- Name - National ID no. - Gender - Address - Age	- Name - National ID no. - Gender - Address - Age	
Social network*	- Marital status - Family situation *Might* be found as a note	Relatives or other close contacts can be found as a part of SIP	
Lifestyle*	Smoking habits and other risk factors *might* be found as a note		
Living conditions*			
Biology	- Height - BMI		
Medications*	- Prescriptions - Dosages	- Medication list is sometimes given with the security receipt - Need of medications and/or ApoDos can be found as part of ADL-status	
Health care access	- Care contacts - Listed health center	All involved care contacts can be found in SIP	
Social care access	- Access to home service - Access to home care	Listed social care facilities during enrolment	
Inpatient notes	- Allergies - Implanted devices	-Accommodations during enrolment -Notes to consider after discharge	

Health data	Collected in the region (by TakeCare)	Transferred between the region and the municipality (by Webcare)	Collected in the municipality (by Social Systems)
Measurements	- Blood sugar - Blood pressure		
Vaccinations			
Activities*	- Diagnosis - Treatments - Consultations - Screening		-Completed visits -Carried out actions during visits
Test results	Results from: - Blood test - Transfusion medication - X-ray - Physiology - Pat-/cytolab - Chemlab		
Forms	-Life-sustaining treatment -Multidisciplinary results -Cancer notification	Missing information	Need assessment form
Other records	- Ambulance records - Emergency records		
Care plans	- Activity plans - SIP - Bookings	SIP	-Implementation plans - Care plans - Planned actions - Planned visits
ADL status*		Need help with: - Food intake - Moving around - Food intake - Shower and bath - Toilet visits - Continence - Dressing and undressing - Medication - ApoDos	

Health data	Collected in the region (by TakeCare)	Transferred between the region and the municipality (by Webcare)	Collected in the municipality (by Social Systems)
Consent	"Access blocks"	- Note of verbal consent - Personal data protection test	
Enrolment*	Can be found in notes	- Enrolment time - Status - Listed clinic - Hospital - Unit -Accommodation	
Discharge*	Can be found in notes	- Discharge ready - Discharged to - Inpatient notes - Security receipt with medication list	
Case closure		- Reason - Time	
Housing assessment		- Information on wether or not there is a need for a house assessment	Results of house assessment
Investigation of care need			- Contacts for investigation - Results of investigation
Notes			- Deviations - Health care info.

* Issues around this health data have been mentioned during the interviews.

Chapter 5

Discussion

In this chapter, the main findings are highlighted and discussed. Moreover, information about the project's limitations and suggestions for future work are described in a broader context.

5.1 The reality of multi-morbid elderly

A key finding from the conducted literature review is that the reality of multi-morbid elderly individuals is one of the significant demands in today's ageing society. Caring for multi-morbid elderly individuals can present a number of challenges for both the individual and their caregivers. Some of the key challenges include:

1. Managing multiple chronic conditions: The presence of multiple chronic conditions can be complex and difficult to manage, with overlapping symptoms and treatment regimens. Hence, functioning information exchange is of particular importance due to the multi-disciplinary nature of needed care.

2. Adverse drug interactions (DDIs): The risk of adverse drug interactions is increased in individuals with multiple chronic conditions, which can further complicate treatment and management. Hence, functioning information exchange is of particular importance, due to the increased risk of DDIs and adverse effects of polypharmacy.

3. Physical and emotional burden: The presence of multiple chronic conditions can lead to physical and emotional burdens, which can negatively impact the elderly individuals' quality of life.

4. Reduced functional ability: The presence of multiple chronic conditions can lead to reduced functional ability and mobility, which can make it difficult for elderly individuals to engage in activities of daily living.

5. Social isolation: The physical and emotional burden of multiple chronic conditions can lead to social isolation, which can further impact the quality of life.

6. Economic consequences: The cost of treating and managing multiple chronic conditions can be high, which can put a strain on both the individual and the healthcare system.

Given the complexity of multi-morbidity in the elderly population, it is important for healthcare professionals to adopt a holistic approach to care. This may involve coordinating care across multiple specialities, addressing social and psychological factors that may contribute to the individual's overall health and well-being, and providing support for caregivers.

5.2 Concerns around health data collection and sharing

Health data sharing could potentially help with the challenges that come with ageing and multi-morbidity. By providing a comprehensive overview of an individual's health status, treatment history, and current medications, healthcare professionals can better coordinate care and avoid potential adverse drug interactions. Additionally, health data sharing could provide valuable insights into the effectiveness of different treatment approaches and help identify potential areas for improvement. However, it is important to note that barriers to accessing relevant health data exist.

5.2.1 Relevant health data is difficult to access

A key finding from the interviews was that relevant health data can be difficult and time-consuming to find, especially in TakeCare, and the barriers behind this were identified to be the following:

1. The majority of the health data is documented as free text notes in TakeCare (4.1, 4.3).

2. A lot of the health data has no measurement value or number to be linked with (4.7).

3. Different systems are used in different healthcare facilities (4.3, 4.6).

4. Different templates and styles for documentation in TakeCare are used in different areas of the same healthcare facility (4.3).

5. TakeCare is perceived to be outdated (4.3).

The fact that different medical record systems are used in Sweden and even in Stockholm compromises patient safety. For instance, if a patient cannot explain his or her background, double work must be done by obtaining information about a patient in another medical record system.

Consequently, there is a need to standardise medical records. This need is in line with the findings from the literature review. For instance, by making all involved health social actors use the same system or to better integrate the existing ones. This would however not necessarily solve the issue of the notes section having an overflow of information that is difficult to navigate through. Hence, using certain templates for all documentation could be a better solution. This could help make the information in the notes section, more accessible. However, the templates could be considered time-consuming by health providers, especially when it comes to complex cases where a template cannot be applied, and cause them to use their phones more often to exchange health data.

Furthermore, there was a need to link the information in medical record systems and make it more structured and searchable. This could be possible by using new data-driven methods that can find patterns in the collected data. The patterns should be able to help find, for example, what the risk factors are for different diagnoses and thereby help with the prevention of various diseases. Some risk factors that can offer valuable information for early diagnosis, are smoking habits, alcohol use, physical activity, eating habits, genetics and social networks.

However, new technology, especially if it includes artificial intelligence, could take many years to implement in health- and social care. Especially because of laws and regulations and also the attitudes of health providers towards new technologies.

Overall, the concerns that have been mentioned during the interviews need to be addressed. As it can be seen in 2, it is highly important for health actors to have access to comprehensive and up-to-date patient information to facilitate the delivery of effective and coordinated care to elderly patients. And as it can be seen in 4, there is a challenge in determining the relevance of the information at the time it is viewed, as it can be difficult to get a complete

picture of past treatments and other changes in the record. This is further complicated by the temporal nature of medical information and the need for follow-up. Hence, the lack of access to relevant health data can have serious negative consequences for the care of elderly patients and can impact the quality, efficiency, and safety of care.

5.2.2 The possibility of linking health data should be investigated

During interview 4.6, it was mentioned that the medical record systems currently do not show the links that exist between symptoms and diagnosis. Hence, whether the symptom or the diagnosis is being treated cannot usually be seen either. Moreover, the diagnoses have different conditions and are linked in different ways. Finding the links and including them in the medical record systems could be used for health prevention, especially when it comes to patients with many diagnoses and different treatments which is the case of the multi-morbid elderly. This should be further investigated when finding new data-driven solutions for better health data exchange.

5.2.3 The absence or lack of a medication list is a recurrent problem

The medication list is often non-reliable, and the barriers behind this issue were identified to be the following:

1. The responsibility to update the medication lists is on the involved physicians from primary care, whom cannot possibly have all the necessary information to be able to do so (4.3).

2. There are many health actors that are involved in giving the medication list 4.3.

3. Not all involved health actors have access to Pascal (4.1). Sometimes the home-care's staff may need to administer other medicines, which often goes undocumented (4.6).

4. Not all patients are dose patients and not all medicines are available in ApoDos (4.6).

5. The actual intake is missing (4.3, 4.6).

Consequently, there is a need to transfer health data from home monitoring and give the assistant nurses in home care access to Pascal and more medicines available in ApoDos. However, the use of ApoDos system and Pascal brings up an interesting point; who develops these systems and do they consider the user needs? Perhaps, they need to work more closely with the clinical profession to better integrate their systems.

5.2.4 There is a risk that elderly with cognitive impairment do not receive the care that they need

Cognitive impairment may have a strong impact on daily activities and communication. As a result, elderly people with cognitive impairment may not be able to give the necessary information to the assessors when they apply for social care services. Because the assessors are dependent on the information that is given by the applicant, there is the risk that the applicant does not receive the care that they need.

Hence why contact information for the people that can advocate for the person's needs becomes highly important data to the assessors in Social Care. Even a diagnosis from TakeCare might be critical information, especially when a person has no one to advocate for his/her needs. However, the assessors do not have access to the diagnosis.

There is also a need to see changes in condition in a timely manner. A solution could be to transfer the deviations that are documented by the health providers from home care and home services to the region. This information could be exchanged by documenting it directly in TakeCare. However, this could be lost in the abundance of information that already exists in TakeCare.

5.3 How to better support multi-morbid elderly

Managing multimorbidity can be challenging for both patients and healthcare providers, as it requires careful coordination and monitoring of multiple medications and their potential interactions. In order to better support multi-morbid elderly patients who have access to home care and home services, it is important to share relevant health data that can inform the care and management of the chronic conditions that are mentioned in 2. Some of the health data that are currently being collected and may be relevant to share in this context include:

- Medical history: This includes information about the patient's past and current diagnoses, treatments, and procedures, as well as any allergies or sensitivities. Medical history can provide important context for the care and management of chronic conditions and can help identify potential risks or complications. This is currently not being exchanged.

- Medication list: This includes information about the patient's current medications, including the name, dosage, frequency, and purpose of each medication. Medication lists can help ensure that patients are taking their medications correctly and can also alert healthcare providers to any potential drug interactions or contraindications.

- Laboratory results: This includes information about the patient's blood work, imaging, and other diagnostic tests, as well as the results and any relevant interpretation or recommendations. Laboratory results can help inform diagnoses and treatment decisions and can also support the monitoring of chronic conditions.

- Symptoms and vital signs: This includes information about the patient's current symptoms, such as pain, fatigue, or shortness of breath, as well as their vital signs, such as blood pressure, heart rate, and temperature. Symptoms and vital signs can provide important clues about the patient's health status and can help identify potential issues or changes in their condition.

- Functional status: This includes information about the patient's ability to perform activities of daily living (ADLs), such as bathing, dressing, and toileting, as well as their mobility and cognitive function. Functional status can help assess the patient's independence and needs and can inform care and support plans.

- Care plan: This includes information about the patient's care goals and objectives, as well as the strategies and interventions that have been put in place to achieve these goals. Care plans such as SIP can help coordinate and integrate the care provided by different healthcare providers and can also support the patient's participation in their care.

Overall, the relevant health data that can help support the care and management of multi-morbid elderly patients who have access to home care and home services, exists in the HIE systems that are used in Stockholm. However, several barriers exist that make it difficult to access relevant health

data. This could be a major problem for the care of multi-morbid elderly individuals because of the complexity of their reality. Moreover, it is important for individuals with multi-morbidity to work closely with their healthcare team to ensure that their treatment plan is safe and effective, and to report any concerns or adverse reactions to their medications. This is especially true for individuals with dementia to help slow the progression of the disease and improve their quality of life. This may include medications, therapies, and support for caregivers. Therefore, new HIE solutions need to be considered.

5.4 Sweden's readiness to adopt the European Health Data Space

The European Health Data Space is a proposed initiative by the European Commission that aims to enable individuals to have increased digital access to and control of their electronic personal health data and to support the free movement of this data [46]. It also aims to provide a consistent, trustworthy, and efficient setup for the use of health data for research, innovation, policy-making, and regulatory activities [46].

While it is difficult to draw a conclusion on the readiness of a healthcare system to meet the vision of the European Health Data Space, it can be discussed that it will depend on various factors, including resources, infra-structure development, and the willingness and ability of healthcare providers to adopt new technologies and practices.

Sweden has a well-regarded healthcare system with a high level of invest-ment in healthcare technology and infrastructure, but this study shows that while there are many opportunities to adapt (many effective technical solutions already exist), there are also many barriers that need to be considered first. The issues with access to relevant health data and the integration of medical record systems in Sweden are no small issues. They may hinder the country's readiness to adopt the European Health Data Space. Addressing these issues is critical and may involve implementing new technologies and practices and addressing regulatory or policy barriers.

5.5 Future research

There is a need for future research on relevant health data to exchange around multi-morbid elderly people in order to better understand and address the

challenges and barriers to effective data sharing in this context. Some potential areas for research include:

- Data security and privacy: As the sharing of patient data becomes increasingly prevalent, it is important to ensure the security and privacy of patient information. Research is needed to identify best practices and technologies for protecting the confidentiality, integrity, and availability of patient data, and to understand the ethical and legal implications of data sharing.

- Data interoperability: To facilitate the sharing of patient data among different healthcare providers and systems, it is important to ensure the interoperability of different data systems. Research is needed to identify and evaluate standards, protocols, and technologies that can support the interoperability of patient data, and to understand the challenges and barriers to achieving interoperability

- Data quality and accuracy: To ensure that patient data is useful and reliable, it is important to ensure the quality and accuracy of the data. Research is needed to identify and address sources of error or bias in patient data, and to develop methods and tools for assessing and improving the quality of patient data.

- Data complexity and diversity: The complexity and diversity of patient data can present challenges for effective data sharing, particularly in the context of multi-morbid elderly patients. Research is needed to understand the types and sources of patient data that are most relevant and useful for the care of multi-morbid elderly patients, and to identify strategies for integrating and synthesizing diverse data sources.

- Patient preferences and needs: It is important to consider the preferences and needs of patients when deciding what health data to share. Research is needed to understand the patient perspectives on data sharing, including their concerns, expectations, and preferences, and to develop approaches that respect and support patient autonomy and rights.

Overall, future research on relevant health data to exchange around multi-morbid elderly people can help identify and address the challenges and barriers to effective data sharing, and support the delivery of coordinated and holistic care to elderly patients.

Moreover, more research is needed to explore risk factors for multi-morbidity in elderly individuals. In 2 and 4, multiple risk factors were

briefly mentioned. But to effectively reduce the consequences of multi-morbidity in elderly individuals, such as loneliness and cognitive impairments, interventions should be based on firm evidence. This evidence needs to be further investigated. regarding risk factors for loneliness in that population. Some risk that was mentioned and that can be explored are: not being married/partnered, partner loss, a limited social network, a low level of social activity and poor nutrition.

For others working in this area, a suggestion would be to arrange a workshop with the health actors that are commonly involved in the care of the multi-morbid elderly (physicians and nurses from the inpatient care and nurses, assistant nurses, care assistants and welfare officers from home care and home services). Patients/ clients should also be involved, to find out what health data they wish to be exchanged, to better support their needs.

5.6 Limitations

Limitations of the results included limited information on the medical record systems and the fact that no real definitions of the health data could be obtained. This was mainly due to laws and regulations on who can gain access to medical records. For this research, no access could be given to the medical record systems and as a consequence, the study was dependent on what was said during the interviews. Furthermore, no patients or clients were involved in this study, due to the limited time of research. Hence, the elderly individuals' perspective could not be included.

Moreover, there are several limitations that can make further research of this study difficult:

1. Lack of access to data: Digital health technologies generate large volumes of data, which can be difficult to access for research purposes. This can be due to data privacy and security concerns, as well as the complex systems used to collect and store the data.

2. Limited funding: Research in the field of digital health can be expensive, and funding may be limited. This can make it challenging for researchers to secure the resources needed to conduct their studies.

3. Complexity of the healthcare system: The healthcare system is complex and can be difficult to study. This can make it challenging for researchers to accurately assess the impact of digital health technologies and systems on patient outcomes and healthcare delivery.

4. Regulatory barriers: Digital health technologies and systems are often subject to various regulatory requirements, which can make it difficult for researchers to access and use these technologies in their studies.

5. Ethical considerations: Research involving digital health technologies and systems can raise ethical concerns, such as data privacy and informed consent. Researchers must carefully consider these issues and ensure that they are addressed in a responsible and ethical manner.

Overall, these limitations can make it challenging to conduct research in the field of digital health, but they are not insurmountable. By addressing these challenges, researchers can make important contributions to the understanding of these technologies and their impact on healthcare delivery and patient outcomes.

Chapter 6

Conclusions

The following research questions were addressed in this study:

1. **What health data is collected and exchanged around multi-morbid elderly individuals, with a need for both health care and home care, in Stockholm?**
   An abundance of health data is collected in the utilised HIE systems in Stockholm, but there are barriers to accessing some relevant health data. The use of different medical record systems and the difficulty of accessing data from the free text notes can make it difficult to effectively share and use this data. Consequently, there is a need to standardize medical records and use data-driven methods to find patterns in the collected data in order to make the information more structured and searchable. Therefore, new HIE solutions should be considered. However, the implementation of new technology, including artificial intelligence, may be hindered by laws and regulations and the attitudes of healthcare providers towards new technology. It is important to address these concerns in order to facilitate the delivery of effective and coordinated care to elderly patients.

2. **How does the exchanged health data represent the reality of the multi-morbid elderly individuals?**
   The exchanged health data is not enough to represent the reality of the multi-morbid elderly individuals. The reality of multi-morbidity is a significant challenge in today's ageing society. It can present a number of difficulties for both elderly individuals and their caregivers; including managing multiple conditions, increased risk of adverse drug interactions, physical and emotional burden, reduced functional ability,

social isolation, and economic consequences due to high care utilization. It is important for health and social actors to take a more holistic approach to care for elderly individuals with multi-morbidity, which may include coordinating care across multiple specialities, addressing social and psychological factors, and supporting their desire to age at home.

3. **What health data should be exchanged to more effectively support elderly individuals with multi-morbidity?**
   There are relevant health data that are currently being exchanged, including medical history, medication list, laboratory results, functional status, and care plan. To better support multi-morbid elderly individuals, more health data should be exchanged, including changes in motor skills, eating habits, cognitive status, electronic frailty index, risk factors for dementia and loneliness, contact information to people that can advocate for the elderly individual's health, and a more reliable medication list.

Overall, this study added to the existing knowledge on the HIE systems that are currently utilised in Stockholm's health and social care system, and how to better support individuals that are ageing with multi-morbidity. This was done by collecting and identifying health data, barriers and needs. This provides a foundation for further exploration of other factors that were outside the scope of this study, such as legal and organizational considerations.

However, further research is necessary to understand the challenges and barriers to effective data sharing in the context of multi-morbid elderly patients, and to address these challenges through research focused on data security and privacy, data interoperability, data quality and accuracy, data complexity and diversity, and patient preferences and needs. In addition, more research is needed to identify risk factors for multi-morbidity in elderly individuals and to develop interventions based on this information. This can help improve the care and support of multi-morbid elderly patients and help adopt the vision of the European Health Data Space.

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