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# **PATIENTS' SELF-EMPOWERMENT – PATIENTS AND INFORMAL CAREGIVERS TAKING THE LEAD**

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Cover illustration: Marie Lind – “Patients and informal caregivers lead the way in collaboration with healthcare professionals”

# Patients' self-empowerment – patients and informal caregivers taking the lead

## Thesis for Doctoral Degree (Ph.D.)

By

**Therese Scott Duncan**

The thesis will be defended in public at Karolinska Institutet, Inghesalen, Stockholm, 2023-03-17, 13.30 o'clock

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*My heart is full of good intentions.  
I want to help using all I know.  
I know a lot you don't know about  
diagnosis, treatment, risks, benefits, statistics.  
How can I assure you know enough  
so you can make the right choices?  
I protect my heart so I am safe  
from making choices, from sharing your life.*

*My heart is full of life.  
I know a lot you don't know about  
love, hope, grief, fear, illness, mortality.  
How can I help you know enough about who I am  
so you can help me make the right choices?  
So we can share our knowledge and our lives?*

Stu Farber. Living Every Minute.  
Journal of Pain and Symptom Management.

2015;45(4)



## Popular science summary of the thesis

To have a chronic condition, or being affected by one, is often considered as a burden. To handle self-management, navigate through health care, and other organizations in society are tasks put upon people often without ability or strength to fight for their rights. But sometimes there are patients or family caregivers who have the power to take control, and with this control they help others in the same situation. They also collaborate with health care and other organizations in society to ensure there are guidelines and easy paths to walk for those who need it. This thesis was done to understand how these patients and family caregivers take control using different behaviors, different technical solutions, and what motivates them. I also invite healthcare professionals to share their attitudes and experience of working together with patients and family caregivers taking control. The research was done through interviews and questionnaires. We could see that patients and informal caregivers taking control often create their own data through monitoring their condition, they learn from it, share their knowledge, and collaborate with others. Sometimes they create new solutions for their self-management and for solving existing problems. They also search a lot of information outside health care. Different behaviors used are:

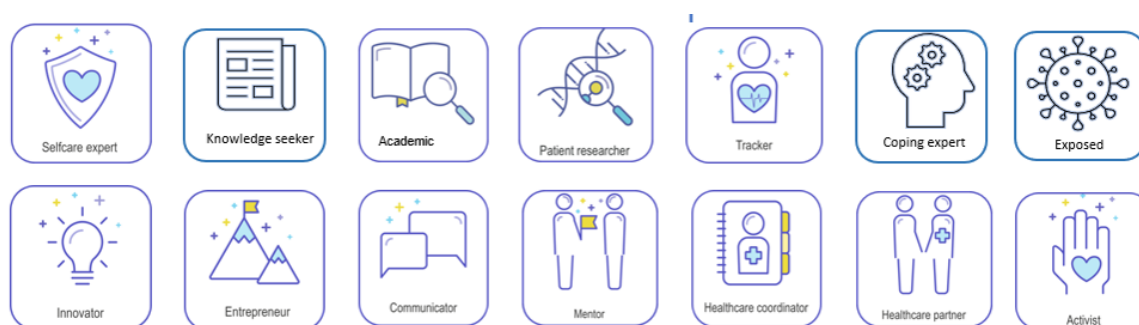


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Some of these behaviors were experienced as forced upon the patients and informal caregivers and not voluntary. Other behaviors they wished to do more of. This could lead to difficult situations with healthcare professionals, not always having the time. Still, healthcare professionals had overall positive attitudes towards patients and informal caregivers with control. But there were no existing workplace support or guidelines for meeting these patients and informal caregivers. This thesis provides new knowledge of self-management tasks, benefits and burdens, and different behaviors of patients and family caregivers affected by chronic conditions. This knowledge could be used by developers of self-management solutions and by the healthcare system.

# Populärvetenskaplig sammanfattning

Att leva med kronisk sjukdom, eller vara närstående, är ofta en börda. Det handlar om att hantera sin egenvård, navigera inom hälso- och sjukvårdssystemet samt andra myndigheter och organisationer i samhället. Dessa sysslor förväntas utföras av svårt sjuka personer som ibland inte har styrkan eller kapaciteten. Men ibland har patienter och närstående kraft och möjlighet att ta kontrollen och hjälpa andra, samarbeta med hälso- och sjukvården samt med myndigheter och organisationer i samhället. Detta för att hjälpa sig själva men också andra genom att se till att det finns rimliga riktlinjer att följa. Den här avhandlingen ger kunskap om hur dessa patienter och närstående tar kontrollen över sina liv med hjälp av olika beteenden, tekniska lösningar, och genom att vara motiverade. Hälso- och sjukvårdspersonal har även deltagit i forskningen, och ger sin syn på att jobba tillsammans med patienter och närstående som tar kontroll. Intervjuer och enkäter har använts för att samla in information till forskningen. Det visade sig här att patienter och närstående som tar kontroll skapar sina egna data genom att mäta olika aspekter av sin sjukdom. De lär sig från sina data, delar med sig av sin kunskap och samarbetar med andra. Ibland skapar de egna lösningar för sin egenvård och för att lösa hälsorelaterade problem. De söker också mycket information utanför hälso- och sjukvården. De olika beteenden som används är:

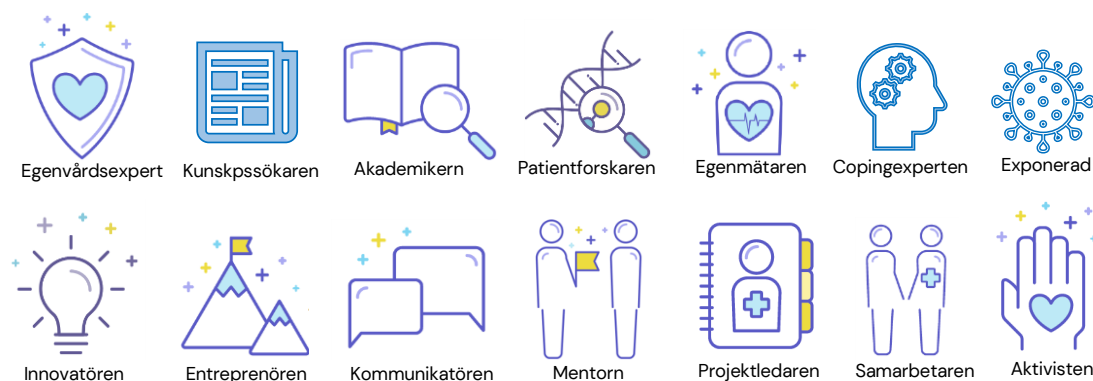


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Några av dessa beteenden upplevdes som ett måste och var påtvingat, medan andra beteenden önskade deltagarna få göra mer av. Dessa olika beteenden kunde ibland leda till svåra situationer med hälso- och sjukvårdspersonal, speciellt när de inte hade tid för patienterna och närstående. Ändå så upplevde hälso- och sjukvårdspersonalen att det är positivt med patienter och närstående som agerar utifrån dessa beteenden. Även fast de inte hade något stöd eller riktlinjer från arbetsplatsen att möta dessa beteenden. Den här avhandlingen ger mer kunskap om egenvårdssysslor, positiva och negativa aspekter med dessa sysslor, och patienters och närståendes olika beteenden. Denna kunskap kan användas av utvecklare av hälso- och sjukvård, digitala stöd för egenvård, och av hälso- och sjukvårdssystemet.



# Abstract

**Background:** It is rather common for patients and informal caregivers affected by chronic conditions to experience aspects of disempowerment being in a paternalistic structure. Patient empowerment is often understood as a power to achieve control over the determinants of a person's quality of life, as well as being authorized by healthcare professionals and steered from a healthcare perspective on self-management and care. Patient self-empowerment, on the other hand, describes patients' and informal caregivers' power to perform activities that are not mandated by health care and to take control over their own lives and self-management with increased self-efficacy and confidence. Self-empowered patients and informal caregivers are described in the literature by many different concepts and can be the key to future development of health care and diffusion of innovation solutions for themselves and their peers. Knowledge about self-empowering behaviors and motivation of patients and informal caregivers is scarce. Further, the perspective of healthcare professionals and their attitudes, experiences, and workplace support when working with self-empowered patients and informal caregivers has not been researched extensively.

**Aim:** To further understand how patients and informal caregivers can take the lead in their own care and self-management, the overall aim of this thesis is to study the driving forces and self-empowering behaviors of patients and informal caregivers affected by chronic conditions, and how healthcare professionals and the healthcare systems meet these behaviors.

**Methods:** This is a mixed methods thesis with four studies deriving from two projects. Qualitative data collection was done through semi-structured interviews (study I-III) and focus groups (study III), and quantitative data was collected through surveys (study II & IV). Patients and informal caregivers affected by chronic conditions and with self-empowering behaviors participated in study I (n=15) and study III (n=48), and persons with Parkinson Disease performing self-tracking participated in study II (n=187). Healthcare professionals were respondents in study IV (n=279). The data were analyzed using five different approaches: Framework analysis (study I), Conventional content analysis (study II), Thematic analysis (study III), Direct content analysis (study III), and Descriptive analysis (study II & IV). Inductive, deductive, and abductive reasonings were used to process the data to draw conclusions.

**Results:** As self-empowered patients and informal caregivers, the second generation of e-patients generated health data and learned how to handle their situation from it. Further, they invented self-management solutions for themselves and their peers, as well as innovations to co-operate with healthcare professionals. This was done in line with support for their psychological needs; relatedness, competence, and autonomy. Still, to generate own data through self-tracking always came with the risk of being obsessed of

their own condition. Other behaviors were experienced as forced upon the patients and informal caregivers and not completely voluntary, whereas some behaviors were wished to be expanded. This might lead to difficult situations with healthcare professionals, not having the time or understanding of these self-empowering behaviors. Still, there were overall positive attitudes from healthcare professionals, even though they lacked experiences of working together with self-empowered patients and especially informal caregivers. There were no existing workplace support or guidelines for meeting patients and informal caregivers with self-empowering behaviors.

Conclusion: This thesis makes a unique contribution by analyzing patient self-empowerment as well as healthcare professionals' attitudes towards self-empowering behaviors. With a rather limited understanding of self-management tasks, healthcare professionals are here provided with a better understanding of self-empowering behaviors and needs among patients and informal caregivers. Self-empowerment will continue to influence the development of participatory healthcare. Hence, to understand the behaviors of the users of health care are essential to further develop towards experienced-based participatory design, person-centered health care, and support for healthcare professionals to partner with patients and informal caregivers in a joint empowerment.

Keywords:

Empowerment, patient participation, self-management, chronic conditions, behaviors, e-patients

# Prologue

I was born into a so called “funkis family” during the 1970s. This meant I had a three-year older brother, named Kenneth, with severe disability, and that our family most of the time adjusted our everyday life in regard to him. During the 70-ties it was not considered appropriate for parents to take care of such a sick child. My parents were told to give Kenneth away to be institutionalized, and that he would only live three years in due to his disabilities. Still, my parents decided not to listen and never to give up on their child. My mother quit her job and took care of him full time, e.g. to feed him one meal took her two hours. When I later in my life, as a young adult, got a chronic condition, these experiences gave me the insight of how to deal with self-management for better health, as well as for survival.

My thesis project started 2017 with my involvement in the project “Patient Lead Users” (“Spetspatienter” in Swedish) (2-year project financed by Vinnova, the Swedish Governmental Agency for Innovation Systems, grant number 2017-01221), that aimed to change both research and healthcare settings in regard to person-centeredness and patient participation. Here I decided to perform my research about the new concept of patient lead user. What motivated these patients and informal caregivers and how did they act and behave? Informal caregivers often make difficult decisions for the most vulnerable patients, either adults or children. To examine this, I reviewed the literature for existing concepts that described empowered patients and informal caregivers affected by chronic conditions. This resulted in studying the perspective of e-patients in my licentiate thesis from 2020. In the second part of my doctoral studies, I focused on healthcare professionals’ perceptions of self-empowered patients and informal caregivers, and now the concept patient lead users was part of the research project “The patient in the driver seat” (6-year project financed by Forte, the Swedish Research Council for Health, Working Life and Welfare, grant number 2018-01472). This project entailed patient driven innovations that enabled patient and informal caregiver participation in healthcare. This thesis focuses on a combination of perspectives from both patients and informal caregivers as well as healthcare professionals.

## List of scientific papers

- I. **Duncan Scott T**, Riggare S, Koch S, Sharp L, Hägglund M. From Information Seekers to Innovators: Qualitative Analysis Describing Experiences of the Second Generation of E-Patients. J Med Internet Res. 2019; 21(8):1 – Paper was also included in the licentiate thesis
- II. Riggare S, **Duncan Scott T**, Hvitfeldt H, Hägglund M. “You have to know why you’re doing this”: a mixed methods study of the benefits and burdens of self-tracking in Parkinson’s disease. BMC Medical Informatics and Decision Making. 2019;19(175) – Paper was also included in the licentiate thesis
- III. **Duncan Scott T**, Engström J, Riggare S, Hägglund M, Koch S. Meeting the burden of self-management: Qualitative study investigating the empowering behaviors of patients and informal caregivers. J Particip Med. 2022;14(1) – A former version of the paper was included as manuscript in the licentiate thesis
- IV. **Duncan Scott T**, Riggare S, Bylund A, Hägglund M, Stenfors T, Sharp L, Koch S. Empowered patients and informal caregivers as partners? – a survey describing healthcare professionals’ perceptions (submitted)

## Additional publications

Hägglund M, Scott Duncan T, Kai-Larsen K, Hedlin G, Krakau I. IntegrIT-Towards Utilizing the Swedish National Health Information Exchange Platform for Clinical Research. Studies in Health Technology and Informatics. 2017;235:146-150.

Scott Duncan T, Hägglund M. Understanding Study Participants Views on Co-Creation of Data and Use of EHR in Clinical Studies. Studies in health technology and informatics. 2018;247:341-345.

Scott Duncan T. Paving the way: the second generation of e-patients, their experiences, actions and driving forces. Licentiate thesis, Karolinska Institutet, 2020. KI Open Archive. URL: [Paving the way : the second generation of e-patients, their experiences, actions and driving forces \(ki.se\)](#)

# Contents

1	Introduction .....	1
2	Literature review .....	3
2.1	Conceptual background .....	3
2.1.1	Patient empowerment .....	3
2.1.2	Self-empowerment .....	4
2.1.3	Self-care.....	4
2.1.4	Self-management in the digitalization era.....	4
2.2	Related concepts that describe empowered patients and informal caregivers .....	6
2.2.1	E-patients.....	6
2.2.2	Expert patients.....	7
2.2.3	Lead users .....	8
2.3	Theoretical background .....	9
2.3.1	The Model of Illness Related Work.....	9
2.3.2	The Taxonomy of Burden of Treatment.....	10
2.3.3	Self-Determination Theory .....	10
3	Thesis rationale and aims .....	13
4	Materials and methods.....	15
4.1	Study I .....	16
4.1.1	Study design I.....	17
4.1.2	Study sampling I.....	17
4.1.3	Data collection I.....	17
4.1.4	Data analysis I.....	17
4.2	Study II .....	18
4.2.1	Study design II .....	18
4.2.2	Study sampling II.....	19
4.2.3	Data collection II.....	19
4.2.4	Data analysis II .....	19
4.3	Study III .....	20
4.3.1	Study design III .....	20
4.3.2	Study sampling III .....	21
4.3.3	Data collection III .....	21
4.3.4	Data analysis III.....	21
4.4	Study IV .....	23
4.4.1	Study design IV .....	23
4.4.2	Study sampling IV .....	23
4.4.3	Data collection IV .....	23
4.4.4	Data analysis IV.....	23

4.5	Ethical considerations.....	24
4.5.1	Informed consent.....	24
4.5.2	Privacy and confidentiality.....	24
5	Results.....	25
5.1	From information seekers to innovators (Study I).....	25
5.1.1	Non-digital factors influencing active engagement.....	26
5.1.2	Digital solutions to support active engagement.....	27
5.2	Benefits and burdens of self-tracking (Study II).....	28
5.2.1	Why I self-track.....	28
5.2.2	How and what I self-track.....	29
5.2.3	Lessons learned from self-tracking.....	29
5.2.4	Risks related to self-tracking.....	30
5.2.5	Self-tracking and health care.....	31
5.3	Self-empowering behaviors of patients and informal caregivers (Study III).....	32
5.3.1	Patterns of exploratory behaviors.....	34
5.3.2	Patterns of influencing behaviors.....	35
5.4	Healthcare professionals' perceptions (Study IV).....	35
5.4.1	Patient knowledge.....	36
5.4.2	Innovative patient self-care behaviors.....	36
5.4.3	Patients and informal caregivers navigating the healthcare system.....	37
6	Discussion.....	39
6.1	Discussion of the findings.....	39
6.2	Discussion of the findings in relation to the literature.....	42
6.2.1	Health inequity perspective.....	43
6.3	Methodological considerations.....	43
7	Future work.....	45
8	Conclusion.....	46
	Epilogue.....	
	Acknowledgements.....	
	References.....	

## List of abbreviations

FA	Framework analysis
LoC	Locus of control
PD	Parkinson disease
PwP	Persons with Parkinson disease
SDT	Self-determination theory
TA	Thematic analysis
WHO	World Health Organization





# 1 Introduction

Self-management today differs from when I grew up, mostly because of the rapid development of digitalization. With smartphones we have the knowledge of the whole world in our pockets. With the help of applications, we can measure disease progress, symptoms, and stay in control over our lifestyles. With the help of a digital device, we can measure our pulse or understand our sleeping-patterns. From this data the device then can give you advice whether to rest or to perform physical activity. With the use of a small computer, a raspberry pie, more innovative self-managers within e.g. diabetes can program an artificial pancreas using an open-source approach [1,2] and thus make the code available for others to use and extend. These helpful digital solutions for self-care did not exist when I grew up, or as a young adult newly diagnosed with a chronic condition. Mine and my family's empowerment came from aspects of family values, social networks, and environment. Today digital solutions for self-care help people to become self-empowered.

This thesis covers different patient and informal caregiver concepts, the evolution of e-patients, theories that describe patients' and informal caregivers' motivation, and participatory health care. I will introduce patient self-empowerment by moving away from the notion that patient empowerment is offered from healthcare professionals. This is a process that happens in line with the digital development of self-management and in collaboration between healthcare professionals and patients or their informal caregivers. Perspectives from both patients/informal caregivers and healthcare professionals are important when consider patient self-empowerment and participatory healthcare. The Swedish Patient Act [3,4] states that patients should be involved when health care is being planned and performed. Informal caregivers have the same opportunities for involvement if considered appropriate and in line with regulations of confidentiality and professional confidentiality [3,4]. So how can patients and informal caregivers take the lead in their own care and self-management?

The outline of this thesis integrates different perspectives on behaviors of self-empowered patients and informal caregivers; namely patient and informal caregiver perspectives (studies I-III) and adding the healthcare professional perspective (study IV). These perspectives in relation to the four studies are illustrated in Table I.

**Table I.** Outline of thesis.

<b>Project</b>	<b>Study</b>	<b>Perspective</b>
Project one – Licentiate thesis	I, II, III	Patients and informal caregivers
Project two – Doctoral thesis	III, IV	Patients and informal caregivers & Healthcare professionals

## 2 Literature review

It is rather common for patients and informal caregivers affected by chronic conditions to experience aspects of disempowerment occurring in a paternalistic healthcare system [5]. In this thesis a chronic condition is defined as a noncommunicable disease with a long duration, mostly with a gradual progression, and a consequence from genetics, environmental and behavioral factors, as well as by chance [6]. Patient empowerment is often described as a power authorized by healthcare professionals to patients and informal caregivers [7]. Self-empowerment, however, comes from the patient's and informal caregiver's own ability and motivation and can be described through different constructs that affect human behaviors, such as believe a person can be in control over one's life by making different choices. These rather proactive behaviors are described below through concepts of empowered patients and informal caregivers and different theories.

### 2.1 Conceptual background

#### 2.1.1 Patient empowerment

Patient empowerment is in the literature described as a process to activate and involve patients in their care and self-care. It is also described as patient participation [8]. WHO's definition of patient empowerment describes a process where healthcare professionals provide patients with an understanding of their part of the health and care process, with knowledge and skills, an understanding of the facilitating environment, and encourage patients to participate in their care. This will, according to WHO [8], lead to patients and informal caregivers gaining a greater control over their health decisions and activities [8]. To be empowered will emphasize patient participation, since obtaining a relationship with healthcare professionals often requires control over health decisions and actions [9]. The meaning of patient empowerment thus depends on healthcare professionals to convey power to patients and informal caregivers, meaning that without healthcare professionals, patients and informal caregivers would be without control and autonomy [7]. Hence, the concept of patient empowerment emphasizes a healthcare professional's point of view [10,11]. Empowerment has a goal to achieve control over the determinants of a person's quality of life. This requires increased autonomy with an ability to critically reflect and to have needs and desires to pursue and act upon. This, however, does not mean that there always is freedom to act upon these needs and desires. Hence, autonomy and freedom are not linked, still autonomy is necessary to achieve empowerment [12]. Even though many attempts have been made to conceptualize patient empowerment in the literature, there is a continuing deficiency of clarity and consistency in what is being measured [13].

### **2.1.2 Self-empowerment**

In the literature there are also other definitions of patient empowerment, such as Zimmerman's definition [14] which is rather similar to WHO's. Patients should have the belief of own capacity to change the situation, understand what actions to take to accomplish the intended outcome, and to take control and influence the surrounding environment [14]. This definition however goes outside the healthcare context of patient empowerment and to manage a chronic condition. It leads into patient self-empowerment that rather grows from interactions in personal social settings instead of as a consequence of an external process such as being empowered by healthcare professionals [15]. To be self-empowered includes to take control over one's life with an increased self-efficacy and confidence. This is however not always beneficial for the health-outcome if self-empowered patients overrule prescriptions and do not value medication adherence [9]. Patient empowerment and health literacy are not conjoined twins, as Schulz PJ et al state [16]. Still, patient self-empowerment is an important aspect to efficiently manage self-care.

### **2.1.3 Self-care**

Self-care is understood as the broader concept of taking responsibility for health and well-being with health promotion, disease prevention, and self-management when having an illness. It is performed in everyday life and requires driving forces and self-efficacy to achieve the goals of living a healthy life [17,18]. This includes preventive measures such as screening as well as contraception to avoid unintended pregnancies. Reasons for different self-care interventions are e.g. to increase health for individuals, decrease healthcare costs for society and individuals, to avoid healthcare encounters for individuals expecting stigma, for individual convenience, or because it makes individuals feel confident and empowered [19]. The definition of self-care by WHO [19] is: "*the ability of individuals, families and communities to promote their own health, prevent disease, maintain health, and to cope with illness and disability with or without the support of a health worker*" [19].

### **2.1.4 Self-management in the digitalization era**

Self-management is described in the literature as managing aspects of having a chronic condition and is part of the broader concept of self-care [20]. These managing aspects include three fixed tasks: *medical management*, *role management* and *emotional management*, as stated in the model of illness-related work [21]. These tasks include e.g. medical intake, handling symptoms from medication as well as the condition itself, managing disability, physical activity, specific diets, create new behaviors, navigating through different systems in society, coordinating their health and care, searching for information, dealing with coping strategies, grief, and existential beliefs [22]. Choices made within self-management can have consequences for the direction and course of the condition, if e.g. a dialysis patient find a strict diet too difficult it will affect the treatment

and hence the course of the condition [21]. Self-management also sometimes requires collaboration with healthcare professionals, and thanks to the digitalization new ways to collaborate have occurred [23,24]. One kind of support are different digital solutions used to increase a person's own control over their life and to provide self-empowerment. These tools often aim to improve patients' competences, adherence, and enhance their health-literacy [25]. In the literature there are examples of online management and digital interventions for different chronic conditions. Here self-management is understood as cost-effective, timely, and able to meet the needs of patients and informal caregivers [26,27]. Hence, the interest in digital solutions is increasing and digital interventions are understood as a promising approach for reaching out with self-management support [28,29]. These aspects emphasize the perspective from health care, rather than from patients and informal caregiver. However, digital self-tracking gives further notion of a patient perspective, when patients gather and evaluate self-collected data from their own interest and needs, it leads to efficient learning opportunities [30]. Online social networks also offer users to add and share their collected and tracked data [31]. Further self-tracked data can be combined with patient innovations and provide solutions to adjust symptoms and medication. Such as program an artificial pancreas from a raspberry pie with an open-source loop system for anyone to share, to be able to adjust insulin intake for diabetes patients [2].

#### *2.1.4.1 Self-tracking*

To track one's health is part of both self-care and self-management when having a chronic condition. It is also part of the larger concept of personal science and the quantified self-movement [30,32]. This movement origins from managing chronic conditions and providing a more patient-centered health care. Even though it started from a healthcare perspective to seek assistance from patients tracking their own symptoms, with more easily accessible and affordable digital devices for tracking, it is now increasingly patient-steered. Patients are trying to understand their symptoms and situation in a better way and will share their tracked data when necessary [30,33]. Self-tracking lets patients be in connection with their condition and learn how their body reacts in different situations. These learning opportunities increase the knowledge and provide for a change in roles when patients collaborate with healthcare professionals [34]. To share self-tracked data is also part of personal science and quantified self. Here N-of-1 studies are considered as an opportunity for patients as individuals to influence research by establishing their own agenda and share their knowledge from their own self-tracked data [35]. This also includes when to design new solutions for e.g. self-management, to start from issues identified as important by patients rather than the issues set by the developers [36]. Quantified self-methods and personal science lead to patient empowerment through means to be in control over the situation and condition [33]. Still,

patients that perform personal science most likely have high autonomy and patient empowerment already [36].

## **2.2 Related concepts that describe empowered patients and informal caregivers**

In the literature, there are many different concepts that describe active and engaged patients and occasionally this also includes informal caregivers. Sometimes the concepts origin from healthcare needs [20,37,38,39], while other concepts aim to understand patients' and informal caregivers' needs and behaviors.

### **2.2.1 E-patients**

The concept of e-patients has been described as patients and informal caregivers (e.g., family caregivers) with high self-empowerment and engagement as well as being enabled and equipped. Their behaviors were evaluating and equal in their relationship with other peers and healthcare professionals. The concept was inspired by the digital expansion in the society in the early 2000s. Patients and informal caregivers searched the Internet for new knowledge that helped them in their self-management and in clinical encounters. The Internet was also used to be part of online communities with peers helping each other with further lived experiences or coping strategies [23]. Ferguson and Frydman [40] were early promoters of the concept, when noticing these behaviors among patients, as the authors called the first generation of e-patients. Moving forward from year 2000, the first generation of e-patients has followed the evolving digitalization in the society, not necessarily accompanied with the same development within health care. The evolution of e-patients was led by patients that used personal eHealth solutions to provide the Internet with their own self-tracked data [30,32]. E-patients used the patient accessible electronic health record to be able to follow up clinical encounters [41] and developed their own innovative digital solutions for their health [1]. E-patients as a concept has also acknowledged the important role of informal caregivers, since among those who searched the Internet for health-related information, 81% searched for a family member or a friend [23]. Whether e-patients are empowered to use digital solutions or if digital solutions provide empowerment for e-patients is not stated within the concept.

#### *2.2.1.1 Patients and informal caregivers as superusers*

Superusers as a concept can be understood as one part of being an e-patient, since they are users of online health communities. With their active engagement they influence others to be engaged in sharing their lived experiences, often in relation to their self-management. These online communities often become a structure for self-management support [42] and superusers keep the communities relevant and sustainable. Superusers are driven by a curiosity of their own condition and motivation of helping their peers, in particular when self-management support is lacking from healthcare professionals. Often

their engagement increases when their lived experience grows. However, this is often accomplished without recognition from their healthcare professionals [43]. The concept of superusers in this context is not to be confused with super users in computer science, that describes users with privileges of unlimited access to different computer applications, and who are qualified to teach other users [44].

#### *2.2.1.2 Internet informed patients*

This concept describes patients as highly informed and with high e-health literacy, having the ability to assess health information digitally for an existing health need [45]. Internet informed patients search for information either through different webpages or from online communities. These communities also contribute with support from peers in similar situations, when healthcare professionals do not support the Internet informed patients [46].

### **2.2.2 Expert patients**

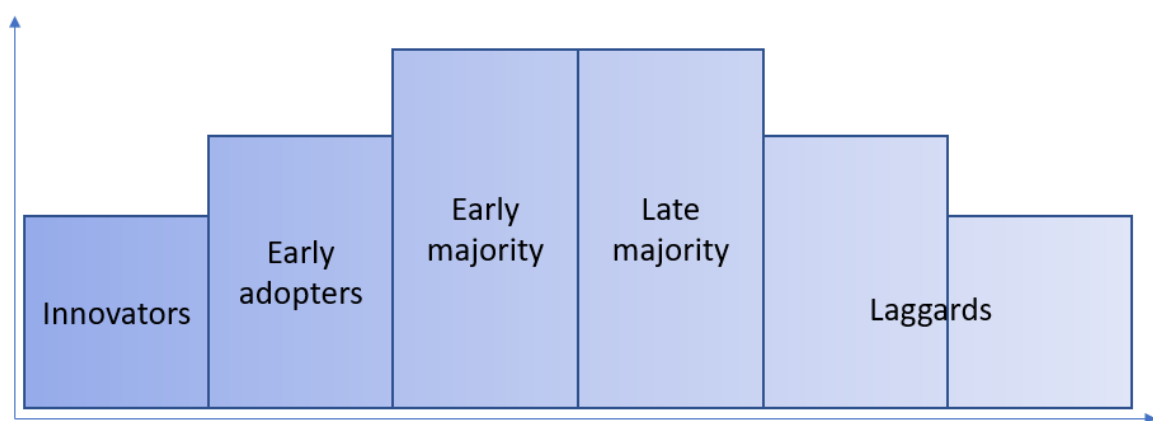
This concept describes “user-led self-management for chronic diseases” [47] and was established by the Department of Health in the United Kingdom with inspiration from Lorig’s [20] work of chronic condition self-management programs. They considered patients to be experts in their self-management and therefore should have a platform within the healthcare delivery system to contribute and share their expertise with other peers. The Department of Health believed self-management to be of great importance in improving patients’ self-efficacy and confidence in handling their condition, expert patients should work as mentors within self-management programs to improve the healthcare delivery and decrease healthcare meetings. User-led self-management should also lead to a cultural change for healthcare professionals, if healthcare professionals better understood patients’ work and self-management [47,48]. Expert patients are described to be helpful in clinical situations, to educate other peers as well as healthcare professionals, contribute to research, be patient-representatives, and to lobby to healthcare organizations [48].

#### *2.2.2.1 Peer support workers*

In the context of health care, peer supports may be used in different disciplines, for example when recovering from mental illness, peer support workers are involved to mentor their peers [49]. Similarly to expert patients, peer support workers are involved and often employed within healthcare organizations to support their peers, and work for a cultural change within the healthcare structure. Peer support workers are however mainly involved in mental health as addition to existing staff-teams, with focus on recovery. With their lived experience they are able to co-produce services together with healthcare professionals to provide for patient empowerment and person-centered care [50].

### 2.2.3 Lead users

Within the field of innovation research, the term *lead users* describe users with high motivation for a solution for a personal need, that the general market cannot offer them. Hence, lead users innovate a product or process to meet their needs [51]. The general market can then continue produce the solution without any request from the lead user, since the aim was never to earn money from it. Lead users have context-specific knowledge [52], and their solutions for novel products or processes seldom goes beyond their lived experiences [51]. Over time, the solution gains momentum, spreads, and people part of a specific social system will embrace the solution. Such distribution or diffusion is described in the Theory of diffusion of innovations by Rogers E.M [53]. It is not a Gaussian process and there will be different stages of adoption to accomplish a diffusion. Different people will adopt the solution later than others, as described by different adopter categories in Figure I. This comprises an awareness of the innovation and if there is a need for it. Hence, people will decide whether to accept or refuse the innovation, to test the innovation, and continue to use it [53]. Figure I describes how innovators will take a risk and try new solutions for their need, or even to become lead users. Early adopters represent opinion leaders and are knowledgeable about their needs for change. Early majority can adopt new solutions before the average of people. However, they often need proof of effectiveness before adoption. Late majority are skeptical of change and will not adopt an innovation before the majority of people have tried it. The laggards are often traditional and will not adopt an innovation before other adopter groups pressure them to do so [53].



**Figure I.** Different adopter categories according to the Theory of diffusion of innovations [53].

#### 2.2.3.1 Patient Lead Users

To take the concept of lead users into the context of health care, means that the users are patients or informal caregivers leading the way for future solutions in regard to their lived experiences and context-specific knowledge [52]. The difference here is that their lived experience is often shared by their peers, and the motivation is to find a solution for



all persons with similar conditions. One definition of patient lead users is: "Patients or family members who take a larger responsibility for their own health and well-being. They meet their health-related challenges in a constructive and knowledgeable way, while taking their physical and mental abilities as well as capacity into account. Patient lead users make use of their own experiences to improve health care, on all levels of the system, for the sake of both themselves and other patients. Often you do not become a patient lead user by choice, it is something that you do to be able to manage and navigate the complex healthcare system" [54]. Patient lead users are described to often use digital solutions and being innovators or early adopters that try new solutions for their needs. As early adopters they know what to change in regard to their self-management or individual behaviors, however sometimes the change is about a process or new behaviors on the system level. Here patient lead users promote and support innovative ways of change [52].

## **2.3 Theoretical background**

In this thesis three theories, relevant to involve when examining patient self-empowerment and self-management for patients with chronic conditions, were used: The Model of Illness Related Work, The Taxonomy of Burden of Treatment, and The Self-Determination theory.

### **2.3.1 The Model of Illness Related Work**

The model of illness related work is based upon the trajectory framework and describes how to gain control over self-management tasks when having a chronic condition. This framework is developed from studies of chronic conditions by Strauss [21] to provide for a nursing model that generates support to, and teaching patients when performing self-management. The trajectory framework describes the evolving course of managing a chronic condition, that means a chronic condition has a course that varies over time [21]. The model of illness related work describes three tasks: *medical management*, *role management*, and *emotional management* [21,22]. To achieve these tasks, six self-management skills are described within the model: 1) to solve problems, 2) to make correct decisions, 3) to be able to establish partnership with healthcare professionals, 4) to find and apply accurate resources, 5) to plan to act when necessary, and 6) to adapt these self-management skills to the chronic condition [20,55]. This model moves away from the notion of self-management as merely medical management and illness specific, towards an understanding of patients' complex situation trying to shape the course of the condition. This may lead to consequences for the patient's identity, physical health, well-being, and performance of activities in everyday life [21].

### 2.3.2 The Taxonomy of Burden of Treatment

Since self-management is becoming rather complex and sometimes difficult for patients with chronic conditions, it is essential to understand the potential burden of self-management. This is described in the taxonomy of burden of treatment by Tran et al [56]. Coming from a patient perspective, the burden of living with a chronic condition is described to be from healthcare tasks, consequences from these tasks, and factors that aggravate the burden. Burdens of self-management are often described to be imposed on patients and can lead to difficulty with adherence to treatment or other aspects of self-management, this in turn leads to poor health and well-being [56,57]. The taxonomy of burden of treatment gives further directions for interventions to minimize the burdens of self-management and treatment [56].

### 2.3.3 Self-Determination Theory

Motivation to perform self-management tasks and different behaviors are sometimes described as nonvoluntary and imposed on patients. This is further described in the theory of self-determination (SDT). This theory aims to explain how to understand patients' experienced motivation. Motivation can stem from internal values or external coercion, such as intrinsic, extrinsic, or even amotivation. This goes from self-determination by interest, joy, and satisfaction, towards nonself-determined with lack of control and not voluntary. Intrinsic motivation facilitates a long-lasting motivation to perform a specific activity, by value of the activity itself rather than the outcome of the activity [58,59]. This is further described in the self-determination continuum in Figure II.

	Nonself-determined					Self-determined
<b>Motivation</b>	Amotivation	Extrinsic Motivation				Intrinsic Motivation
<b>Source of motivation</b>	Impersonal	External	Somewhat External	Somewhat Internal	Internal	Internal
<b>Regulation of motivation</b>	Nonintentional, Nonvaluing, Incompetence, Lack of control	Compliance, External Rewards & Punishments	Self-control, Internal Rewards & Punishments	Personal importance, Conscious valuing	Congruence, Awareness, Synthesis with self	Interest, Enjoyment, Inherent satisfaction

**Figure II.** The Self-Determination Continuum [59].

SDT further describes three psychological needs for individuals: *autonomy*, *competence*, and *relatedness*, and how these have to be supported in order to be self-determined. Autonomy indicates a freedom and ability to make correct decisions for one-self. Competence specifies the ability to master different situations and to act efficiently. Relatedness implies the sense of meaningful relationships with other persons. Social contexts with support for autonomy and competence ought to improve the self-

determination and a person's intrinsic motivation. Whereas external rewards and pressured situations instead undermine the support and leads to external motivation or even amotivation [59,60].

### 2.3.3.1 *Related constructs that affect behavior*

Other related constructs alongside SDT, that may affect patient self-empowerment are *locus of control (LoC)*, *self-efficacy* beliefs, *Grit*, and *Sense of coherence (SOC)*. Here LoC is described as one important aspect when explaining health-related behaviors, and the construct is derived from the social learning theory by Rotter [61,62]. LoC describes persons motivation and self-determination by internal or external control. Here an internal health LoC implies persons to be in control over their situation and to understand themselves as able to impact e.g. health outcomes. This leads to increased learning possibilities and is highly relevant when to seek information, perform self-management, give up unhealthy behaviors, and to understand and be able to act upon different symptoms. External control is rather the opposite, and describes persons' behaviors as derived from chance, faith, or under control and dominance by others [9,61,62]. Both internal health locus of control and self-efficacy are essential constructs of patient empowerment and medication adherence, which leads to a better healthcare professional-patient partnership [9]. Self-efficacy can be described as believing in a person's own capacity to organize resources and handle different challenges [63]. High self-efficacy is assumed to be related with better health and higher medication adherence [9,63]. Grit, as related construct to affect behaviors, considers motivation as an ability to stay motivated despite setbacks and misfortune [64,65]. High grit is related to internal locus of control and perceived well-being [66], as well as the tendency to ignore negative aspects by instead focus on positive memories. This is called the fading affect bias [67]. Sense of coherence (SOC) entails the meaningfulness as a creator of motivation. When a person is able to create a meaning to life, despite difficulties and crisis, there is a sense of coherence. This will lead to experienced well-being and high quality of life, despite symptoms [68]. Other aspects that affect behaviors of self-empowerment are described in the literature to be genetic predispositions, what kind of support exists, the possibility of repetition, and ability to pursue an outcome [64].



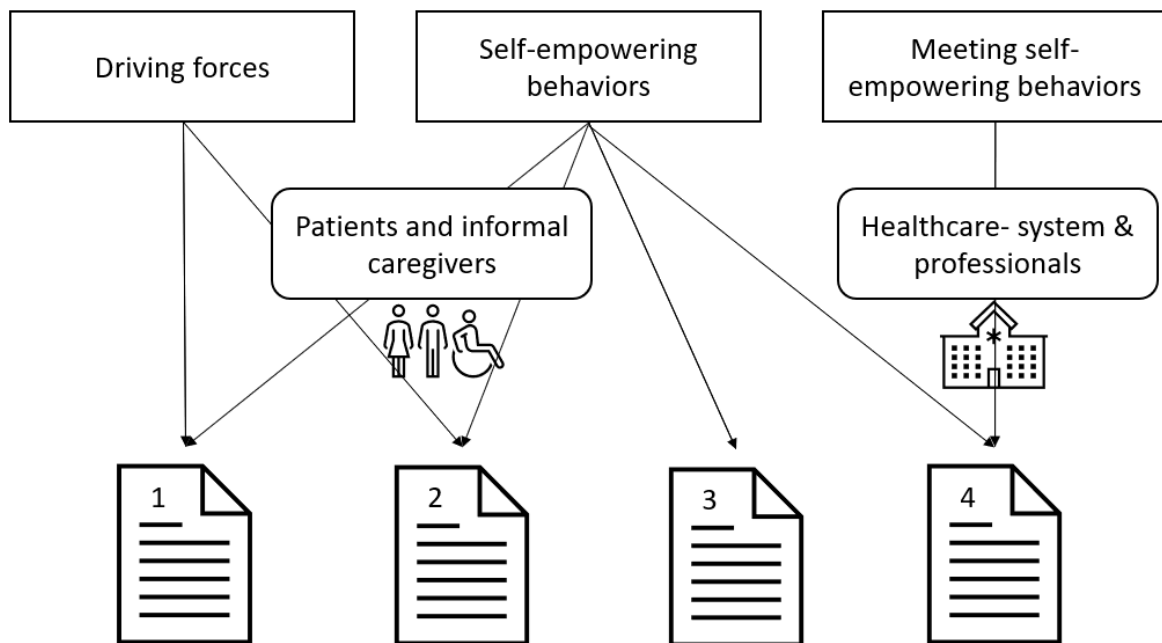
### 3 Thesis rationale and aims

Self-empowered patients and informal caregivers can be described by many concepts. One of those concepts is further described in this thesis, through study I. E-patients are used as concept to describe patients and informal caregivers that use digital solutions to empower themselves. Self-empowered patients and informal caregivers might be the way forward for healthcare development from a user perspective, and for self-management innovations derived from their and their peers needs. For this to happen, healthcare organizations need to move towards increased patient participation [23], with positive attitudes from healthcare professionals. Knowledge about self-empowering behaviors for self-management and co-care, and motivation of patients and informal caregivers are scarce. Further, the perspective of healthcare professionals and their attitudes, experiences, and workplace support when working with self-empowered patients and informal caregivers has not been researched extensively.

The overall aim of this thesis is therefore to study the driving forces and self-empowering behaviors of patients and informal caregivers affected by chronic conditions, and how healthcare professionals and the healthcare systems meet these behaviors (Figure III).

The overall aim was reached by completing the aims of the four sub-studies:

- Study I: To describe the second generation of e-patients through exploration of their active engagement in their self-care and healthcare contexts.
- Study II: To explore the opinions and experiences of Persons with Parkinson (PwP) in Sweden of using self-tracking for Parkinson Disease (PD).
- Study III: To explore empowering behaviors from a patient- and informal caregiver perspective in the context of self-management, and to understand how health care could meet these behaviors.
- Study IV: To explore healthcare professionals' attitudes towards and experiences of meeting empowered patients and informal caregivers as well as healthcare professionals' perception of workplace support in these situations.



**Figure III.** Overview of the focus of the thesis.

## 4 Materials and methods

This is a mixed method thesis with four studies performed to meet the overall aim. Data collection for the qualitative parts of the method was completed by semi-structured interviews and focus groups, and surveys were performed for the quantitative parts. The data were analyzed with five different approaches: Framework analysis (FA), Conventional content analysis, Thematic analysis (TA), Direct content analysis, and Descriptive analysis. Inductive, deductive, and abductive reasonings were used to process the data to draw conclusions (Table II).

**Table II.** Overview of the methods used in the four studies.

Study	Data collection	Reasoning	Data analysis
I	Semi-structured interviews (n=15)	Deductive – SDT was used as theory, to go from an assumption of e-patients to be motivated, towards a specific conclusion of e-patients' motivation.	Framework analysis (FA)
II	Semi-structured interviews (n=7)  Survey (n=180)	Inductive – observed PwP perform self-tracking to conclude a generalization of the sample size's experiences.	Conventional content analysis  Descriptive analysis
III	Semi-structured interviews (the same data as for study I)  Focus groups (n=6, total number of participants=33)	Inductive – observed e-patients to conclude a generalization of self-empowering behaviors.  Abductive – moved from the generalization of behaviors as an incomplete set of observations, towards a deeper understanding and reliable conclusion.	Thematic analysis (TA)  Direct content analysis
IV	Survey (n=279)	Deductive – used the conclusion from study III as an assumption to make a specific conclusion of attitudes and experiences of healthcare professionals in the study sample.	Descriptive analysis

A summary over age and gender, as well as affected by chronic condition for the participants, and occupation for the respondent, is provided in Table III.

**Table III.** A summary of the participants' characteristics of the four studies.

Study	Role/Chronic condition	Age n (%)	Gender n (%)
I	Patients (n=10/67%) and Informal caregivers (n=5/33%) with: Connective tissue disease, Fatigue syndrome, Fibromyalgia, Systemic sclerosis, Mental illness (n=2), Irritable bowel syndrome, Motility disorder, Parkinson disease, Rheumatic disease, Myocardial infarction, Kidney cancer, Multiple sclerosis, Hypersensitivity, Thymus neoplasms, Down syndrome, Heart failure, Pulmonary fibroses, Liver cancer.	18-45: 5 (33) 46-65: 7 (47) >66: 3 (20)	Female: 10 (67) Male: 5 (33)
II	Patients (n=187/100%) with: Parkinson disease	18-45: 7 (4) 46-65: 82 (44) >66: 98 (52)	Female: 93 (50) Male: 94 (50)
III	Part 1 – Same as study 1.  Part 2 – Patients (n=27/82%), Informal Caregivers (n=4/12%), and Both (n=2/6%) with: Breast cancer (n=4), Ovarian cancer, Uterine cancer, Myelodysplastic syndrome, Colonic cancer, Prostatic cancer, Brain cancer, Parkinson disease (n=8), Rheumatic disease (n=5), Diabetes type 1 or 2 (n=5), Multiple sclerosis (n=2), Mental illness (n=2), Whiplash injury, Stroke, Meningo-myelocoele, Cyst-liver & Cyst-kidney, Heart failure, Myalgic encephalomyelitis /Chronic fatigue syndrome, Irritable bowel syndrome, Irritable bowel disease.	Part 1 – Same as study 1  Part 2 – 18-45: 8 (24) 46-65: 14 (43) >66: 11 (33)	Part 1 – Same as study 1  Part 2 – Female: 25 (76) Male: 8 (24)
IV	Nurses (n=129/46%), physicians (n=47/17%), other licensed health professions (n=66/24%), and non-licensed health professions (n=37/13%) Primary healthcare (n=70/25%), specialized healthcare (n=195/70%), digital healthcare (n=3/0%), other (n=30/11%)	18-49: 183 (66) >50: 96 (34)	Female: 250 (90) Male: 27 (9) Other: 2 (1)

## 4.1 Study I

There was a need to explore the concept of e-patients, to understand how they were engaged and active in their self-management and together with healthcare professionals. Here we wanted to describe the second generation of e-patients by using a deductive reasoning approach [69], since the participants were expected to be motivated. A comparison with the three psychological needs was performed, to make specific predictions about the outcome.



#### **4.1.1 Study design I**

Study I was a qualitative study with semi-structured interviews. Ten patients and five informal caregivers self-identified as e-patients participated. The interview guide comprised four areas: *Background, Your health journey, Health behavior, and Your role in self-care and healthcare*, with open-ended questions to ensure that the participants' opinions and thoughts were shared [70,71].

#### **4.1.2 Study sampling I**

The sampling process was accomplished with help of the project "Patient Lead Users". An online advertisement was published at the Webpage of the project and through a newsletter. Overall, 67 expressions of interest were collected, as well as suggestions of e-patients according to the description presented in the advertisement: "Engaged patients or informal caregivers that do more in their self-care and in collaboration with healthcare, than expected of them. E.g. searching for health information online, have ideas of new solutions/innovations for their self-care and in communication with healthcare, or track their health to gain further knowledge." The participants were intentionally selected through convenience and snowball sampling [72,73], to cover different characteristics. Inclusion criteria set: patients with one/several chronic conditions or an informal caregiver, age over 18, and considered themselves being an e-patient.

#### **4.1.3 Data collection I**

The semi-structured interviews were performed over telephone (n=6) or face-to-face (n=9) from October to December 2017, by the first author of the study with help from members of the project. The data collection resulted in an average of 40 minutes recorded conversations and 152 verbatim transcribed pages. A priori thematic saturation was achieved [74] and no further data collection was considered necessary to exemplify SDT.

#### **4.1.4 Data analysis I**

FA was used for data analysis. Here SDT was applied as an initial framework [75], based on e-patients as motivated to be active and engaged. FA was here used to further analyze whether the interview data matched the three basic psychological needs: autonomy, relatedness, competence (See Figure IV) [58-60], or if other themes emerged [75]. The verbatim transcribed data was applied to achieve the steps of FA:

- 1) Familiarization – A familiarization of the collected data from the interviews was achieved. The recorded material was listened through and the interviews were labeled in a chronological order. Key ideas were developed about emerging themes.
- 2) Identified a thematic framework – By using the emerging themes in the data, a thematic framework was identified. The key ideas from the familiarization phase was used to clarify and categorize the collected data.

- 3) To index – Sections of data were mapped into specific themes by using spreadsheets in Excel.
- 4) To chart – Coding the data into subcategories, categories, and themes. The data elevated from the participants' narratives and all data was placed in charts, still being labeled to the raw data.
- 5) To map and interpret – As an iterative process the themes were updated several times. Relationships and concepts were discovered through mapping and all new findings were included [75,76].

At least two authors (the first author and one/several more) of the study analyzed the data and were always involved, to decrease the subjectivity.

## **4.2 Study II**

A mixed method approach with sequential studies was used. Method triangulation ensured both range and depth when exploring the same aim through two different methods. This gave the opportunity to enhance the accuracy and the validity of the data [72]. The result of seven semi-structured interviews was utilized to generate the questions for the survey, for further data collection. In this inductive approach we concluded a generalization of the participants' experiences and did not use any predefined models or theories [69].

### **4.2.1 Study design II**

#### *4.2.1.1 The qualitative part*

From the knowledge gaps in the literature of PwP's experiences of using self-tracking, together with the aim of the study, an interview guide was established. It was first tested with three PwP, not being included in the study sample. Prior to the pilot, the guide was adjusted and consisted of four sections: *Background information*, *Disease characteristics*, *Self-care and self-tracking*, and *Interaction with healthcare and self-tracking* (Study II, Attached file 1).

#### *4.2.1.2 The quantitative part*

A survey was designed by the authors of the study, by reusing the themes from the qualitative part [72,77]. It resulted in six sections: *Background* (A1-5), *Experience of self-tracking* (B1, B3), *Reasons for self-tracking* (B2, B4), *Approach and use of self-tracking* (B5, B6), *Self-tracking's influence on relationships with healthcare* (B7), and *Challenges and risks associated with self-tracking* (B8) (Study II, Attached file 2). The questions were closed multiple-choice options, as well as a Likert-scale with five options of answers (*strongly disagree* to *strongly agree*) to different statements. To decrease the risk of internal bias when answering the survey, we included the option of choosing *neither* [71].

## **4.2.2 Study sampling II**

### *4.2.2.1 The qualitative part*

Seven participants were hand-picked from personal networks and contacts from the first author, as a purposive sampling [72,73]. This because it was important to find PwP with specific experiences of performing self-tracking. The participants were sampled based on lived experience, different backgrounds, gender, age, and location within Sweden. Since PD is a rather diverse condition, different PD characteristics, treatment, symptoms, and severity of disease were part of choosing the sample.

### *4.2.2.2 The quantitative part*

A non-probability sampling approach was used for data collection [72], by distributing an open public survey. The survey was distributed through social media to patient associations and personal networks of the first author. By using social media to target PwP using the Internet, it was possible to cover a broad geographical area [78].

## **4.2.3 Data collection II**

### *4.2.3.1 The qualitative part*

The semi-structured interviews were performed face-to-face or over telephone by the first author of the study and another PwP. After seven interviews an inductive thematic saturation was achieved [74]. Redundant information started to appear, and there was lack of new themes. The recorded material was transcribed verbatim, and the total duration was 283 minutes, average of 40 minutes per interview.

### *4.2.3.2 The quantitative part*

The respondents used an online link to answer, and all data was gathered using Google forms. It was a risk that not all PwP within the study population were reached when collecting an exploratory sample with focus to generate new perceptions and models. However, as 95% of the Swedish population have reported using the Internet to some extent [79] an online survey was considered appropriate. From a total of 280 PwP responses, 180 (64%) reported experiences from self-tracking and were included in the final sample.

## **4.2.4 Data analysis II**

### *4.2.4.1 The qualitative part*

A conventional content analysis was used to analyze the qualitative data [80,81], to be able to measure the frequency of different themes and categories as a foundation for the survey. The data guided the analysis process [80,81]:

- 1) The transcribed text was read through multiple times.
- 2) Two content areas: *self-tracking* and *collecting data in collaboration with healthcare* were organized from the transcribed data.
- 3) Relevant data from the content areas was selected into one text and became the unit of the analysis.
- 4) Condensed meaning units were made from the text in regard to the context and labelled with codes.
- 5) The codes were compared and organized into six categories: *Reasons for self-tracking*, *Knowledge needed to do self-tracking*, *Skills needed to do self-tracking*, *Self-tracking's impact on relationships with healthcare*, *Knowledge gained from self-tracking*, and *Challenges and risks associated with self-tracking*.

#### 4.2.4.2 *The quantitative part*

Descriptive analysis was used to rank assigned numerical values from the Likert-scale to simplify and summarize large values. Used types of data were categorical ordinal and nominal [72,82], that helped to simplify and summarize large values. Frequency distribution was used to manage the data by identifying participants and fit them into categories. PwP's attitudes concerning self-tracking were cross tabulated in regard to age (Figure 4 in Study II), gender (Figure 10 in Study II), and time since diagnosis (Figure 2 & 5, Table 3 in Study II) [69]. All data were displayed as bar charts [82]. A chi-square-test, with a with p-value (probability) of  $p < .05$  was used to determine if the cross-tabulation reflected a statistical significance [72,82].

### **4.3 Study III**

A qualitative study with two consecutive stages was performed. The first stage consisted of an inductive approach when e-patients were interviewed to generalize self-empowering behaviors. These behaviors were assumed to be an incomplete set, therefore stage two was performed through focus groups to test and validate the knowledge from stage one. With an abductive approach, stage two gave us a deeper understanding and reliable result regarding self-empowering behaviors for patients and informal caregivers.

#### **4.3.1 Study design III**

##### 4.3.1.1 *Stage one*

The interview data from study I were used for stage one (section 4.1.1) (the interview guide is to be found in Study III, Attached file 2).

##### 4.3.1.2 *Stage two*

The result from the semi-structured interviews in stage one was used as a foundation for the protocol of the focus groups. Prior to the actual data collection, the questions were tested on ten individuals that worked within patient associations and within healthcare

system related topics. The protocol was adjusted and the final version consisted of three sections: *demographics, everyday life activities regarding self-care or collaboration with health care, and patterns of behaviors describing your activities*. The last section used the categories from stage one as key concepts to start a discussion of how these represented the participants' behaviors (Study III, Attached file 3). It was a multiple-category design using various types of participants affected by chronic conditions [83].

### **4.3.2 Study sampling III**

#### *4.3.2.1 Stage one*

The interview data from study I were used for stage one (section 4.1.2).

#### *4.3.2.2 Stage two*

Purposive sampling was used to recruit participants [73,84]. Adults with chronic conditions and informal caregivers affected by chronic conditions were approached through peer support workers and various patient associations within different geographic regions in Sweden. Inclusion criteria: over 18 years old and experience of chronic condition(s). The study sample consisted of six focus groups with a total of 33 participants.

### **4.3.3 Data collection III**

#### *4.3.3.1 Stage one*

The data collection was the same as for study 1 (section 4.1.3).

#### *4.3.3.2 Stage two*

All focus groups were physically performed at different geographic regions in Sweden, with one moderator and one or two observers present. Each focus group session lasted on average 1 h 43 min, and the total duration was 618 min for the six focus groups. Saturation was reached [73]. The focus group sessions were recorded and transcribed verbatim.

### **4.3.4 Data analysis III**

#### *4.3.4.1 Stage one*

TA with an inductive approach was used for stage one, and the authors performed the six phases of the analysis [85,86] in parallel with the data collection. The six phases comprised:

- 1) familiarization of the data,
- 2) categorize the data into units to find codes,
- 3) to search the units for patterns to generate themes,

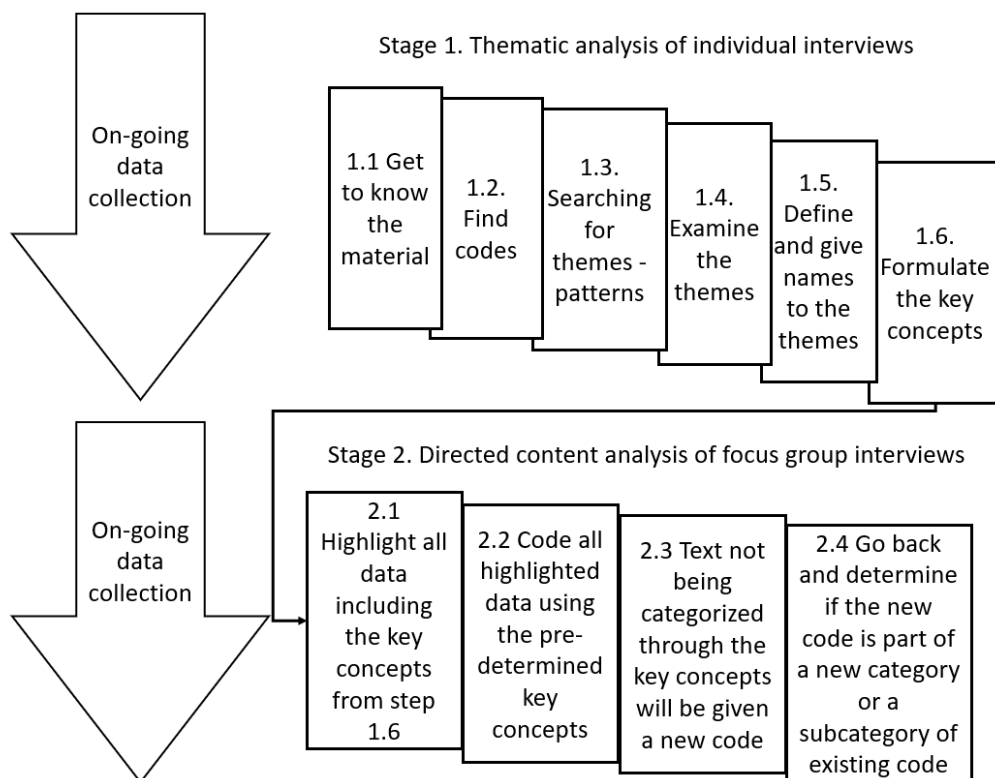
- 4) locate all coded data into themes from phase three,
- 5) define and name the themes in regard to how they fit the aim of the study,
- 6) formulate the key concepts from the eleven categories [85].

#### 4.3.4.2 Stage two

Directed content analysis was used for data analysis of stage two, with an abductive approach [80,81]. The eleven key concepts from stage one (phase six in Figure IV) were used to start the coding process as part of step one in the analysis. In total four steps were followed by the authors to explore how these key concepts emerged as self-empowering behaviors [81]:

- 1) All focus group data was highlighted, and when valid mapped into the key concepts.
- 2) All highlighted data were coded.
- 3) Data that did not match the key concepts were provided with new code.
- 4) Iteratively we go back to determine if the new code is part of a sub-category of existing code or become a new category.

These four steps resulted in three new explorative behaviors that were established as categories. The whole analysis process for the two stages is illustrated in Figure IV.



**Figure IV.** Illustration of the analysis for the whole study. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [87]

## 4.4 Study IV

A quantitative survey design was used for study IV. Here the conclusion from study III was used as a general assumption. This deductive approach gave us a more specific conclusion in regard to healthcare professionals' attitudes and experiences of working with self-empowered patients and informal caregivers.

### 4.4.1 Study design IV

A multi-center web survey was conducted in Swedish by the research team. The 14 self-empowering behaviours from study III were used as a guide [87]. To test the web survey-questions, cognitive interviews were performed with six healthcare professionals (one physiotherapist, two nurses, three physicians) not part of the respondents. Before the distribution of the web survey, it was pilot tested with 30 physicians and nurses from one single site (part of the respondents). The web-survey comprised a demographic section with closed multiple-choice options. The topic sections contained statements (5-point Likert-scale from *strongly disagree* to *strongly agree*) mandatory to answer, and free text options. The survey ended with supplementary open-ended response questions (Study IV, Attached file 1).

### 4.4.2 Study sampling IV

Participants in the study were engaged through non-probability sampling [72]. The link to the survey was distributed to different healthcare settings managing diabetes, neurology, oncology, psychiatry, and rheumatic patients. All represented the patient driven innovations in the research program the study was part of. Since this distribution resulted in low participation (n=86/478, 18%), a second distribution was performed (n=193/536, 36%). This time the survey was distributed through social media (Facebook) with an advertisement, performed by Karolinska Institutet's communication and public relations office, targeting healthcare professionals working within primary, secondary, and specialized healthcare settings. Inclusion criteria were healthcare professionals within Sweden, speaking Swedish, and being 18 years or older.

### 4.4.3 Data collection IV

Data was collected between April 2021 and February 2022, via Microsoft Teams® for the web survey. One reminder was sent out within this timeframe. The overall response rate for both distributions was 28% with 279 respondents.

### 4.4.4 Data analysis IV

A descriptive approach and Microsoft Excel was used to analyze the answers from the survey [82]. Dichotomization was used in the text for similar responses from the Likert-scale. Instead of five ways to report the answer, there were three options: positive ("agree", "strongly agree"), neutral, or negative ("somewhat disagree", "strongly disagree").

The topic sections from the survey were used (“Knowledgeable patients and informal caregiver”, “To learn from patients and informal caregivers”, “Need for alternative ways to interact with health care”, “Coordinating healthcare contacts between different healthcare units”, “Patients performing self-tracking on their own initiative”, “Use of digital solutions to manage health conditions”, “Innovations by patients and informal caregivers”, “Patient and informal caregivers communicating their experiences”, and “Patients’ and informal caregivers’ engagement in the healthcare unit’s development”) to emerge three main themes. The open-ended responses from each topic section and the three free text questions helped to illustrate the quantitative data with quotes. All open-ended responses were divided into different categories to see their frequency and to allocate them into the three main themes.

## **4.5 Ethical considerations**

Ethical approvals were provided by the Regional Ethical Review Board in Stockholm for studies I, II, and III, and the Swedish Ethical Review Authority for study IV. In accordance with decisions 2015/1572-31/4 and 2020-05805, research performed for studies I, II and IV did not required an ethical review. For study III decision to grant the ethical approval 2018/2294-32 was made.

### **4.5.1 Informed consent**

All participants attending the semi-structured interviews and focus groups received the research information both orally and in writing before the interviews, whereas survey-participants only had it in writing. The information consists of the aim of the study, data management, option to leave the study at any time, and how the communication of results would be completely anonymized. All participants gave informed consent to participate, before inclusion.

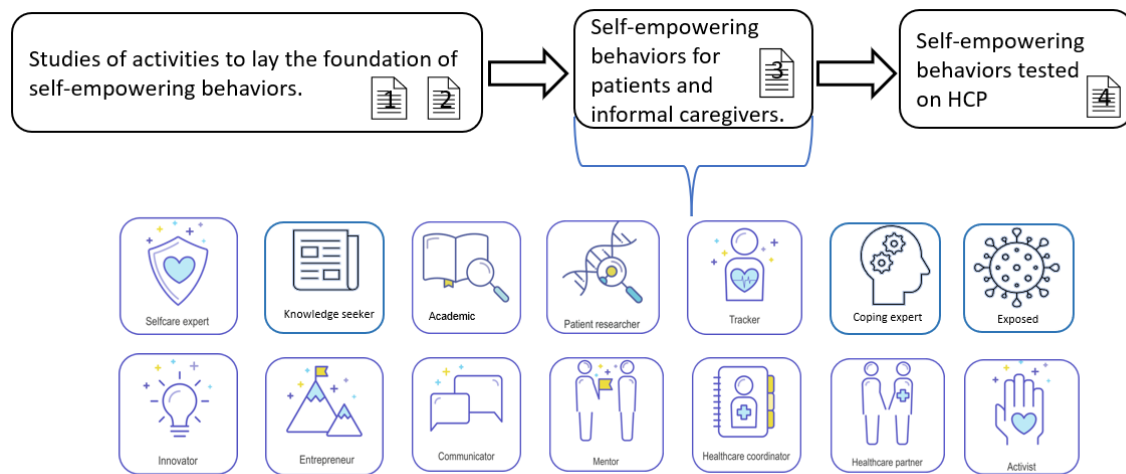
### **4.5.2 Privacy and confidentiality**

All personal data in the four studies are restricted and anonymized in accordance with the EU General Data Protection Act [88]. This mean that data possible to trace back to individual participants were not published. The confidentiality was considered while telling the participants’ story [70,72]. For all qualitative data, quotes have been used with individual codes that described each participant, to protect their privacy [69]. The participants had the possibility to read the papers before submission to correct any misinterpretations. This was used by one participant in study I.



## 5 Results

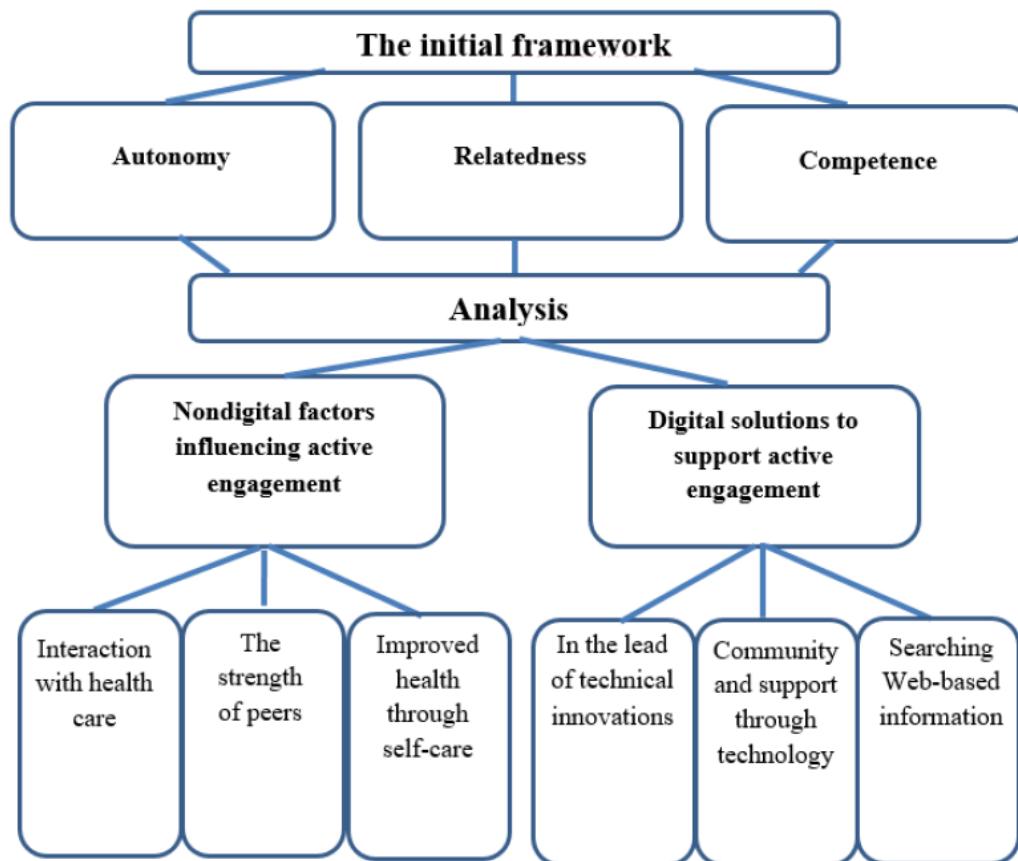
Displayed in Figure V are the relationships of the four studies and how the self-empowering behaviors are discovered.



**Figure V.** Relationships of the four studies. Illustration by Spetspatienter. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>)

### 5.1 From information seekers to innovators (Study I)

Study I aimed to explore the second generation of e-patients' active engagement through qualitative data. For this an existing theory (SDT) was used to examine if the study samples' motivation was self-determined. From the analysis two themes emerged (Figure VI) when the second generation of e-patients' progression was described: "Non-digital factors influencing active engagement" and "Digital solutions to support active engagement".



**Figure VI.** Overview of the analytic process. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [89]

### 5.1.1 Non-digital factors influencing active engagement

To be listened to and taken seriously by healthcare professionals and among peers increased the participants relatedness as one psychological need. This led to participants continuing to be active and engaged within their condition and health. It included to share their lived experiences with healthcare professionals and peers. Here the participants described the importance of not to be greeted with distrust, and to get the correct diagnosis to avoid unsafe situations for the patient.

*I got a lot of help [from health care], but it wasn't the kind of help that I needed.*

The psychological need of competence was met when the participants had the possibility to collaborate with healthcare professionals. The collaboration included to receive feedback in regard to their self-management, as well as when health care provided for better flexibility of different kinds of engagement. Further, to increase their competence, the participants searched information within the literature, as well as gained knowledge from healthcare professionals. The participants believed to share their knowledge should

be a positive experience for healthcare professionals, since to have a high workload might not give the healthcare professionals time to explore the existed literature and research.

*I have read a lot of research, and when I had a physician that was interested in research, we used that to decide on my medication together.*

The participants considered that being part in quality development of a healthcare unit was something helpful, since it was something they did to help improve the healthcare organization for healthcare professionals as well as for other patients coming after. This increased the participants autonomy, as the third psychological need.

*... it is part of how I lead my life, we have to help each other out. That is what keeps me going.*

### **5.1.2 Digital solutions to support active engagement**

The participant reported using different eHealth solutions for their self-management, to be in contact with peers, and to collaborate with healthcare professionals. As part of their collaboration with health care, a few participants had even developed digital solutions to support different healthcare organizations' quality improvement work. Other participants had ideas of innovations that might improve the collaboration between patients and healthcare professionals. This active engagement was explained to increase the participants' psychological need of competence.

*I have digitalized a questionnaire for primary care to be able to decide where to send referrals for rare diseases... in order for the patients to get the correct diagnosis faster.*

The participants psychological need of relatedness increased by use of social media to interact with peers in online communities. However, the participants also needed a better collaboration with healthcare professionals to gain feedback on the information and knowledge found through online communities and when to google a condition.

*The answer can never be not to google. It has to be: 'let's talk about this – how can we relate to this?'*

To increase the psychological need of autonomy the participants used digital solutions that facilitated their self-management such as tracking solutions for heart rate, blood pressure, and oxygen uptake. Accessing their electronic health records online was also frequently mentioned. The participants also express how they used digital solutions to help facilitate their disabilities.

*I am bedridden six to nine months a year so, technology is crucial for me to be active... I use video calls a lot.*

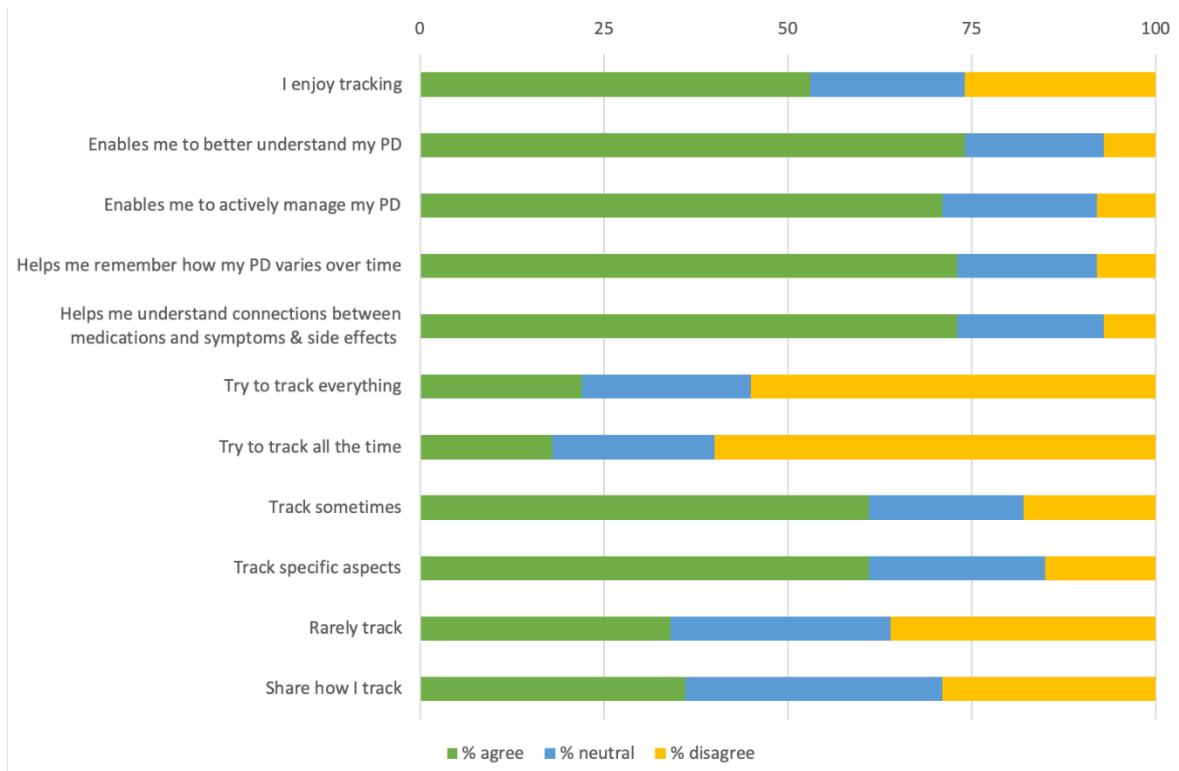
## 5.2 Benefits and burdens of self-tracking (Study II)

Study II is a mixed methods study that involves People with Parkinson disease (PwP) and an exploration of their opinions and experiences from performing self-tracking. The study sample of PwP were measuring different aspects of their condition and medication. Self-tracking was done using different tools; in their head, by usage of digital solutions, or with pen and paper. Five categories describing aspects of self-tracking in Parkinson’s disease were identified: “Why I self-track”, “How and what I self-track”, “Lessons learned from self-tracking”, “Risks related to self-tracking”, and “Self-tracking and health care”.

### 5.2.1 Why I self-track

The motives for self-tracking were mainly to achieve a deeper knowledge of the disease and how it is affected by lifestyle and medication (74%, n=133/180). It was also important to be reminded of how their symptoms fluctuated over time (73%, n=131/180). The PwP of the survey also stated that self-tracking enabled them to be more active in their self-care, as well as together with healthcare professionals (71%, n=128/180). To achieve these aspects made self-tracking enjoyable (53%, n=95/180) to half of the respondents (See Figure VII).

*To me it is positive that it makes me more aware. You cannot stick your head in the sand, the disease will catch up with you no matter what you do.*

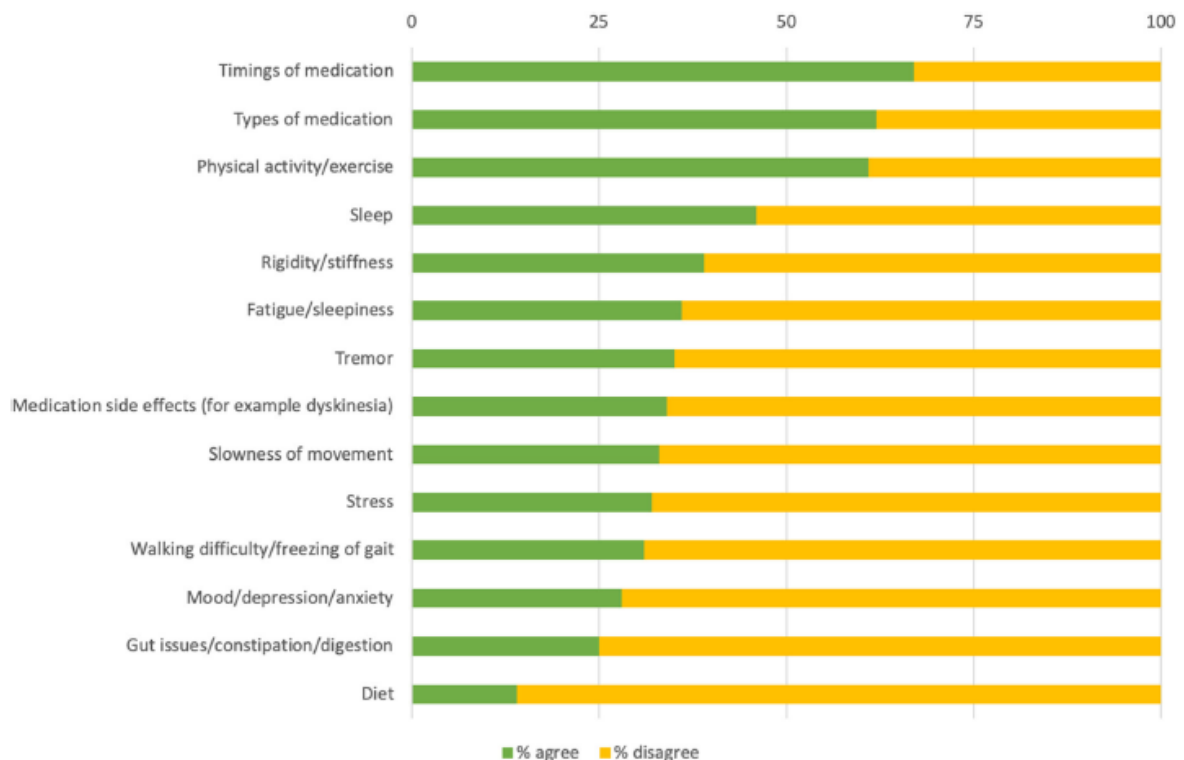


**Figure VII.** Why I self-track. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [90]

### 5.2.2 How and what I self-track

The primary aspect to perform self-tracking was to optimize the participants' medication intake; to learn when to take it regularly (67%, n=121/180), what type of medication should be ingested at what time (62%, n=112/180), and how much, without transcend the daily maximum dosage. Other aspects of self-tracking are e.g. physical activity, sleep patterns, and stiffness (See Figure VIII).

*It is important to take your medication right, at the right time. You can get a bad effect... this mean that you need to make it more evenly distributed.*

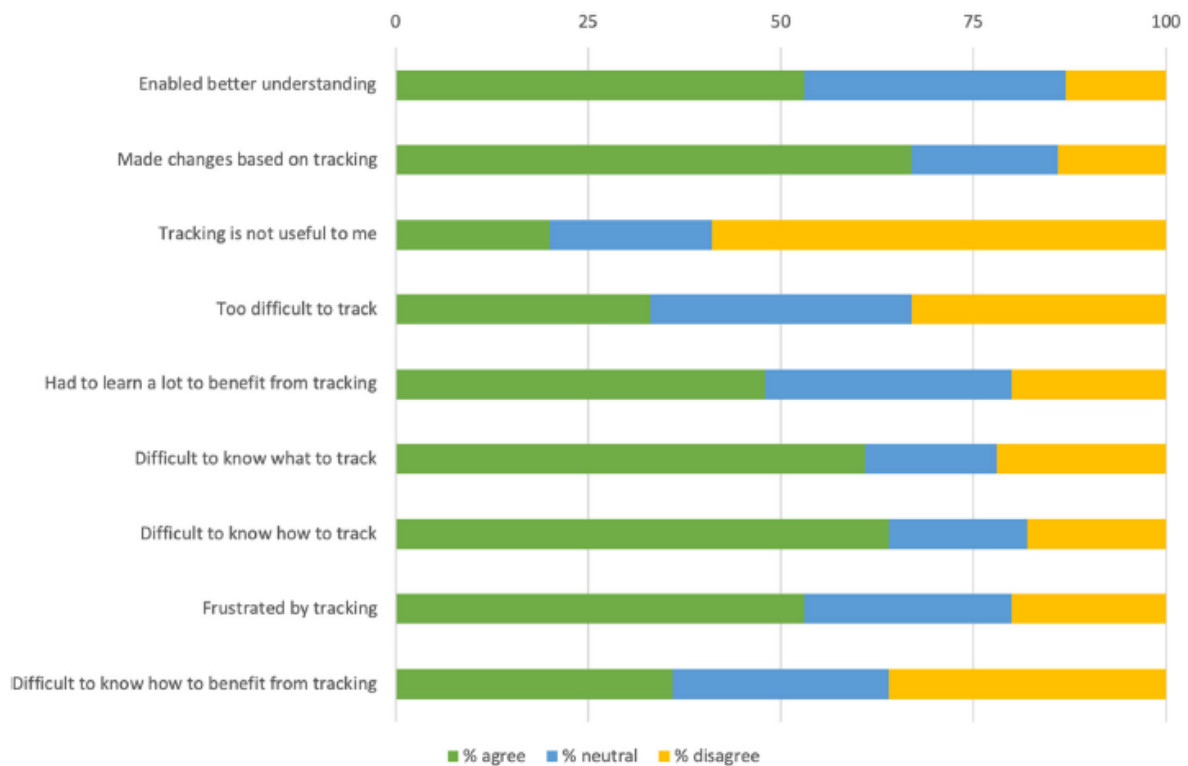


**Figure VIII.** Aspects of PD tracked. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [90]

### 5.2.3 Lessons learned from self-tracking

Self-tracking comes with vast learning opportunities of the condition itself, and aspects that affected the symptoms, hence 67% (n=121/180) of the participants had made changes based on their self-tracking. Participants however expressed how frustrating and difficult it was to not know what to track (61%, n=110/180) and how to track (64%, n=115/180). A few of the participants also found it difficult to know how to benefit from self-tracking (36%, n=65/180) (See Figure VIII).

*It is difficult to tweak medication timings, there are so many influencing factors; stress, food, lack of sleep, it is all inter-connected.*

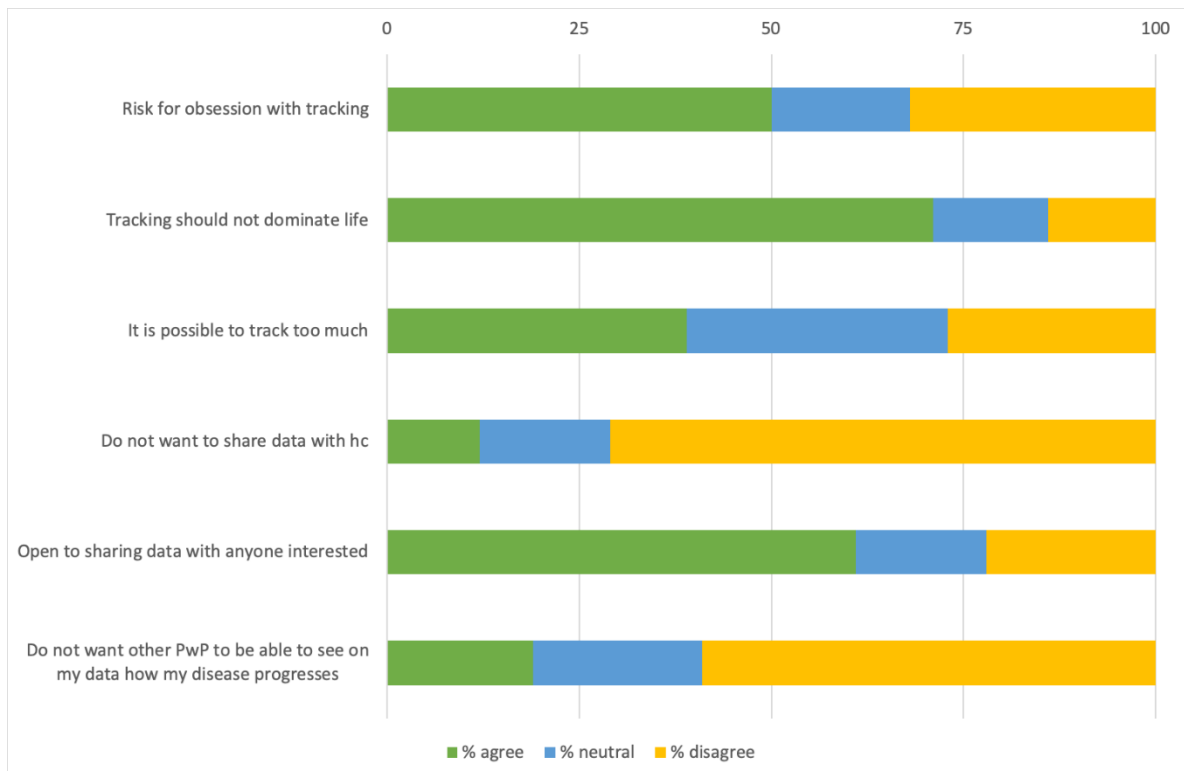


**Figure IX.** Lessons learned from self-tracking. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [90]

#### 5.2.4 Risks related to self-tracking

There are however risks with self-tracking according to the participants. It is easy to become fixated with measurement of different aspects of the condition (51%, n=92/180). A proposed solution was not to measure all the time, only when a problem existed, or in preparation for a healthcare encounter (53%, n=95/180, See Figure XI). The PwP in the study believed that the healthcare system handled their private data in correct manner (72%, n=130/180) and did not see any major risks with shared self-tracked data (See Figure X).

*I do not think you should be doing it all the time if you do not know what you want to use it for. Just tracking, that is pointless. You have to know why you are doing this.*

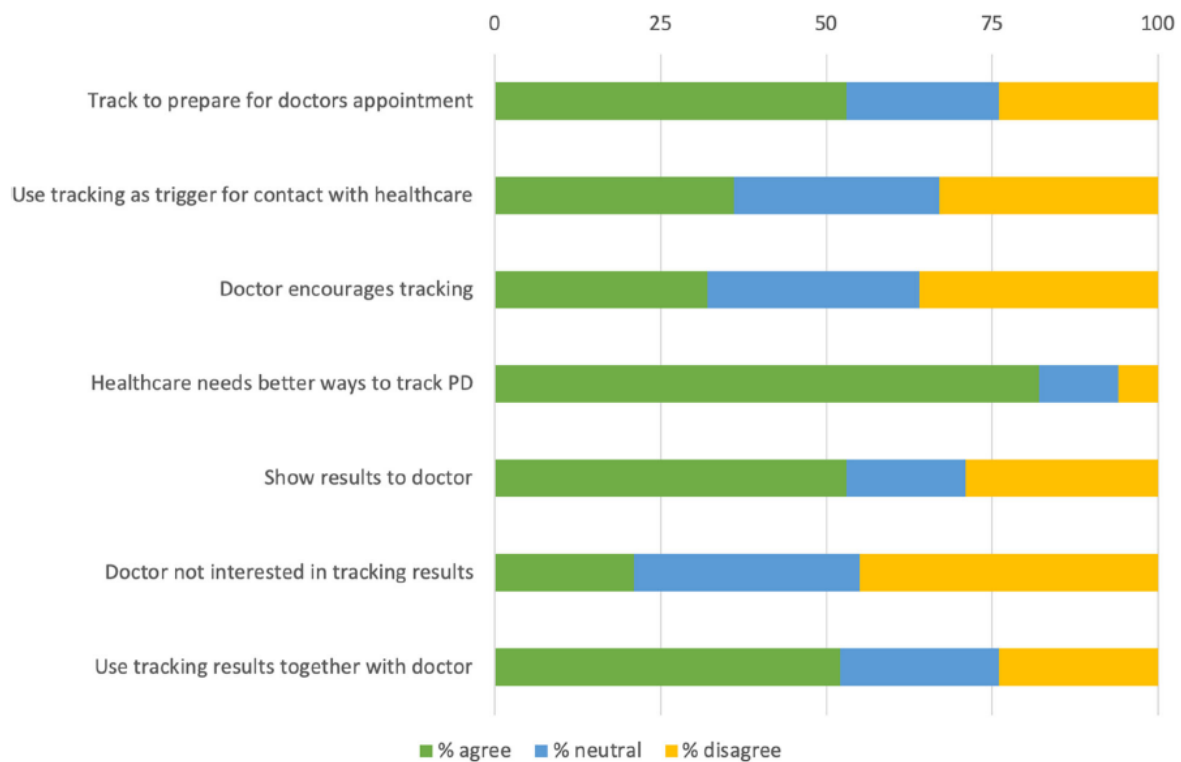


**Figure X.** Risks related to self-tracking. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [90].

### 5.2.5 Self-tracking and health care

The partnership between PwP in the study and healthcare professionals can be strengthened or be influenced negatively in regard to self-tracking and shared data. The participants were aware of the stressful context that healthcare professionals worked in, and therefore expressed that it might not always be positive to add their tracked data to that stress. Hence, 53% (n=95/180) of the participants shared their tracked data with healthcare professionals, however only 21% (n=38/180) believed their physician to be interested in that data. Among the participants 32% (n=58/180) had experienced that healthcare professionals had encouraged them to perform self-tracking (See Figure XI).

*Sometimes I have been allowed to present my tracking but there does not seem to be much interest from healthcare. I think it has to do with the attitudes of doctors. I get the feeling that they want to do their assessment without involving my tracking.*



**Figure XI.** Self-tracking and health care. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [90].

### 5.3 Self-empowering behaviors of patients and informal caregivers (Study III)

Study III was a qualitative study with two different data collections, involving e-patients and a broader group of patients and informal caregivers. The aim of exploring empowering behaviors from a patient and informal caregiver perspective resulted in 14 different types of self-empowering behaviors and two overarching themes (see Table III): “Exploratory behaviors” and “Influencing behaviors”.

**Table IV.** Overview of self-empowering behaviors.

Categories/Type of behavior	Example activities
THEME – EXPLORATORY BEHAVIORS	
The self-care expert	Develops self-care strategies, performs far-reaching lifestyle changes, creates a balance in life according to emotional aspects, diets, and medication.



The knowledge seeker	Searches for information from social media, peers, research articles, and healthcare professionals, to develop knowledge.
The academic	Systematically searches and reads academic research, compiles research, learns how to read and interpret academic research, finds connections to their condition, develops deep knowledge on their condition.
The patient researcher	Engages as a research partner and/or academic researchers, uses scientific methods to examine their condition and to identify potential new treatment.
The tracker	Uses methods systematically to measure (sleep, mood, time of medication, etc.), track health issues to be able to adjust treatment, establishes patterns, learns through data, uses eHealth solutions.
The coping expert	Deals with stressors by acceptance or to avoid the stressors by changing their emotional responses.
The exposed	Has an emotional struggle to deal with a complex situation, do not accept, and feel alienated.
THEME – INFLUENCING BEHAVIORS	
The innovator	Generates new ideas of health-related digital and non-digital solutions and for collaboration with healthcare professionals, at individual- and system level.
The entrepreneur	Based on lived experience from health care the entrepreneur creates companies with services that helps others, finds solutions for their own needs as well as for others.
The communicator	Shares knowledge with others, spreads statements, and communicates about lived health experiences, through conferences, meetings, articles, blogs, and social media to creates awareness, and debate in a public environment.
The mentor	Supports care processes for peers, shares guidance, inspires, provides with settings for activities and communication with peers.
The health care coordinator	Builds strategies and develops special skills to manage different actors, builds relationships, coordinates different healthcare relations, and adjusts their lives according to knowledge gained.

The healthcare partner	Develops profound relations with healthcare professionals, collaborates with them in a strategic way to solve needs for the healthcare partner as well as for his/her peers.
The activist	Changes guidelines and policies in healthcare, representing others as patient advocates, challenges paternalistic structures, and acts as an influencer online and offline.

These self-empowering behaviors often spanned over several years and were experienced according to different contexts the participants came in contact with. The behaviors never occurred in isolation, hence several of them were integrated with each other. This depended on the participants' situation.

### 5.3.1 Patterns of exploratory behaviors

To explore the conditions of the participants, it was necessary to gain information and find learning opportunities by developing partnership with peers and healthcare professionals.

*My therapist and I are 'research friends'. Together we try to tackle new aspects of my mental illness... I think it is interesting since she does not try to be superior me, even though she has a lot of knowledge... but we are on the same page regarding how to perform research together...*

To find learning opportunities also included to learn from the participants' own tracked data. By systematically measuring aspects such as e.g. physical activity, food intake, sleep patterns, and how they feel, the participants learned how to adjust and take care of their health. This was also helpful in the partnership with healthcare professionals.

*I adjusted time and dosage during the day, not exceeded my daily maximum dosage of medication set by the physician. It resulted in me improving my health... and my self-efficacy in regard to healthcare collaboration increased, since I realized that physicians can only give me guidelines regarding my Parkinson disease. Then it is up to me to adjust according to my situation.*

To live in a complex situation with a chronic condition engendered that the participants sometimes felt exposed. This could be caused within their own families, in society, or within health care when the participants tried to collaborate with healthcare professionals. Emotionally the participants needed to cope with all stressors surrounding them.

*I worry when I walk in the city, because of my injury I can get very dizzy just by stepping off a curb... perhaps the police think I am drunk...*

### 5.3.2 Patterns of influencing behaviors

To have influencing behaviors included to make a positive change for the participants as well as for others. Whether it was to innovate new solutions or to start a company, it was raised from a strong need to try make a change in the surrounding environment, to help the participants' peers and to help healthcare professionals in their profession.

*I met two other patients who have multiple sclerosis who had never been in contact with someone they could relate to... Then the idea was born to try to reach out to other young patients by me programming a webpage for this target group, since we felt it was empowering to be able to talk to someone who really understands you.*

To make a positive change for others was achieved by become a mentor for other peers to spread inspiration and information. To share lived experiences made the disease visible in new ways and gave newly diagnosed a direction of how to handle their condition and navigate health care. To further inform healthcare professionals and other groups of people about their lived experiences, the participants communicated through conferences, articles, social media, and wrote and published books.

*I believe it is appreciated when I inform healthcare professionals at meetings and conferences about my everyday life... I believe it could lead to better treatments if we could collaborate in a new way... The patient has so much valuable information that is needed in health care as well, and that is where my heart is, try to bridge a gap between health care and the patients.*

Often the participants required many different healthcare contacts because of multi-morbidity or a complex condition. This coordination required skills to handle different actors by finding useful resources, to have enough knowledge to develop relationships with these actors, and hopefully make them collaborate. These efforts were not always voluntary and something the participants wished to be replaced by other more meaningful behaviors, such as have a deeper partnership with healthcare professionals. To have a partnership was considered a learning opportunity and the participants felt valuable.

*I need to coordinate primary care, the heart clinic and... the habilitation... as well as dental care since that is very important when living with heart failure. I have tried to make them all collaborate...*

## 5.4 Healthcare professionals' perceptions (Study IV)

Study IV was a quantitative study investigating healthcare professionals' situation in regard to working together with empowered patients and informal caregivers. Three different categories exemplify healthcare professionals' attitudes, experiences, and

workplace support in situations when working together with self-empowered patients and informal caregivers: “Patient knowledge”, “Innovative patient self-care behaviors”, and “Patients navigating in the healthcare system”.

### 5.4.1 Patient knowledge

Respondents’ perception of knowledgeable patients (96%, n=268/279) and informal caregivers (97%, n=270/279)) were positive, and patients (85%, 237/279) and informal caregivers (83%, n=231/279) that shared their lived experience and knowledge with others were also perceived as positive. Learning experiences existed (88%, n=246/279 learning from patients, 69%, n=193/279 learning from informal caregivers) among the respondents, as well as experiences of discussions of existed knowledge with their patients (88%, n=246/279) and informal caregivers (65%, n=181/279). However, regular follow-ups of what the respondents learned from patients and informal caregivers was unusual (24%, n=67/279). Experiences of having encouraged patients (56%, n=156/279) (Figure XII) and informal caregivers (47%, n=131/279) to share their experiences with others were less frequent.

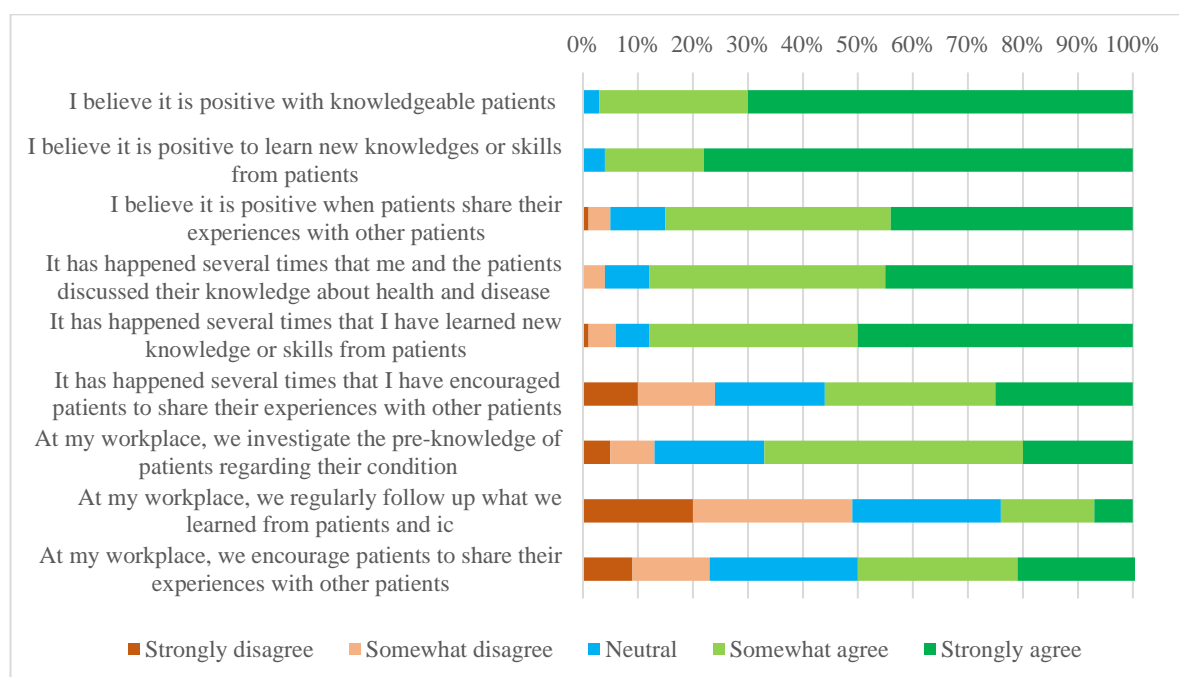
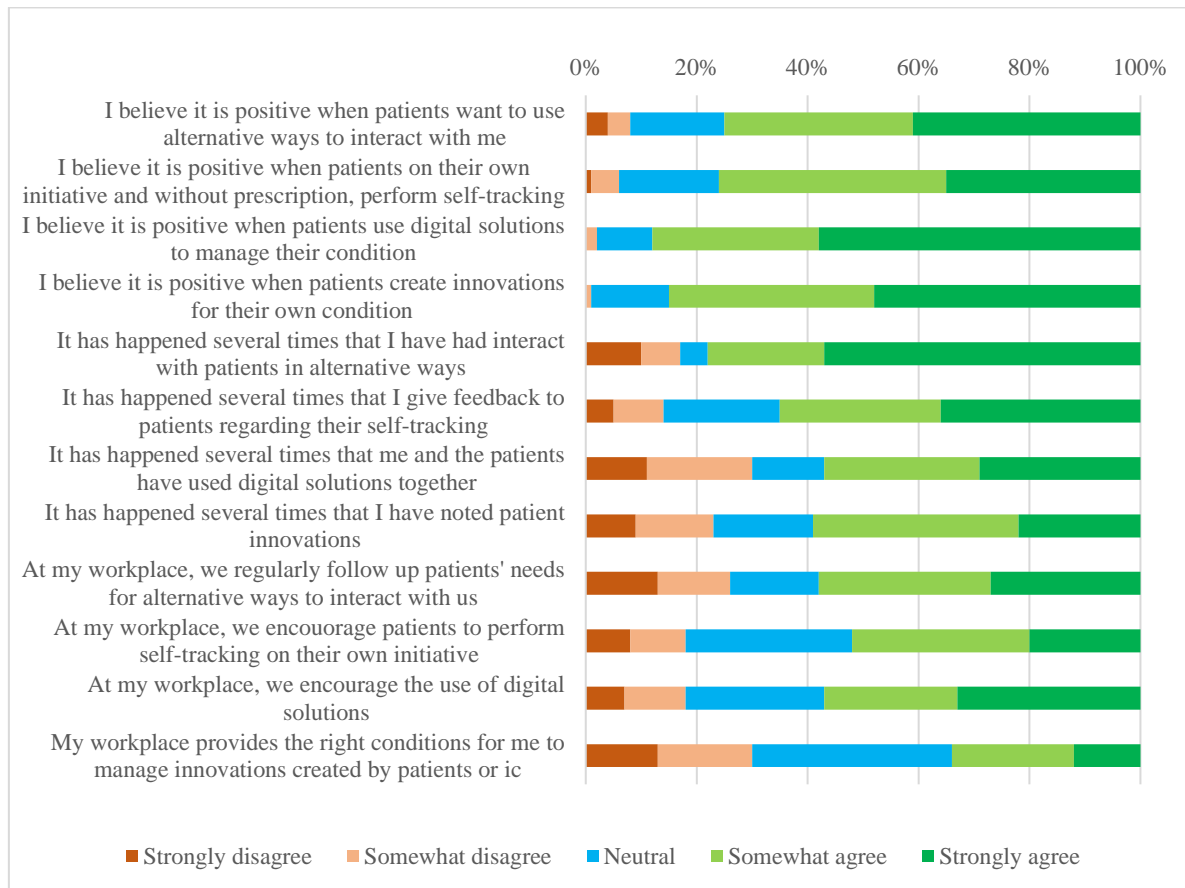


Figure XII. Attitudes and experiences of knowledgeable patients and informal caregivers (ic).

### 5.4.2 Innovative patient self-care behaviors

Patients (85%, n=237/279) and informal caregivers (76%, n=212/279) that innovated for their own condition were considered positive among the respondents, as well as patients (88%, n=245/279) and informal caregivers (77%, n=215/279) that used digital solutions to perform self-management and collaborate with healthcare. To interact with health care in alternative ways (75%, n=209/279) and perform self-tracking (76%, n=212/279) were considered positive, and the respondents had experiences of giving feedback on patients

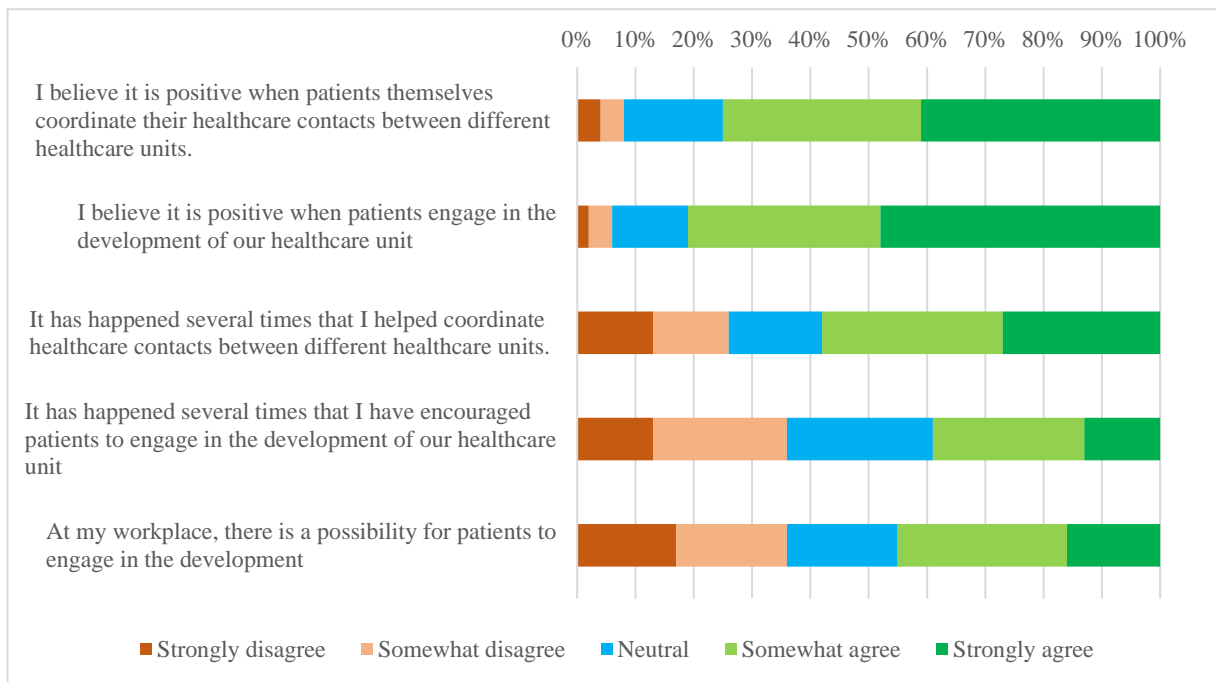
self-tracked data (65%, n=181/279). To be involved in patient innovations (59%, n=165/279) and innovations by informal caregivers (44%, n=123/279) was not as frequent, and workplace support for management of these innovations was rather low (34%, n=95/279). Workplace encouragement for patients that performed self-tracking (52%, n=145/279) and used digital solutions (57%, n=159/279) were considered positive among half of the respondents (Figure XIII).



**Figure XIII.** Attitudes and experiences of innovative patient self-care behaviors.

### 5.4.3 Patients and informal caregivers navigating the healthcare system

Patients (81%, n=226/279) and informal caregivers (66%, n=184/279) that engaged in the healthcare organization's development was overall considered positive, even though the attitudes were more positive in regard to patients. Patients (75%, n=209/279) and informal caregivers (78%, n=218/279) that coordinated between different healthcare sites were considered positive, even though some concerns were raised in regard to it not to be for everyone. Still, only 58% (n=162/279) of the respondents had experiences of support to patients and informal caregivers when they coordinated their care. Even fewer had experiences of encouragement to patients (39%, n=109/279) (Figure XIV) and informal caregivers (27%, n=75/279) when engaged in the organization's development.



**Figure XIV.** Attitudes and experiences of patients navigating the healthcare system.

## 6 Discussion

This thesis provides for a better understanding of patients and informal caregivers with different chronic conditions that use self-empowering behaviors. It includes different degrees of motivation regarding these different behaviors, risks and benefits from performing some of these behaviors, as well as healthcare professionals' attitudes towards self-empowering behaviors.

### 6.1 Discussion of the findings

This thesis' contribution is the introduction of self-empowering behaviors of patients and informal caregivers affected by chronic conditions. This was achieved by observing the movement of e-patients from information seekers towards innovators and providers of own data as a second generation of e-patients. Together with a broader group of patients and informal caregivers, the second generation of e-patients had developed extraordinary behaviors regarding their self-management tasks. Self-empowering behaviors were always initiated by the patients or informal caregivers themselves, in order to achieve self-efficacy, confidence, and take control over tasks necessary to manage a chronic condition. One of these self-management tasks was to track their own condition. The main reasons for self-tracking were to manage physical activity and medication intake, with benefits of enhanced decision-making. However, there were also risks of focusing solely on their chronic condition and challenges in their lives. Healthcare professionals had overall positive attitudes regarding self-empowering behaviors among patients and informal caregivers. Still, experiences of working together with self-empowered patients and informal caregivers were scarce. Workplace support and organization guidelines for working together with self-empowered patients and informal caregivers were scarce as well.

Empowerment aims to achieve self-determination and high autonomy through critically reflecting, pursuing, and acting upon needs and desires. However, there is not always freedom and possibility to act upon these desires [12]. Extrinsic motivation and rewards of any kind can undermine the autonomy of a person [59]. The self-empowering behaviors described in this thesis did not always reach intrinsic motivation and high autonomy. Mapping the self-empowering behaviors that were elicited in this thesis towards the self-determination continuum by Ryan and Deci [59] illustrates how patients and informal caregivers adopted different behaviors in different situations (Figure XV). The participants that experienced feeling *exposed* in different situations stated that their autonomy was undermined. The participants that needed to act as *healthcare coordinators* experienced an external force and punishment if they did not coordinate their health and health care. They felt that it was expected from them, and they would be the only ones to suffer if it would not be performed. *Activists* tried to change the surrounding environment and the healthcare system, and participants *coping* with difficult situations, also experienced

extrinsic motivation. However, these behaviors were also influenced by internal rewards and punishments. The participants felt forced by themselves (internal punishment) to make a change, both in their own mindset as well as in the healthcare system. The reason being that they had the capacity to do so. I interpret that some behaviors such as the *knowledge seeker*, the *academic*, and the *tracker* are driven by personal importance in the self-determination continuum of behaviors (Figure XV). These behaviors provided the participants with learning opportunities and better perceived health. These learning possibilities increased their competence as one of the psychological needs for self-determination. On the contrary, tracking own data also included some risks, such as letting it dominate their lives, and searching for information was sometimes done by the knowledge seeker or academic due to insufficient information provision from health care. Since the participants believed healthcare professionals had no time to explore research, the participants intention was to improve the encounters by providing it themselves. The participants stated that their self-tracked data enabled them to better understand their condition over time, which contributed to their ability to discuss their findings during encounters, even though it seemed difficult for healthcare professionals to handle patients' self-tracked data in an efficient way. As a potential result of that, PwP who self-tracked considered their physicians not being encouraging towards self-tracking. Further, I understood the *self-care expert*, *patient researcher*, *entrepreneur*, and *communicator* as behaviors being part of the participants' identity and increasing their competence (Figure XV). These behaviors made them conscious of their own condition and situation in relation to the surrounding environment. Nevertheless, I consider these behaviors still as extrinsic motivation, not being long-lasting, since they existed because of lack of support, information, or other contextual factors and were thus forced upon patients and informal caregivers. I propose that if society or the healthcare system could provide sufficient support for these behaviors, patients and informal caregivers would perform these tasks on a voluntary basis. From the results there are three influencing behaviors that I regard as completely voluntary and joyful: *innovators*, *mentors*, and *healthcare partners* (Figure XV). These long-lasting behaviors are of great interest and satisfaction, being essential in the lives of the participants. These three self-empowering behaviors strengthened the relatedness of the participants, were perceived as rewarding, and were not experienced as a burden of self-management or treatment. The participants also expressed that they desired to perform these behaviors to a greater extent. When focusing on innovating solutions for their own as well as their peers' needs, being role models for peers as mentors, or being valued as healthcare partners, the participants experienced high autonomy, control, and self-determination. Encouragement and feedback being a healthcare partner are important aspects to increase the self-determination and will lead to intrinsic motivation [60].



Amotivation	Extrinsic motivation			Intrinsic motivation	
The exposed	The healthcare coordinator	The coping expert	The knowledge seeker	The self-care expert	The innovator
		The activist	The academic	The patient researcher	The mentor
			The tracker	The entrepreneur	The healthcare partner
				The communicator	

**Figure XV.** The self-determination continuum of behaviors [59].

From a healthcare professional perspective, the behaviors of self-empowered patients and informal caregivers were considered positive in general, with some exceptions. To innovate and use digital solutions, according to the respondents in study IV, could imply negative experiences for patients and informal caregivers such as increasing their anxiety. Using digital solutions was also believed to decrease face-to-face contacts and to enhance health inequality. Coordinating one's health care could lead to inequality, since everyone could or should not coordinate their care according to the respondents. This goes in line with the believes of self-empowered patients and informal caregivers, feeling forced to coordinate rather than wishing to do so. However, in contrast to healthcare professionals, patients and informal caregivers using or innovating digital and non-digital solutions for their own needs never stated that this increased their anxiety. Even though healthcare professionals had experiences from giving feedback to patients performing self-tracking, they considered it difficult to provide patients with the most optimal support to encourage self-tracking. Since healthcare professionals believed the organizational structure for this support was lacking, it was difficult to follow up preferred ways of being in contact with their patients. It was also difficult for the respondent to understand the use of digital solutions and innovations for patients and informal caregivers, preferred ways to share their experiences with others, and to encourage involvement in the organizational development. The main challenge for healthcare

professionals working with self-empowered patients and informal caregivers was lack of time. The respondents also had less experiences of working together with informal caregivers, since they were considered a group challenging to satisfy and not always representative for the patient's requirements.

## **6.2 Discussion of the findings in relation to the literature**

Similar to the self-empowering behaviors described in this thesis, there are other frameworks and taxonomies in the literature [18,56,91]. For self-management support different strategies are described that match the behaviors of the coping expert, knowledge seeker, activist, self-care expert, and the coordinator. These strategies are described as accepting the situation, performing medical management, exercise, and change diet. Using complementary medicine when necessary, networks for belonging and information, solving problems when necessary, seeking information, self-advocating, and coordinating healthcare needs [18]. Similar strategies are described in Audulv et al [91], with the addition of social strategies that are tactics used to manage different situations in society. As described for the exposed, these strategies often include avoidance of social participation [91]. Strategies for the exposed include trying to hide their condition, due to potential stigma and feeling like a burden for their families or informal caregivers [56]. There were concerns from our participants and respondents about tasks being forced upon them, implying an obligation to focus on negative aspects from living with a chronic condition. One example of this is to be required to self-track your condition. Self-tracking has to be from the patient's own initiative, and with high autonomy and authenticity, to become beneficial [92]. Otherwise, it will only end up as a solution not being used. Despite the vast selection of digital and wearable solutions for self-tracking on the market [93], our participants mostly preferred to track in their head. This could be the effect of insufficiently addressing the users' needs. When digital solutions for e.g. self-management have high attrition rates and are not considered effective enough, this could be a result of not facilitating for the users to be part of the requirements' elicitation process [94,95]. The second generation of e-patients and their interest in new innovations is in line with the progressing digital environment in the society [24]. Early adopters and innovators are essential for the innovation and implementation of new solutions for self-management and self-care, as well as for the development of health care towards a person-centric system. Since the late majority are to follow, it is better for them to have a road map to follow, and different solutions to choose from [96].

Overall, healthcare professionals in study IV were positive in regard to this progression and the involvement of patients and informal caregivers in health care, in contrast to other studies in the literature [97]. Barriers such as lack of communication skills and confidence, inadequate attitudes, and having a strict focus on clinical factors among physicians have been reported [98], as well as structural factors with too difficult regulations, guidelines, and policy support [99]. A desire to increase the involvement in health care is particularly

expressed by informal caregivers in the literature [100–102], whereas healthcare professionals in study IV considered informal caregivers a group too difficult to satisfy. From an organizational point of view, health care reported to have problems meeting self-empowering behaviors. Different aspects were described by our respondents, such as concerns of losing control and being undermined. There was uncertainty of where responsibilities lie, especially in regard to self-management. However, a new law has been proposed in Sweden in regard to this, describing responsibilities of self-management [103], which may help to reduce this barrier in the future.

### **6.2.1 Health inequity perspective**

One aspect from the healthcare professionals' perspective and a barrier for engaging patients and informal caregivers with self-empowering behaviors, is health inequity. There are concerns that these active and engaged persons do not represent everyone, especially when new solutions are being developed. Patient innovators and early adopters are often seen as designing for their own needs and not for the needs of late adopters and laggards [53,104]. A further concern is that patients and informal caregivers will be forced to use more digital tools and services, and resources are increasingly invested in digitalization for self-management [46]. This could lead to unrealistic expectations for patients and informal caregivers with reduced ability and empowerment [105].

An assumption that everyone would like to be empowered can be a risk, since it fits the healthcare system from an economic perspective. It could also become a risk if self-empowerment is conceptualized as a choice, especially if not engaging in self-management would result in blaming patients for meagre health. This could further lead to stigmatization and health inequity if treatment is based on these choices [92,106]. Burden of treatment and self-management describe the difficulties of being empowered and performing self-management tasks [56]. Perhaps patient empowerment is not the most desired aspect of living with a chronic condition [24], since empowering behaviors do not solve the paternalistic culture in health care with power inequality [5]. If patients and informal caregivers could choose, it might be more important for them to perform tasks and actions they consider meaningful, in addition to medical management.

## **6.3 Methodological considerations**

SDT was used as a theoretical background in the thesis, in order to clarify motivation of different behaviors. However, another possibility would be to use social learning theory, examining how persons manage their thoughts and learn from observing consequences of different behaviors [63], or to explore how patient behaviors might change according to different behavioral change models.

Using exclusively a Swedish context for the samples, as well as convenience and snowball sampling for the qualitative parts of the research, might affect transferability of the results

[73,84]. Convenience sampling resulted in PD and Cancer as chronic conditions being overrepresented in the sub-studies. This because of personal and work connections by two of the authors within the sub-studies. The purposive sampling resulted in increasing the plausibility and validity of the sub-studies, when involving participants in key positions, with knowledge expertise and interest for the performed research [72]. Focusing exclusively on a Swedish context where 94% of the population report using the Internet almost daily [107], may make it difficult to transfer the results to other contexts. End-users in Scandinavia have historically had strong influence in the design process of IT-systems [108]. In addition, Sweden has a strong social safety net, which empowers an e-patient movement [109]. Still, through the thesis' literature review, I found different related concepts describing self-empowered patients and informal caregivers. These concepts originate from other contexts than a Scandinavian one, and it is therefore assumed that the result from this thesis is at least transferable to these countries.

To understand what happened when PwP in study II performed self-tracking and when healthcare professionals got to reason about self-empowering behaviors in study IV, a descriptive analysis was used. This to summarize collected data from a sample, not to develop a theory that could be generated on a whole population. The focus was to reach a broad range of respondents through online media, hence the generalizability and possibility to calculate response rates were rather decreased. A non-probability sampling [69] was performed to collect an exploratory sample, since there was a risk of not reaching the entire study population when applying online surveys [78]. Standardized surveys involving self-tracking for PwP, as well as healthcare professionals' attitudes, experiences, and workplace support in regard to self-empowerment, were lacking. Hence, new surveys were developed, despite the absence of comparability [82].

For the qualitative data, four different types of data analyses were performed. This was accomplished to ensure a good match between the research questions of each study and the analysis methods used, and to be able to further test the assumptions made. The research started with an assumption of e-patients being motivated, hence FA was used to analyze the data [75], using SDT [58-60] as a framework. Still, to not miss any important data from e-patients, an inductive TA [85,86] was used as well, and from the TA twelve self-empowering behaviors of e-patients arose. To further test these behaviors, an abductive reasoning was used with a direct content analysis [80,81]. This analysis was used to validate the twelve behaviors, from an understanding of them as an incomplete framework. For the mixed method study (II) an inductive reasoning was used, however with the need to quantify the data by measuring the frequency of categories in order to produce a survey. For this a conventional content analysis [77] was preferred.

Living with a chronic condition made it important to distinguish between my role as researcher and as chronic patient, to neutralize the subjectivity throughout the research and to ensure reliability [70]. This was also considered during the analysis process, to

provide for validity by discovering recurrent themes within the data, and to stay focused on the research questions [70]. Still, my lived experience of self-management has given me perspectives when performing this research, that most likely would be different if the same research would have been performed by another researcher.

## 7 Future work

- To deeper examine healthcare professionals attitudes and possibilities for organizational change and guidelines towards meeting the identified self-empowering behaviors.
- The self-empowering behaviors provide a knowledge-base of self-management aspects in chronic conditions. This could be used to further examine what innovative solutions could be valuable for behaviors not regarded as self-determined.
- To examine if early adopters and innovators behaviors meet the needs for late adopters and laggards.
- To compare patients' self-empowering behaviors with informal caregivers', to see if there are differences and needs for different solutions in regard to being a patient or an informal caregiver.



## 8 Conclusion

The thesis shows how intrinsic and extrinsic factors affect the degree of self-empowerment. Patients and informal caregivers experienced that those circumstances affected their psychological needs. Sometimes they felt forced and did not always have an intrinsic autonomy, such as when forced to coordinate their own health and care and when feeling exposed. Other contextual factors did however engage an inherent satisfaction and increased their relatedness, such as to be a mentor for others and to have the opportunities to innovate solutions for their own needs. The participants' competence increased when tracking their conditions in relation to medication and lifestyle factors. Further to have a good relationship with healthcare professionals increased their competence, even though this was often lacking in their lives, the self-empowered patients and informal caregivers wished to become healthcare partners. From the healthcare professionals' perspectives, they were overall positive towards working together with self-empowered patients and informal caregivers, even though they did not have extensive experience of it, and even less support from their organization to do so.

This thesis makes a unique contribution in analyzing patient empowerment from the perspectives of patients and informal caregivers with self-empowering behaviors, as well as healthcare professionals' attitudes towards these behaviors. With a rather limited understanding of self-management tasks, healthcare professionals are here provided with a better understanding of self-empowering behaviors among patients and informal caregivers. Self-empowerment will continue to influence the development of participatory healthcare, innovations and digital solutions for self-management and collaboration with health care. It is therefore essential to gain knowledge of self-empowering behaviors to understand patients' and informal caregivers' needs and development, and to provide healthcare professionals with tools and support to partner with them in a joint empowerment. So, to support the non-determined behaviors, and provide for time and opportunities for self-determined behaviors are essential to further develop towards experienced-based participatory design and person-centered health care.

## Epilogue

With the help of self-management performed by my mother and father as informal caregivers, my brother survived 11 years longer than what was medically expected. When he was three years old, I was born, and was blessed to have him in my life for 10 years. Even though self-management not always saves our lives, my personal story together with many of those I have interviewed witness of years saved. When having a severe chronic condition or being affected by one as informal caregiver, every year, every month, every day, every minute counts.



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