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# **PAVING THE WAY – THE SECOND GENERATION OF E-PATIENTS, THEIR EXPERIENCES, ACTIONS AND DRIVING FORCES**

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Paving the way – the second generation of e-patients,  
their experiences, actions and driving forces  
THESIS FOR LICENTIATE DEGREE (Ph.Lic.)

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*The real question is 'What will we be like in the future?' Not 'What will technology be like?'*  
Sherry Turkle, MIT

*We must redefine the patient's role to emphasize autonomy, emancipation and self-reliance...*  
Angela Coulter, Picker Institute Europe



## **ABSTRACT**

**Background:** E-patients are described as patients and informal caregivers who are empowered, equipped, enabled and engaged, and use digital solutions for their self-care and in healthcare contexts. Self-care can be understood as health related activities and behaviors regarding life styles and environmental aspects. The self-determination theory can be used to understand aspects of motivation and to provide an understanding for the basic psychological needs of persons, and how their autonomy, competence and relatedness are supported. Understanding e-patients also includes understanding their use of different consumer health informatics applications. These are digital solutions where patients and informal caregivers as citizens are the end-users. In the beginning of this century, e-patients were described as persons using the Internet to find information about their condition or to prepare for clinical encounters, as well as engaging in online communities. They were called the first generation of e-patients. Today there is a broader use of and an increased access to better digital solutions. Therefore, the first generation of e-patients has evolved largely in tandem with the evolving environment. The overall aim for this thesis is to examine the experiences, actions and driving forces of the second generation of e-patients, and their applicability to a broader group of patients with chronic conditions and their informal caregivers.

**Methods:** Three studies were performed. Study I consisted of a qualitative approach conducting semi-structured interviews with 15 e-patients. Deductive framework analysis was used, with the self-determination theory as an initial framework. Study II was a mixed method study with seven semi-structured interviews and a survey with 180 included respondents having Parkinson disease and self-tracking experience. Inductive conventional content analysis was applied for the interviews and statistical analysis for the survey. In study III the 15 semi-structured interviews from study 1 were analyzed using inductive thematic analysis resulting in 12 key concepts. These concepts were tested in six focus groups with 33 patients with chronic conditions and their informal caregivers. An abductive direct content analysis was used for the focus groups.

**Results:** The second generation of e-patients generate their own data, are early adopters or innovators of new solutions for themselves as well as for other peers. They are characterized by relatedness towards others, autonomy concerning themselves, as well as increased competence. Learning aspects seem to generate from self-generated data, and self-tracking provides persons with Parkinson's disease with tools to improve their decision making as well as more active communication with healthcare professionals. To track one's health and medication can be time consuming, and it is considered important to find the right balance between tracking efforts and expected outcomes. When comparing activities and behaviors of e-patients to other active patients and informal caregivers, some variations seem to exist between the two groups. Therefore two different frameworks regarding role specific competencies emerged.

**Conclusion:** This thesis shows different levels of being an e-patient. The e-patient movement is thriving towards generating own data, being early adopters of new solutions, and evolves as

innovators, as in contrast to other active patients and informal caregivers. In tandem with the progressing digital environment the second generation of e-patients has the possibility to influence the future of participatory design within healthcare contexts as well as consumer health informatics applications. It is therefore important to follow and understand this development.

Keywords: E-patients, self-care, behaviors, digital solutions.

## LIST OF SCIENTIFIC PAPERS

- I. **Scott Duncan 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
- II. Riggare S, **Scott Duncan 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)
- III. **Scott Duncan T**, Engström J, Riggare S, Koch S. Towards a framework for patients’ and informal caregivers’ behaviors and activities: a qualitative study with e-patients as outset (in manuscript).

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## **LIST OF ABBREVIATIONS**

eHealth	Information and communications technologies for healthcare
FA	Framework analysis
LOC	Locus of control
PAEHR	Patient accessible electronic health record
PD	Parkinson disease
PwP	Persons with Parkinson disease
SDT	Self-determination theory
TA	Thematic analysis

# 1 INTRODUCTION

There is a necessity for patients with chronic conditions and their informal caregivers to coordinate their care and navigate the healthcare system in order to get the care they need. Chronic conditions are globally common, with an estimation of 57% currently (year 2020) living with one or several conditions [1]. In the U.S. an estimated 50% of the population have one chronic condition, and 24% have multiple chronic conditions. However, the current healthcare delivery systems are not primarily designed for continuing and coordinated care, they are designed to handle acute conditions [2,3,4]. Thus, some patients with chronic conditions and their informal caregivers create innovative solutions for their self-care and collaboration with healthcare providers, often using information and communications technologies (eHealth). In this thesis the definition used for chronic conditions is health conditions anticipated to last more than one year and result in functional variations and/or a need for continuing medical care [2,3].

From living with chronic conditions for several years, I never hesitated to begin my research looking into the experiences of persons affected by chronic conditions. Being part of the Swedish project “Lead patients” (“Spetspatienter” in Swedish), my research began looking into the concept of *e-patients*. Being innovators and early adopters of new digital solutions makes e-patients an interesting outset for the rest of the community of persons with chronic conditions.



## 2 BACKGROUND

E-patients are described as patients and informal caregivers who are *empowered, equipped, enabled and engaged*, and use digital solutions for their self-care and in healthcare contexts [5, 6]. The “e” in “e-patients” is further associated with qualities such as *evaluating* and *equal*. Through assessment, e-patients evaluate the information they find, taking the trustworthiness of the source into account. E-patients also assume an equal relationship with their healthcare providers, regardless of support [5, 7], and their peer-driven behaviors could become an important element within the healthcare system. The important role of informal caregivers has been acknowledged since more e-patients (81%) searched the Internet for a friend or a family member, than they searched for a diagnosis or condition of their own (58%) [5]. Often informal caregivers are the ones making decisions for the most vulnerable patients.

In addition to the term *e-patient*, there are other concepts describing active and engaged patients. The Department of Health in the United Kingdom (UK) introduced the concept of “user-led self-management for chronic diseases” (Tattersall R, 2016, p1), with the premise of *expert patients* that could work as mentors for others to follow when it comes to patient participation and self-care expertise [8]. This was an important role to play within self-management programs organized by healthcare providers, and had the potential to improve healthcare delivery [9]. Expert patients have developed expertise in managing their self-care, which led to increased health, better coping abilities and better management of different challenges regarding their condition [5]. Another concept close to expert patients are *peer support workers*. This concept also originates from the UK, with employed patients within mental health services, aiming for organizational change and recovery for peers. Co-producing innovations and solutions in conjunction with healthcare professionals offers an incorporated model of healthcare [10]. *Lead patients* are specifically aiming for new innovations regarding their needs [11]. This concept originates from Von Hippel’s *lead users*, describing lay persons having a great need without any available solutions at the market. Lead users will then innovate new solutions for that need, and as a result of this solution, the general market will follow [12,13]. In a study with patients with rare diseases as long-term conditions, 53% out of the 500 survey respondents developed own solutions for their self-management needs, 8% of these were novel for healthcare providers [14]. Another survey from Portugal shows that 1.3% of the general population of patients with chronic conditions have developed own innovative solutions for their health- and healthcare needs. Looking into early adopters of peer innovations, 3.3% used peer driven innovation solutions for their own needs [15]. Creating innovations from their own needs as patients and informal caregivers, is often aligned with the needs of the rest of the community. Another concept describing patients and informal caregivers paying it forward, is the *superuser* within online communities. They give advice through their lived experiences and are often regarded as mentors for the rest of the community. Being the one keeping the community active, by frequently using and sometimes administrating the specific media, their engagement plays a durable part of making the community last. As a result, peers in online communities could facilitate enhanced self-care processes [16,17]. These peers could sometimes be referred to as *internet informed patients*. These highly informed patients use online resources to find

solutions for their needs and problems, and are striving for support from online communities, whenever they meet a lack of support from healthcare professionals [18]. Users of digital solutions for self-care are also described as *digitally engaged patients* [19]. In this thesis we will consider a more general concept of engaged and active patients and informal caregivers that use digital solutions, and therefore focus on *e-patients*, in the past and of today.

## **2.1 THE EVOLUTION OF E-PATIENTS**

In the beginning of this century e-patients were described as patients or informal caregivers using the Internet to find information to prepare for clinical encounters and to check if what had been said in the encounter was correct or not [5]. In the evolving context of digitalization, they were called *the first generation of e-patients* [6]. Today, personal eHealth solutions such as patient accessible electronic health record (PAEHR) are perceived as big facilitators in helping patients to do follow ups regarding their interaction with healthcare providers [20]. We can also see a broader use of and an increased access to better digital solutions. With environmental changes such as the evolution of the World Wide Web, smartphones, and consumer devices for tracking, there is an opportunity to democratize medicine [21,22]. With a culture change including a greater tolerance of patients' searching health information online (googling), and sociological changes between generations, there are different prerequisites for today's patients and informal caregivers. The collaboration between healthcare professionals and patients/informal caregivers – participatory medicine – has found new ways through digitalization. By using the Internet, patients/informal caregivers and healthcare professionals can find new research that will provide better treatment. Patients/informal caregivers can find significant information that prepares them for their encounter, and by using tracking devices, patients can produce new data to discuss. There are today also websites connected to healthcare providers where patients can find useful information [5]. The first generation of e-patients has evolved largely in tandem with the evolving environment [21].

## **2.2 THEROETICAL BACKGROUND**

E-patients could be considered as role models and mentors – paving the way for others. It is preferable to have someone like yourself as a role model, since it makes it easier to connect to and to follow their lead [23]. For example, if it is described in the literature how e-patients critically make assessments regarding trustworthy sources on the Internet [7], other citizens can use these assessments to feel more secure searching online information. It is found to be crucial for survivors from severe diseases to get support from a family member or a mentor, in order to maintain their psychological well-being [24].

### **2.2.1 Self-determination theory**

As a theoretical background for this thesis we have used self-determination theory (SDT), since it is of interest to know whether e-patients behaviors are self-motivated and self-determined. This theory is used to analyse the motivation of e-patients to engage and be active in their self-care and in collaboration with healthcare providers. SDT provides an understanding for the basic psychological needs of persons, and how their *autonomy*, *competence* and *relatedness*

are supported. This has an impact on their growth, social development, and well-being [24,25,26]. Motivation includes having a direction towards a specific goal, having the energy and persistence to fulfil it. Motivation can exist because of internal values or external coercion. Being engaged and active within a specific area because of an individual's own choice and receiving fulfilment from the activity itself, without being rewarded, goes as intrinsic motivation [25,26]. However, according to a subtheory of SDT – a cognitive evaluation theory that aims to clarify the unpredictability in intrinsic motivation – social contexts such as positive feedback and rewards that gives support for a person's autonomy and competence, could increase the intrinsic motivation. On the other hand, tangible rewards, pressured situations and threats rather undermine the support for autonomy and competence. The cognitive evaluation theory only applies for engagement and activities that are of value for the person. Overall, behaviors are motivated by satisfaction of autonomy, competence, and feeling relatedness to other related or devoted persons [26,27].

### **2.2.2 Analogous constructs**

Alongside SDT there are other aspects that could affect behaviors; genes, repetition, effort, support and self-efficacy. Since human personality is built by a person's behaviors and not stagnant, it is possible to change personality, behaviors and allocated roles [23]. However, in order to be motivated, it has to be an active choice and a positive attitude regarding the activity. Another variable to SDT is the internal versus external control of outcome – locus of control (LOC). It describes believes of a person to be motivated. With an external control a person believe it is faith, chance or being under control by dominant others, which control their behaviors. Whereas internal control describes individuals as being in control over their life and making conscious choices made from their experiences and skills. These differences of believing in chance or skills also affect the learning possibilities, it is easier to learn when experience being in control [28]. Grit is another concept describing differences between persons and their motivation. It is described as the ability to maintain motivation and determination over a long period of time, despite setbacks or adversity [23,29]. Grit is also perceived to affect a person's well-being, life satisfaction and harmony, as well as being related to a person's internal LOC and being genuine to one's sense of self [30]. An individual with a higher grit has the tendency to overlook negative aspects in life and grasp positive memories, the so called fading affect bias [31].

### **2.3 SELF-CARE VS SELF-MANAGEMENT**

It takes skills and experience to perform self-care or self-management in a successful way. These two terms are frequently used interchangeably, however there are some distinctions between them. Self-care are health related activities and behaviors regarding life styles and environmental aspects, regardless of a chronic condition or not. Self-care could be perceived as health promotion as well as disease prevention. Self-management are activities that need to be handle due to a health condition [32]. Using the Corbin and Strauss framework for self-management, as well as the US Institute of Medicine's definition, there are three fixed tasks: *medical management*, *role management*, and *emotional management* [32,33]. Within these

three there are tasks such as taking medication, devotion to a specific diet and physical activity by creating meaningful behaviors as their lifestyle choices, and learning to manage difficult emotions [33,34]. Adapting to and manage difficult situations through coping is described as a sense of coherence. This might increase the sense of well-being and perceived health [35]. Being able to perform these tasks, five central self-management skills are mentioned; being able to (1) solve problems, (2) make the right decisions, (3) forming partnership with healthcare providers, (4) apply accurate resources, and (5) take action when needed [34]. Being part of an online community could acquire new ideas of how to handle self-care, as well as to be inspired, to be better prepared prior to a healthcare encounter or before a medical procedure. Online communities could also lead to emotional support and understanding from peers with lived experience of the same situation [17].

### **2.3.1 Self-tracking**

To perform self-management and react to symptoms, requires learning about the chronic condition and how to best manage individual symptoms related to that condition. By collecting patient-generated data, self-tracking is a good method to use to reflect and gain this sort of understanding [36,37]. Together with the trend of digitalization there is an increase of self-tracking tools and patient-generated data [38]. Taking the self-tracking out of the self-care context and learning aspects concerning one self, patient-generated data from self-tracking could as well become learning experiences of many. Performing N-of-1 studies – single subject design studies – can become research for other peers to follow, or help guide the research community to understand the research-needs of patients with chronic conditions [36,37]. Performing self-tracking and patient-generation of data for oneself as well as for peers is well described within the quantified self-movement [39]. Here social networks such as; PatientsLikeMe, CureTogether, MedHelp, Inspire, DailyStrength, SugarStats, are offered [37]. They comprise user-friendly functions for users to add their own individual tracking data and share it with other users [37]. Several of these networks also provide trials performed by the patients within the community, often with protocols that are published online, to support other patients to self-track. With less time than traditional trials driven by healthcare providers, and generating a result rather quickly for the participants and the rest of the patient community, patient-driven research often generate high feasibility. This could be shown when severe diseases such as ALS have excellent adherence [40]. Sometimes self-tracking and patient driven innovations are combined, such as do-it-yourself open loop systems within diabetes. Here Dana Lewis as a diabetes patient has created an artificial pancreas system to track her own data and adjust her insulin doses accordingly [41]. Patient-generated data from self-tracking is also being presented to healthcare professionals as a hope to support the clinical process and clinical decision making [38]. Overall, “quantified self”-methods are acknowledged to empower patients and informal caregivers to be in control over their health and to take a more active role in collaboration with healthcare professionals [39].

### **2.3.2 Empowerment**

Increased involvement in healthcare contexts and patient empowerment in general could be considered the foundation to accomplish successful self-care. Empowerment is defined by the World Health Organization (WHO) as “a process through which people gain greater control over decisions and actions affecting their health” [43]. Patient empowerment includes four components for the patient; (1) understanding their role, (2) acquisition of adequate knowledge for engagement, (3) specific skills, and (4) presence of a facilitating environment [42]. Within healthcare, improved attention on patient empowerment has been a result from focusing on patient-centered care. This includes facilitating for patient independence, self-management, and self-efficacy. However, it is still challenging to achieve an agreement on how to best support and measure patient empowerment, especially together with the support of eHealth solutions. There is also a difficult distinction between the concepts of patient empowerment, activation and engagement, which all have different tools to measure them. They tend to be used interchangeably [43].

## **2.4 CONSUMER HEALTH INFORMATICS APPLICATIONS**

Applications within the field of consumer health informatics (CHI) are digital solutions where patients/informal caregivers and citizens are the end-users. These solutions could be PAEHRs, online communities (including e-mail networks, blogs, vlogs, text messaging, websites with storage opportunities for all communication, and other collaborative technologies) [5], sensors for monitoring, applications for self-tracking, the Internet as a source of health information, different apps to support self-care, and patient portals [44, 45]. These digital solutions facilitate for patients and informal caregivers to perform self-care, and they are also seen as a way to engage in a partnership with healthcare providers and democratize medicine. The ambition is for the users to be in control over their own data and uninhibited from a potentially paternalistic healthcare structure [20, 46, 47]. Well-designed and user friendly CHI applications can only be the reality if the users are involved in the development [45, 37], since patients and informal caregivers are vital to constructing any effective system concerning them. It has been shown that issues patients are concerned about are rather different from the information they receive from healthcare professionals [5]. It is therefore necessary for developers to be willing to provide solutions regarding important issues for patients and informal caregivers, otherwise they as users will meet the same profound cultural deficiencies as they experience within encounters with healthcare professionals [5, 37].

If we know how patients make informed decisions regarding use of CHI applications, it is easier to motivate the use of digital solutions for self-care. To understand e-patients' needs and motivation as early adopters when using digital solutions for self-care and collaboration with healthcare providers, as well as e-patients as innovators, could create a better understanding overall.

### **3 RATIONALE AND AIM**

The first generation of e-patients has been studied and described back in the beginning of 2000. However, the future for e-patients has not been explored and there is lack of knowledge regarding the understanding of the journey of e-patients. E-patients could be the key to future healthcare – to future development and diffusion of innovative solutions for themselves and their peers. Exploring the motivation and strategies of today's e-patients provides an increased feasibility for other active patients/informal caregivers to follow their lead.

The overall aim for this thesis was to examine the experiences, actions and driving forces of the second generation of e-patients, as well as how far these are applicable to a broader group of patients with chronic conditions and their informal caregivers.

The aim was reached by completing the objectives of the three 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 behaviors and activities of e-patients in self-care and healthcare contexts, and to search for similarities and differences compared to a broader group of patients with chronic conditions and their informal caregivers.

## 4 METHODOLOGY

Three studies were performed to fulfill the overall aim of the thesis; to examine the experiences, actions and driving forces of the second generation of e-patients, and how far these are applicable to a broader group of patients and informal caregivers. Figure 1 illustrates how these studies are connected to the aim.

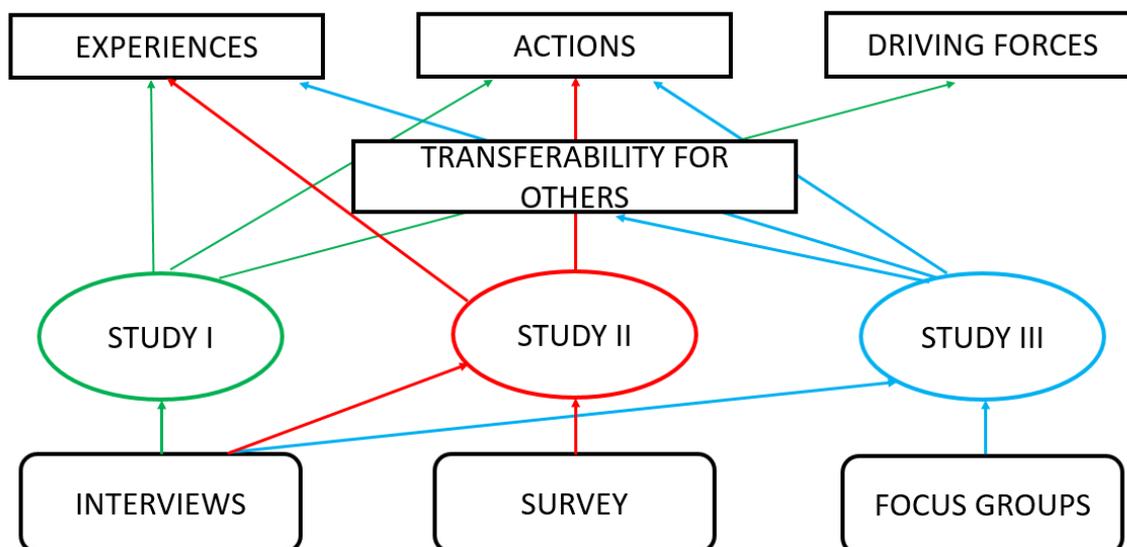


Figure 1. Overview of the thesis.

The three studies are focusing on active and engaged patients with chronic conditions and their informal caregivers' self-care and collaboration with healthcare. It was most appropriate to use a qualitative approach [48] to answer the overall aim, to get a deeper understanding of their motivation, experiences and concerns. Semi-structured interviews, a survey and focus groups were used to collect data, and five different methods for data analysis were used (Table 1).

Table 1. Overview of the three studies.

	Data collection	Data analysis
<b>Study I</b>	Semi-structured interviews (n=15)	Deductive framework analysis (FA)
<b>Study II</b>	Semi-structured interviews (n=7) Survey (n=180)	Inductive conventional content analysis Statistical analysis
<b>Study III</b>	Semi-structured interviews (the same data as for study I) Focus groups (n=6, total number of participants=33)	Inductive thematic analysis (TA) Abductive direct content analysis

We purposely selected participants with different ages, gender, living in different regions within Sweden, and having different chronic conditions. The recruitment process for each study is described in more detail below. An overview over participants' characteristics for all studies is given in Table 2.

Table 2. An overview of the participant characteristics of the three studies.

	<b>Chronic conditions (several participants having one or several conditions)</b>	<b>Age (years)</b>	<b>Gender</b>	<b>Time since diagnosis (years)</b>	<b>Patient/Informal caregiver</b>
<b>Study I</b>	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: n=5 (33%)  46-65: n=7 (47%)  >66: n=3 (20%)	Female: n=10 (67%)  Male: n=5 (33%)	≤5: n=3 (20%)  >6: n=12 (80%)	Patient: n=10 (67%)  Informal caregiver: n=5 (33%)
<b>Study II</b>	Parkinson disease	18-45: n=7 (4%)  46-65: n=82 (44%)  >66: n=98 (52%)	Female: n=93 (50%)  Male: n=94 (50%)	≤5: n=78 (42%)  >6: n=109 (58%)	Patient: n=187 (100%)
<b>Study III</b>	Part 1: Same as study 1.  Part 2: 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-myelocele, 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: n=8 (24%)  46-65: n=14 (43%)  >66: n=11 (33%).	Part 1: Same as study 1  Part 2: Female: n=25 (76%)  Male: n=8 (24%)	Part 1: Same as study 1  Part 2: ≤5: n=8 (24%)  >6: n=25 (76%)	Part 1: Same as study 1  Part 2: Patient: n=27 (82%)  Informal caregiver: n=4 (12%)  Both: n=2 (6%)

## 4.1 STUDY I

When describing the second generation of e-patients, we assumed the participants to be motivated and compared their active engagement with the concepts from SDT. This made us do predictions about the outcome and we therefore used deductive reasoning [49]. Semi-structured interviews were performed with 10 patients and 5 informal caregivers self-identifying as e-patients.

### 4.1.1 Study sampling

The recruitment was performed through an online advertisement published at the Web-page of the project “Lead Patients” (“Spetspatienter” in Swedish), reaching 9054 unique visitors and through a newsletter reaching 1500 subscribers. Overall, 67 suggestions were received and the participants were intentionally selected to cover gender and patients versus informal caregivers, as equal as possible. Different chronic conditions, ways of being active and engaged, locations around Sweden, and age were also considered important to cover during the sampling process. A few of the 15 participants were also selected using snowball sampling – when nominations for participants meeting the inclusion criteria were made as a snowball effect – or through convenience sampling – when the selection of participants to be included in the sample is a result of convenience of the researchers. The latter included choosing participants within a geographical area close to the researcher, or go through contacts of the researchers to find participants as the most feasible approach [50, 51].

#### 4.1.1.1 Inclusion criteria

Inclusion criteria were: being a patient with a chronic condition or an informal caregiver, over the age of 18, and considering themselves being an e-patient. Different persons could also choose to suggest someone else, suitable according to the description of an e-patient that was provided 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.*

### 4.1.2 Data collection

Semi-structured interviews were used to collect data, either over telephone (n=6) or face-to-face (n=9). The interview guide included the following four areas: *Background, Your health journey, Health behavior, and Your role in self-care and healthcare.* It was the responsibility of the interviewers to help the participant to perform a meaningful and coherent reasoning regarding the studied phenomenon, without influencing the answers from predefined conclusions [48, 52]. The data collection was performed by the first author as well as coworkers from the project – “Lead Patients”. Open-ended questions were used and ensured that the transcribed material consisted mainly of words and phrases formulated by the participants [48,52]. The data collection resulted in 152 pages of verbatim transcribed material from interviews with an average of 40 minutes each of recorded conversations. No further sampling

was considered necessary since a priori thematic saturation was reached to exemplify SDT [53].

### 4.1.3 Data analysis

The framework analysis (FA) was used to analyze the data. In line with the aim of the study – the exploration of the second generation of e-patients’ active engagement – the analysis began with identifying an initial framework based on what was already known about this population [54]: the second generation of e-patients is motivated to continue being active and engaged. This steered the analysis towards SDT, and to use FA as an approach to further examine whether the data fitted into the three basic psychological needs of SDT (autonomy, relatedness, competence) [25,26,27], or if other themes emerged [54]. The verbatim transcribed interviews were used to perform the five steps of FA.

- 1) Familiarizing – As a first step we got familiarized with the collected data from the interviews by listening through the recorded material once more, and labeled the interviews according to the interviewer who had performed the interview and in chronological order. This process developed key ideas about emerging themes.
- 2) Identifying thematic framework – Next step was to identify a thematic framework through the emerging themes in the data. By using the key ideas from the familiarization phase the base of a thematic framework is in place and was used to filter and categorize the collected data.
- 3) Indexing – The indexing process included to map sections of the data to specific themes. This was done by using Excel and spreadsheets.
- 4) Charting – The fourth step was to organize the data into subcategories, categories and themes through a coding process. The data was elevated from the narratives of the participants and placed in charts, however the data was still kept as identification to each narrative. All data were part of the charting process, while keeping the links to the raw data by labels.
- 5) Mapping and interpretation – The themes were updated several times during an iterative analysis process. Concepts and relationships were found through mapping and interpretation and all new findings were considered [54, 55].

During the analysing process at least two authors of the study were involved at all time, to decrease the subjectivity of having only one author analyzing. Two themes emerged from the data: *Nondigital factors influencing active engagement* and *Digital solutions to support active engagement*.

## 4.2 STUDY II

We used a mixed method with sequential studies, going from the result of semi-structured interviews to design a survey [50]. Here we base our conclusion on what is observed from the group of participants. In this inductive approach we do not use any predefined models or theories, since the result and conclusion is not predicted in advance [49], but should enable theory- or model building. The in-depth understanding gained from the semi-structured

interviews informed the design of the survey. Using method triangulation ensured a focus on both breadth and depth regarding the aim of the study, and the possibility to improve the accuracy of the data and the validity of the results when examining the same aim with different methods [50].

#### **4.2.1 Study sampling**

The recruitment for study II consisted of two parts; the qualitative and the quantitative part.

##### *4.2.1.1 Qualitative part*

The semi-structured interviews required participants with specific experiences, and it was therefore important to find the right persons for the study. Hence the participants were hand-picked using purposive sampling [50, 51]. Personal networks and contacts were used, since the inclusion criteria included PwP who were familiar with self-tracking, and preferably had performed self-tracking themselves. Seven PwP were selected based on their experience, having varying backgrounds, geographic location within Sweden, different gender, ages and PD characteristics; treatment, symptoms, and severity of disease. However, none of the participants had cognitive impairment.

##### *4.2.1.2 Quantitative part*

The aim for the survey was to collect an exploratory sample, as a way to generate new insights and models. This was done through a non-probability sampling [50], accepting the risk of not reaching all PwP within the study population. The survey was distributed through an online link using the Web-based form Google forms, with an open questionnaire for the public to answer. Using an online survey was deemed appropriate since 95% of the Swedish population considered themselves using the internet to some extent [56]. The survey was disseminated through patient associations, personal networks of the authors and social media. This ensured that the respondents knew who provided the questionnaire, and at the same time, they could still stay completely anonymous. The survey also had the potential to cover a wide geographical area [57]. Internet users within the PwP community were targeted. A total of 280 PwP responded, 180 of them (64%) had self-tracking experiences and were therefore included in the study.

#### **4.2.2 Data collection**

##### *4.2.2.1 The qualitative part*

An inductive thematic saturation was reached after seven interviews. Redundant information regarding self-tracking was starting to show, and no new codes or themes were identified through the simultaneously performed analysis [53]. The pilot tested interview guide consisted of: *Background information, Disease characteristics, Self-care and self-tracking, and Interaction with healthcare and self-tracking* (Study II, Attached file 1). The interviews were conducted by two PwP (one of them was the first author of the study), and the recorded material had an average of 40 minutes each.

#### 4.2.2.2 *The quantitative part*

Due to the lack of standardized questionnaire on self-tracking for PwP, a study-specific questionnaire was developed by the research team to provide more quantitative data. The survey was based on the themes from the qualitative analysis and consisted of six sections: *Background*, *Experience of self-tracking*, *Reasons for self-tracking*, *Approach and use of self-tracking*, *Self-tracking's influence on relationships with healthcare*, and *Challenges and risks associated with self-tracking*. The questions were designed as closed multiple-choice options, as well as a Likert-scale with five options of *strongly disagree*, *disagree somewhat*, *neither agree nor disagree*, *agree somewhat*, or *strongly agree* to different statements. With awareness of the tendency of choosing *neither*, we still choose a five option scale, since the risk of internal bias would otherwise increase [52]. The multiple-choice questions provided a large range of answers, to avoid the participants feeling forced into a specific answer. The questions also provided an *other* category with an open-ended answer alternative (Study II, Attached file 2).

#### 4.2.3 **Data analysis**

A conventional content analysis with an inductive approach was used for the qualitative part of the study [58, 59], to describe the phenomena of PwPs' opinions and experiences regarding self-tracking. This analysis method was chosen to allow quantify the data and to measure the frequency of different themes and categories. This approach was considered the best choice when performing a mixed method with sequential studies [50,60], reusing the themes of the qualitative study to design the questionnaire. For the survey a statistical analysis was used to test for associations through a chi-square test [61, 50], as a broader concept to reach the research question of the study.

##### 4.2.3.1 *Conventional content analysis*

This was an inductive approach where codes and categories were directly connected to the data, and not imposed from other research. Since this approach often is used to describe a phenomenon with limited research literature, it suited well with the research question of study II. The data guided the analysis process [58,59] through repeatedly reading the transcribed text to make sense of it.

- 1) The transcripts were read through several times.
- 2) The text from the transcripts was then organized into two content areas: *self-tracking* and *collecting data in collaboration with healthcare*.
- 3) From these content areas relevant data was selected into one text, and become the unit of the analysis.
- 4) Considering the whole context condensed meaning units were made from the text and labelled with codes.
- 5) These codes were compared and sorted into sub-categories and 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*.

#### 4.2.3.2 *Quantitative analysis*

To rank options by answering different statements such as in a Likert-scale means that the different answers only are assigned numerical values such as from 1-5, it doesn't mean they can be treated as numerical values. Instead the type of data used for study II is categorical ordinal and nominal [61,50]. This kind of descriptive statistics helped us simplify and summarize large values. To organize the data, frequency distribution was used to perceive how many of the participants that fitted into each category. It was also useful to cross-tabulate the participants' opinions regarding self-tracking in relation to their age (Figure 4 in Study II), time since diagnosis (Figure 2 & 5, Table 3 in Study II), and gender (Figure 10 in Study II) [49]. All data was displayed as bar charts since the number of categories was often greater than five and the interpretation of the data would be difficult if pie charts would have been used for instance [61]. To determine if the cross-tabulation reflected a real relationship, a chi-square-test was used. Using a calculation tool online made it possible to define a statistical significance with a p-value (probability) of  $p < .05$  [62].

### **4.3 STUDY III**

Study III consisted of 2 different steps. In the first step we used the same 15 semi-structured interviews as study I, however with a different analysis. This time an inductive approach was used to reassure us not leaving any important information behind regarding behaviors and activities of e-patients. For the second step within study III, an abductive approach was used with six focus groups to test the result from part 1 on a broader group of patients and informal caregivers. This more pragmatic approach [63] gave us the best prediction regarding similarities and differences between e-patients and a broader group of patients with chronic conditions and their informal caregivers.

#### **4.3.1 Study sampling**

For part 1 of this study, the sampling process is described in study I (section 4.1.1).

A snowball and convenience sampling were conducted for the recruitment of participants for part 2 of the study [50,51]. It included patients with chronic conditions ( $n=27$ ) and their informal caregivers ( $n=4$ ), as well as a few being patients and informal caregivers ( $n=2$ ). The 33 participants were all approached through employed peer supporters or patient organizations. The recruiters were located around Sweden, and connected to the "Lead Patient" project.

##### *4.3.1.1 Inclusion criteria*

The inclusion criteria for part 2 of the study were: to have a chronic condition or being an informal caregiver to someone with a chronic condition, to have an active behavior regarding their self-care and/or collaboration with healthcare providers, and over the age of 18 years old.

#### **4.3.2 Data collection**

Data collection for part 1 of the study was the same as for study I (section 4.1.2).

In the second part of the study, focus groups were used to collect data from a broader group of persons with chronic conditions or their informal caregivers. A multiple-category design with different locations, patients, informal caregivers or both as participants, and different chronic conditions was used (Table 3) [64]. All focus groups (n=6) were performed within the geographical region the group belonged to, with participants having one or several chronic conditions. The six focus groups were all moderated by the author, with 1 or 2 observers facilitating the two parts of the focus group sessions, as well as observing how the group worked together and if the questions worked as intended. A semi-structured interview guide was used as a protocol for the sessions. The protocol had been tested as a piggyback focus group (piloted) on 10 individuals beforehand [64]. The sessions had two parts, with the first focusing on answering the questions from the protocol. The protocol consisted of four sections: *Demographics*, *Everyday life activities regarding self-care or collaboration with healthcare*, *The journey*, and *Skills describing your activities* (Study III, additional file 3). The second part of the focus group session aimed to test the framework of e-patients' activities and behaviors (as a result from part 1 in the study), to examine if there were any differences between the study populations. Data saturation was reached after six focus groups (including 33 participants), when there was lack of new information [53]. The recorded material had an average of 1h 43 minutes per focus group, and the verbatim transcribed data consisted of 151 pages.

Table 3. Overview of focus group, dataset 2 within study III.

<b>Focus groups</b>	<b>Patients/Informal caregivers/Both</b>	<b>Chronic conditions</b>
Mixed chronic conditions no 1	2/3/2	Parkinson Disease, Multiple Sclerosis, Mental illness, Irritable Bowel Syndrome, Breast cancer, Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, Stroke, Brain cancer
Cancer	8/0/0	Prostatic cancer, Colonic cancer, MDS GATA 2 Deficiency, Breast cancer, Uterine cancer, Ovarian cancer
Rheumatism	5/0/0	Rheumatism, Irritable Bowel Disease
Parkinson disease	5/0/0	Parkinson Disease
Mixed chronic conditions no 2	4/0/0	Diabetes type 1, Cyst-liver + Cyst-kidney, Parkinson Disease
Mixed chronic conditions no 3	3/1/0	Multiple Sclerosis, Diabetes type 2, Diabetes type 1, Meningo-myelocele, Whiplash injury

### 4.3.3 Data analysis

For dataset 1, inductive thematic analysis (TA) was used [65] to analyze narratives of the lives of e-patients. Direct content analysis using an abductive approach [58, 59] was applied for

dataset 2 when comparing the narratives of e-patients to a broader group of patients and informal caregivers.

#### 4.3.3.1 TA

Using the same collected data as for study I, TA was used inductively to understand behaviors and activities of e-patients [65]. This basic analysis suited this study well, as it is more flexible than other analysis methods as well as theoretically unattached [66]. TA consists of six phases:

- 1) We started with familiarization of the material through reading the transcribed text and listening to the recorded data to get to know the material.
- 2) Next step was to find codes within the material and coded all data into meaning units.
- 3) By going through the codes we could find patterns to construct the themes from.
- 4) All coded data were gathered to different themes, and as an iterative process the themes were once again examined to see if they were accurate or not.
- 5) When the themes and categories were decided, they were named and defined by the essence of how they fit into the overall research concept.
- 6) As a final step of the analysis the data extracts were intertwined to give the reader a convincing narrative about the data, and the categories were illustrated as 12 key concepts within a new framework [65].

From this process the two themes *To explore* and *To influence* emerged. Within these themes 12 key concepts emerged as roles of competences e-patients take: *The Self-care expert*, *The Academic*, *The Patient researcher*, *The Hacker*, *The Tracker*, *The Healthcare coordinator*, *The Innovator*, *The Communicator*, *The Mentor*, *The Entrepreneur*, *The Healthcare partner*, and *The Activist*. These roles provided a new framework regarding e-patients behaviors and activities.

#### 4.3.3.2 Directed content analysis

From the knowledge gained through the first part of the study, with a preliminary framework regarding e-patients, we scrutinized whether this rather incomplete framework could fit into the activities and behaviors of a broader group of active and engaged patients or their informal caregivers. Since this framework could benefit from further research, a directed content analysis was conducted in order to validate the framework [59]. To initiate the coding process, the 12 roles described within the framework were used as key concepts. Four structured steps were performed to conduct the analysis:

- 1) As a first step all data – including the 12 key concepts – were highlighted into codes.
- 2) The next step included all codes to be categorized into the predetermined 12 categories. Sub-categories were made to increase the readability of the data.
- 3) If any highlighted data didn't fit into these 12 predefined categories, it would be given a new code.
- 4) As an iterative process a new assessment was made whether new codes were part of an existing category or subcategory, or if a new category was needed [59]. Through this process

7 of the 12 key concepts were transformed into 4 new categories, and one completely new category arised. This gave us 10 key concepts/categories instead of 12.

Two themes appeared from the data: *Gaining experience and knowledge* and *Using experience and knowledge*, as well as 10 updated categories representing the framework for a broader group of patients with chronic conditions and their informal caregivers.

#### **4.4 ETHICAL CONSIDERATIONS**

Ethical approval was sought for all studies. For study I, study II and part 1 of study III the Regional Ethical Review Board in Stockholm deemed an ethical review not to be necessary according to decision 2015/1572-31/4. For part 2 of study III an approval was made according to decision 2018/2294-32.

##### **4.4.1 Informed consent**

For participants in interviews and focus groups information about the studies was given orally and in writing. Participation in the studies was voluntary and the participants signed an informed consent that could be withdrawn at any time [48,49,50].

Information to survey respondents was connected to the questionnaire, and answering the survey was understood as a consent to participate [50].

##### **4.4.2 Privacy and confidentiality**

During the process of collecting qualitative data and writing the results, care was taken not to reveal information that could be traced back to participants, however still be able to tell the participants' stories. To consider the confidentiality, we choose not to publish any private sections from the data collection that could be traceable [48,50]. To protect the participants' integrity, individual codes have been used, instead of names [49]. To protect personal data from third parties and to reassure individual privacy the European General Data Protection Regulation (GDPR) was followed at all stages of data management [67]. Information has been distributed about the storage of collected data and that the participants could take part of their data, and correct any misinterpretations. This was done by one of the participants within study I.

## 5 RESULT

An overview of the main findings from the three studies and how they relate to each other is displayed in Table 3.

Table 3. Main results and connections between the studies.

Study	Main results and connections between the studies
<b>I</b>	The second generation of e-patients generated their own data, which provided them with learning opportunities. They also provided their data and new innovations to the community of peers. This indicated relatedness towards others, autonomy concerning themselves, as well as increased competence, according to SDT. This kept the second generation of e-patients motivated to continue being active through digital solutions and engaged regarding their own self-care and collaboration with healthcare providers.
<b>II</b>	To manifest what we learned from the second generation of e-patients (study I), we explored the benefits and burdens of performing self-tracking, as one method to learn from self-generated data. Self-tracking provided the participants with tools for improved decision making related to their overall self-care, as well as more active communication with healthcare professionals. However, to track one's health and medication was time consuming, therefore it was important to find the right balance between tracking efforts and expected outcomes.
<b>III</b>	Based on the result of study I and II, we further explored behaviors and activities of e-patients in comparison to other active patients and informal caregivers. They all adopted different role-specific competencies to accomplish specific behaviors and activities, however as we found some variations between the two groups, two different frameworks emerged. The second generation of e-patients acted explorative; setting up self-care strategies and sought information through research, self-tracking and used digital solutions to explore possibilities. As a sequential manner then created solutions and influenced peers and healthcare providers. Other active patients/informal caregivers first sought experience and knowledge within themselves as using different coping techniques and learned how to handle difficult situations. They might stay in those roles or moving forward using experience and knowledge to become influencing forces for peers, together with healthcare professionals, or by challenging old structures.

### 5.1 FROM INFORMATION SEEKERS TO INNOVATORS (STUDY I)

Having the knowledge of e-patients as being empowered, equipped, enabled and engaged made us formalize an idea to presume e-patients also to be very well motivated to continuing actively strengthening their own health and in collaboration with healthcare. Our results showed that e-patients today produce their own data and create innovations to solve their own needs as well as the needs of others. We will use the term the second generation of e-patients throughout the thesis. We explored the second generation of e-patients' active engagement in their self-care

and collaboration with healthcare providers, using SDT as an initial framework for the study. To understand whether the second generation of e-patients' motivation is self-determined through their autonomy, relatedness and competence, or not.

### **5.1.1 Non-digital factors influencing active engagement**

Analyzing the second generation of e-patients' active engagement indicated that the participants spend a lot of effort in trying to interact and collaborate with healthcare providers. The three most important aspects of this collaboration were (1) to be met with respect for their symptoms, (2) to receive feedback, and (3) to have a healthcare system that can adapt to the needs of the patients. The participants described long-winding and difficult situations trying to get the correct diagnosis in the beginning of their chronic condition. It was also expressed that they were not always taken seriously, wishing for a better collaboration with healthcare professionals to set the correct diagnosis, as well as better collaboration regarding their self-care needs. To get feedback regarding self-care, was described as an important aspect when it came to sharing knowledge from performing self-care, as well as asking for related solutions. A major part of the second generation of e-patients' learning experiences of how to recognize symptoms and be in control of their lifestyle assumed to come from performing self-care. These experiences seemed to increase the autonomy. However, sometimes being in control was not the most important thing to pursue, since there were other stressing matters.

*It's more about recovering and learning how to deal with your life so it doesn't consume you.*

The informal caregivers described their role as ensuring good quality of self-care, as well as healthcare. It was therefore relevant to strive for a healthcare system that could meet the participants' expectations of engagement.

*The interaction with healthcare is a lot about calling someone on the phone. However, many of the people I've met in psychiatry have affective and social difficulties, and for them that is very difficult.*

Another factor that influenced the participants' motivation and engagement was the strength of peers – both acting as peer and being supported by other peers. Both perspectives were described as important when insufficient collaboration with healthcare professionals existed. In peer communities, the participants got feedback regarding self-care and could share needs and solutions with others. With a sense of belonging and strength to pursue communication with healthcare as well as the notion of not being alone with their needs and problems, gave the participants strength to continue.

*...all these patients I talk to in social media... their experiences, reflections and stories are really important. They make me feel less lonely.*

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

Digital solutions were part of the participants' everyday life, when finding information, performing self-care, and in communication with peers or healthcare professionals. If there were no existing solutions available for the current situation, the participants could either see a potential for future digital solutions, having ideas of new improvements, or have developed new digital innovations already. Gaining knowledge and competence from living with a chronic condition was considered important to achieve solutions for others. Ideas of new innovations often included aspects of helping peers, or to facilitate for healthcare professionals.

*I have digitalized a questionnaire for rare diseases, to help primary care decide where to send a referral within specialized care. So the patients get the correct diagnosis faster.*

*There are many things to remember since the last encounter, and that is completely impossible for many people. I have an idea of using activity trackers for people with mental health issues, to register important aspects of the disease automatically, as an objective measurement...*

Social media often played an important part when communicating with peers. The participants believed it to be a resource for them to inspire and to spread their knowledge. The second generation of e-patients also wrote blogs, debate articles, books, for newspapers, and used PAEHR to be in control and video conferences when communicating with others.

*I'm bedridden six to nine months a year, so technology is crucial for me to be active...*

## **5.2 “YOU HAVE TO KNOW WHY YOU ARE DOING THIS” (STUDY II)**

An exploration of PwP's opinions and experiences using self-tracking within their self-care was performed. The participants' experiences regarding self-tracking were based on tracking different aspects of their health (physical activity, sleeping patterns, stress, diet) as well as aspects of their medication (timing, type of medication, side effects, stiffness, cognitive aspects, motor skills, and tremor). The participants' opinions regarding self-tracking concerned reasons for self-tracking, risks with performing self-tracking, what have been learned, and usefulness when interacting with healthcare professionals.

### **5.2.1 Why I self-track**

Expectations and reasons for tracking their treatment were mostly concerning increased awareness and the progression of disease over time (Figure 2). It was significantly more likely that PwP younger than 65 years old considered self-tracking facilitating for understanding the disease better (85%,  $p=.001$ ) and taking an active approach regarding treatment and self-care (83%,  $p=.002$ ).

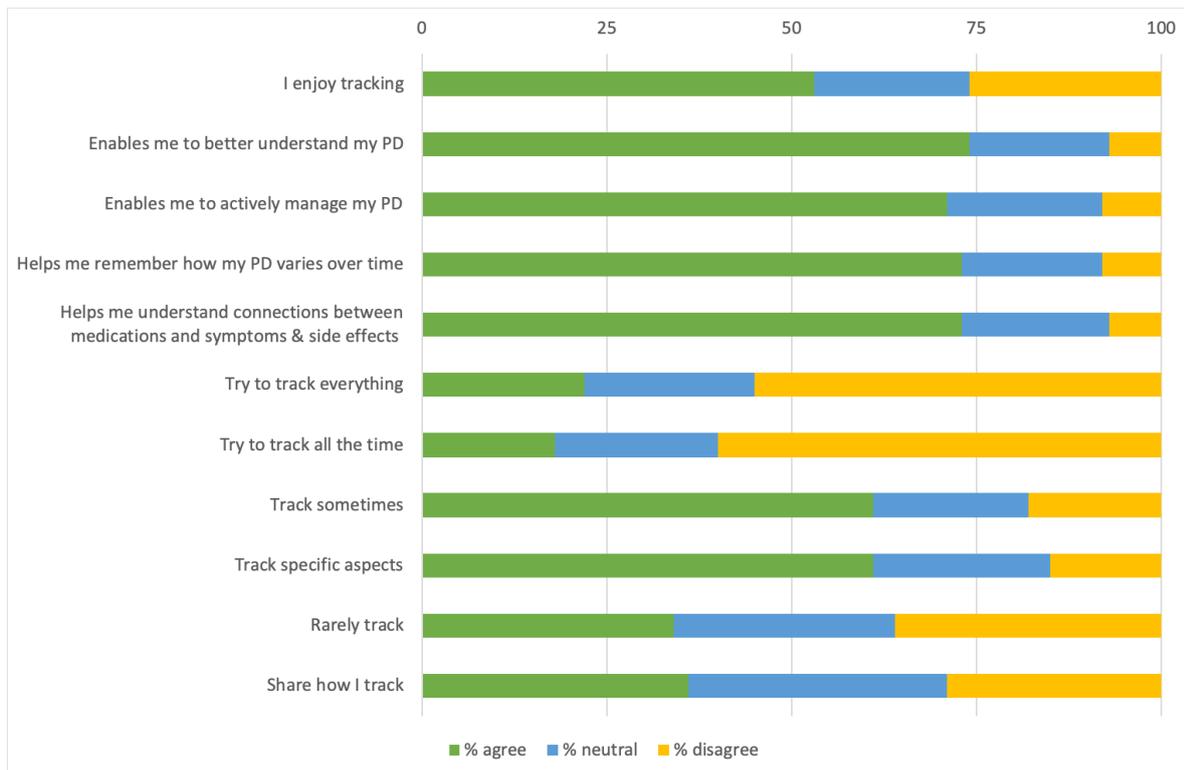


Figure 2. Reasons for self-tracking. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [68]

Another reason for self-tracking was to see the correlation between treatment and symptoms and health status, as a learning experience, and to stay in control.

*I expect tracking to help me see more clearly how my disease really is, since now it is mostly me guessing.*

### 5.2.2 How and what I self-track

PwP experienced their condition as rather complex, therefore it was important to know what to track and how to perform the tracking. Figure 3 shows that the most important aspects to track for the participants were timing and type of medication, and physical activity.

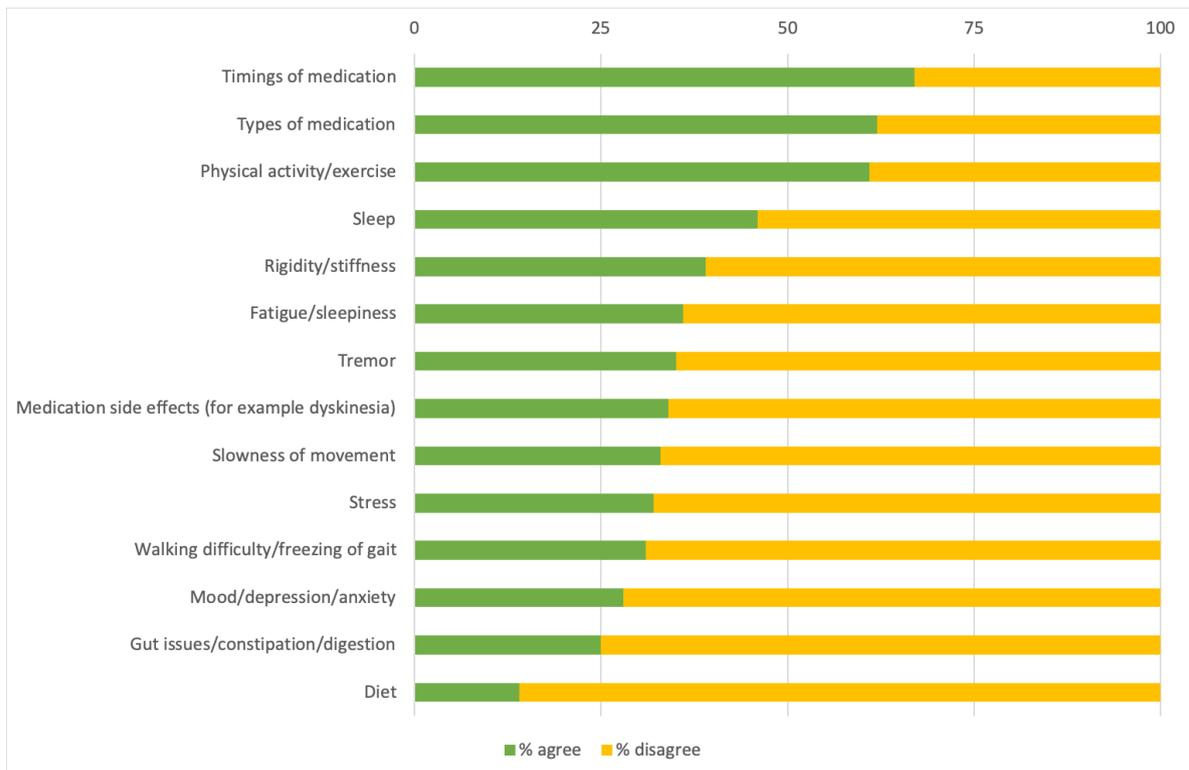


Figure 3. Different aspects of the disease that were tracked. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [68]

*It's important to take your medication correctly, at the right time. You can get a bad effect, it doesn't always mean that you need to increase your dosage, it can mean that you need to distribute the medication more evenly during the day.*

How to track includes different digital solutions for 49% of the respondents, such as smartphone/tablet apps, activity trackers, sensors or a spreadsheet in Excel. Other ways of tracking were described as using pen and paper (56%) or mentally organizing in the participant's head (74%). This was unrelated to age, gender and education level, however PwP diagnosed more than five years ago, were more likely to use pen and paper (66%,  $p=.001$ ).

### 5.2.3 Lessons learned from self-tracking

Even though several of the respondents considered it difficult to know what and how to track, the experience was that self-tracking enabled for making changes (Figure 4) regarding treatment and self-care, and could increase the wellbeing. It was a significantly higher rate (73%,  $p=.05$ ) of PwP younger than 65 years old who reported making changes based on to their tracking.

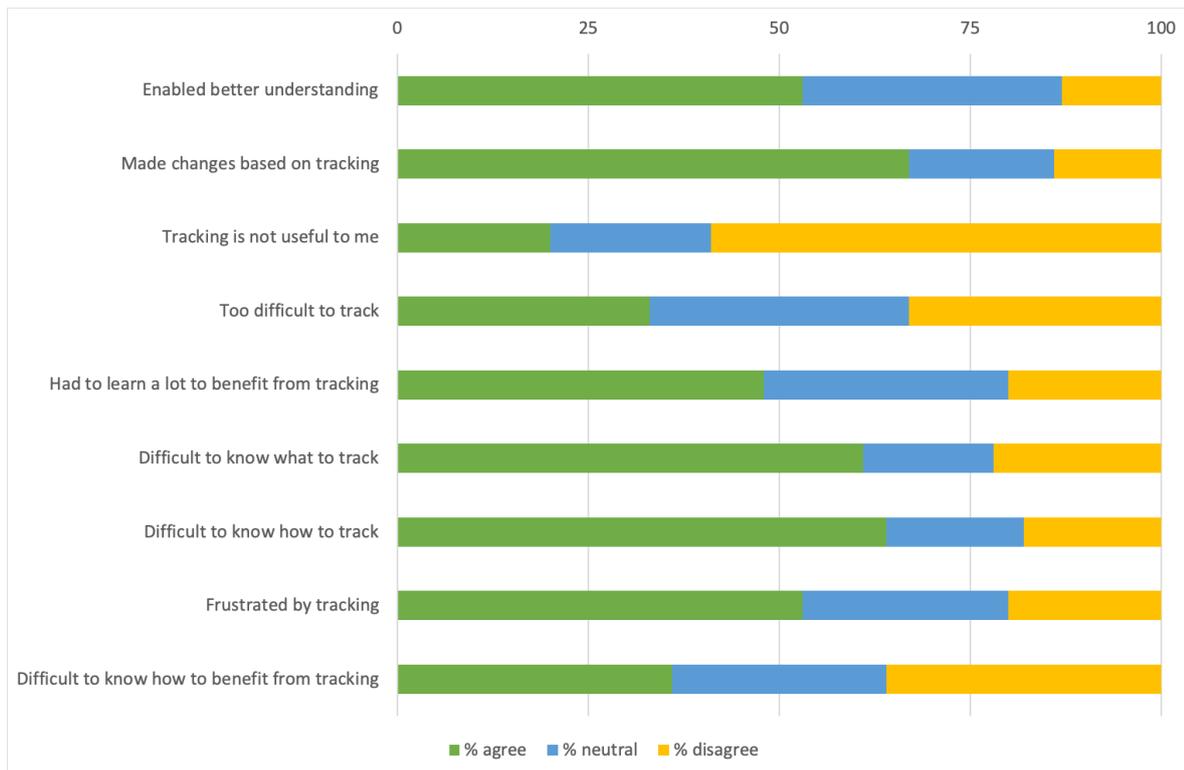


Figure 4. What lessons PwP learned from self-tracking. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [68]

Despite difficulties, one participants described the importance of not focusing on negative aspects with the disease. As an alternative, the “feel-well-time” was measured instead.

*It was really difficult to constantly think about whether I didn't feel pain somewhere, if I didn't feel stiff and so on... It took over my life... So I realized that I have to register something else and I decided to make notes of when I am doing well instead – when my symptoms are on the level I want them to be.*

#### 5.2.4 Risks related to self-tracking

The participants expressed opinions concerning that self-tracking could take over their lives (Figure 5). Instead it was preferable for PwP to track when a problem or need occurred. Participants being diagnosed for more than five years ago were significantly more likely to self-track all the time (21%,  $p=.04$ ), than those being diagnosed more recently (13%).

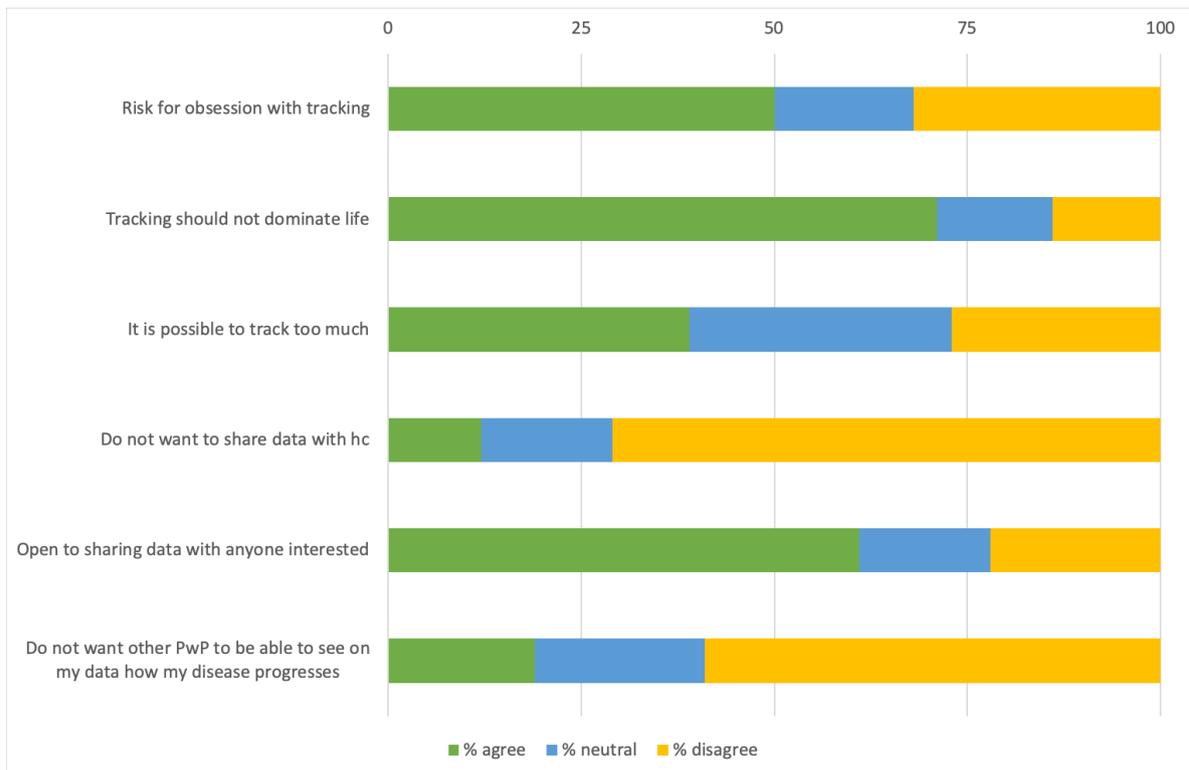


Figure 5. Risk related to self-tracking. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [68]

It was described as important to find a balance between managing the medication and health aspects in relation to everyday life. Even though PwP wanted to learn as much as possible, it was also important not to pay too much attention to the chronic condition.

*I don't think you should be doing it all the time, especially if you don't know what you want to use it for. Just tracking is pointless. You have to know why you're doing this.*

The participants did not consider sharing their self-tracking data with the rest of the society as any major risk. Especially when it comes to sharing data with healthcare providers, 72% of the participants were positive, and 61% were positive to share data with anyone interested.

### 5.2.5 Self-tracking and healthcare

Self-tracking was considered a good method to keep track of symptoms and to know when to contact healthcare professionals. It was also good to perform tracking prior to an appointment as memory support and to have current data to show the physician (Figure 6). Women tended to use self-tracking more than men to prepare for a healthcare encounter (63%,  $p=.02$ ). When interacting with healthcare professionals, a significantly higher amount of PwP that had been diagnosed more than five years ago (60%,  $p=.03$ ) showed tracking data for their physician. The intention was to influence treatment decisions based on tracking data, which was received well sometimes from healthcare professionals, and not so well other times.

*Sometimes I have been allowed to present my data, but there doesn't seem to be much interest from healthcare professionals. I think it has to do with the attitudes of physicians. I get the feeling they would like to do their assessments without my involvement.*

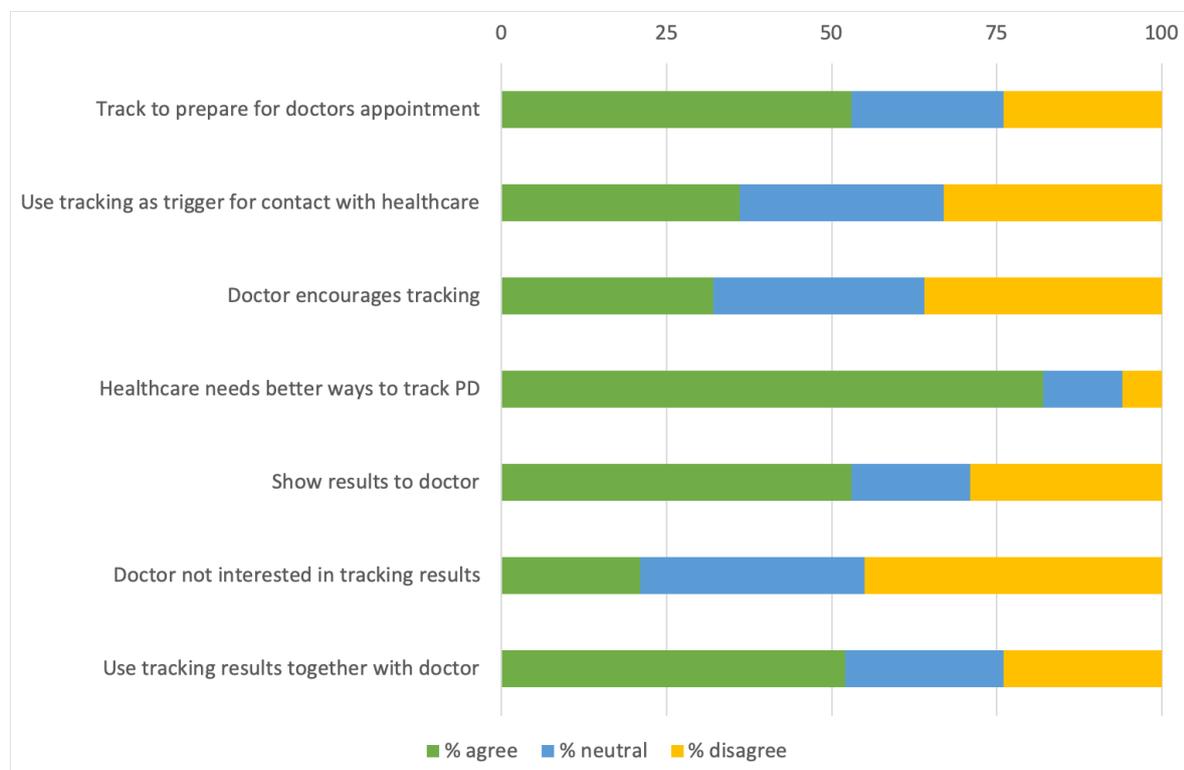


Figure 6. Self-tracking and healthcare providers. Creative Commons Attribution 4.0 International License (<http://creativecommons.org/licenses/by/4.0/>) [68]

### 5.3 TOWARDS A FRAMEWORK FOR PATIENTS' AND INFORMAL CAREGIVERS' BEHAVIORS AND ACTIVITIES (STUDY III)

To further understand the behaviors and activities of the second generation of e-patients, we compared them to a broader group of patients with chronic conditions and their informal caregivers. From this comparison several key concepts emerged in form of two different frameworks describing roles the participants adopted when using role-specific competencies within their self-care and in collaboration with healthcare.

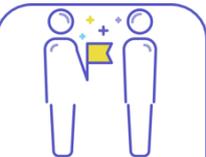
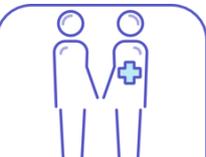
#### 5.3.1 The exploring and influencing activities of the second generation of e-patients

Different behaviors and activities undertaken by e-patients are described within Table 4 as role-specific competencies describing different roles as explorative or influencing. The participants could adopt different behaviors and activities in sequential manners as a process proceeding over a long period of time. E.g an informal caregiver who cared for her severely allergic children by learning about the healthcare system and building a network of healthcare resources, as a *healthcare coordinator*. She systematically searched through academic research to learn about connections regarding her children's' conditions, as an *academic*. She performed

self-management, created strategies for diet and a healthy environment, moved her family to gain better conditions, as a *self-care expert*. She then took the next step into becoming a *mentor* for others with the same issues, to support her peers by using all gained experience and knowledge and share it with others.

Table 4. Framework of roles undertaken by the second generation of e-patients.

Categories/Roles	Example activities/Meaning units	Description of activities	Why performing activities
<b>EXPLORING ROLES</b>			
	Is developing self-care strategies, performing far reaching lifestyle changes, making life changing decisions to create a balance in life.	Excels in self-care regarding the specific condition.	Believes there are no options to be active within their self-care, as no one else will act. Using pre-knowledge to perform self-care.
	Is systematically searching and reading academic research, compiling research, and finding connections to the condition.	Is developing deep knowledge through academic sources.	Believes it to be a requisite for a deeper learning. Using pre-knowledge to search and read academic literature.
	Is engaging as a research partner with health care professionals and examining research to identify potential new treatment.	Uses scientific methods to investigate in health issues and/or is partner with academic researchers.	Believes it to be a requisite for a deeper learning. Using pre-knowledge to engage, and having a supporting environment to be able to continuing being engaged.
	Is using digital services and creating digital solutions to explore possibilities.	Develops expertise in addressing health issues through the use of technology.	Using pre-knowledge to handle digital solutions.
	Is systematically using methods to measure (e.g. sleep, mood, time of medication), establishing patterns, learning through data, using digital solutions, and being a research participant.	Self-monitors health issues in order to modify treatment or other health promotional activities.	Believes there are no options to be active within self-tracking, as no one else will act. Using pre-knowledge to perform self-tracking and believes it to be a requisite for a deeper learning.

 <p>Healthcare coordinator</p>	<p>Is building strategies and developing special skills to manage different actors around the patient, building relationships, and finding pathways to right resources.</p>	<p>Manages and coordinates multiple healthcare contacts for current health issues.</p>	<p>Believes there are no options to be active as healthcare coordinator, as no one else will act. Using pre-knowledge of the healthcare system to manage different relationships and resources.</p>
<p><b>INFLUENCING ROLES</b></p>			
 <p>Innovator</p>	<p>Is suggesting solutions at healthcare system level, having and/or implementing innovative ideas at individual level, and creating digital solutions.</p>	<p>Creates or has ideas about new solutions based on current health and healthcare needs.</p>	<p>Using pre-knowledge of living with chronic condition.</p>
 <p>Communicator</p>	<p>Is sharing knowledge with others, spreading a statement, and debating in public environment.</p>	<p>Communicates about lived health experiences at conferences and meetings. Writing articles, blogs and in social media to create awareness.</p>	<p>Using their pre-knowledge of communicating their lived experience of chronic disease. Believes it to be a necessity to spread their knowledge.</p>
 <p>Mentor</p>	<p>Is supporting others' care processes, sharing advice, inspiring others, and creating venues for communication and activities with other patients.</p>	<p>Acts as a resource for others on how to deal with health-related issues.</p>	<p>Using their pre-knowledge of communicating their lived experience of chronic conditions. Believes it to be a necessity to spread their knowledge and to help others through inspiration.</p>
 <p>Entrepreneur</p>	<p>Is creating a company with services that helps others.</p>	<p>Creates a company or organization based on healthcare experiences.</p>	<p>Using their pre-knowledge of the healthcare system and their lived experience of chronic conditions. Having a supporting environment to be able to continuing being engaged.</p>
 <p>Healthcare partner</p>	<p>Is collaborating with healthcare professionals to solve needs for their selves as well as for others.</p>	<p>Develops deep relationships with one or more healthcare professionals.</p>	<p>Using their pre-knowledge of the healthcare system and from lived experience of chronic condition. Having a supporting environment from healthcare providers, contributes for learning possibilities.</p>
 <p>Activist</p>	<p>Is representing others, challenging paternalistic structures, helping themselves and others stand their ground, and acting as an influencer online and offline.</p>	<p>Fights for changes in policy, structures, and practice related to their health and healthcare needs.</p>	<p>Using their pre-knowledge of the healthcare system and from lived experience. Believes there are no options to be active within helping others to stand their ground, as others might not have the ability to do it.</p>

These 12 different roles could be perceived as a framework of behaviors and activities that e-patients adopt according to their own definition of being engaged, empowered, equipped and enabled.

### 5.3.2 Gaining and using knowledge as a broader group of patients/informal caregivers

Using the 12 roles of e-patients as fixed key concepts for part 2 of the study, the focus became to find similarities and alterations of this framework within a broader group of actively engaged patients with chronic conditions and their informal caregivers. Figure 7 illustrates an alteration of the 12 roles, becoming 10 roles describing role-specific competencies; *The Coping expert*, *The Knowledge seeker*, *The Tracker*, *The Exposed*, *The Communicator*, *The Mentor*, *The Healthcare partner*, *The Activist*, *The Coordinator*, and *The Creator*.

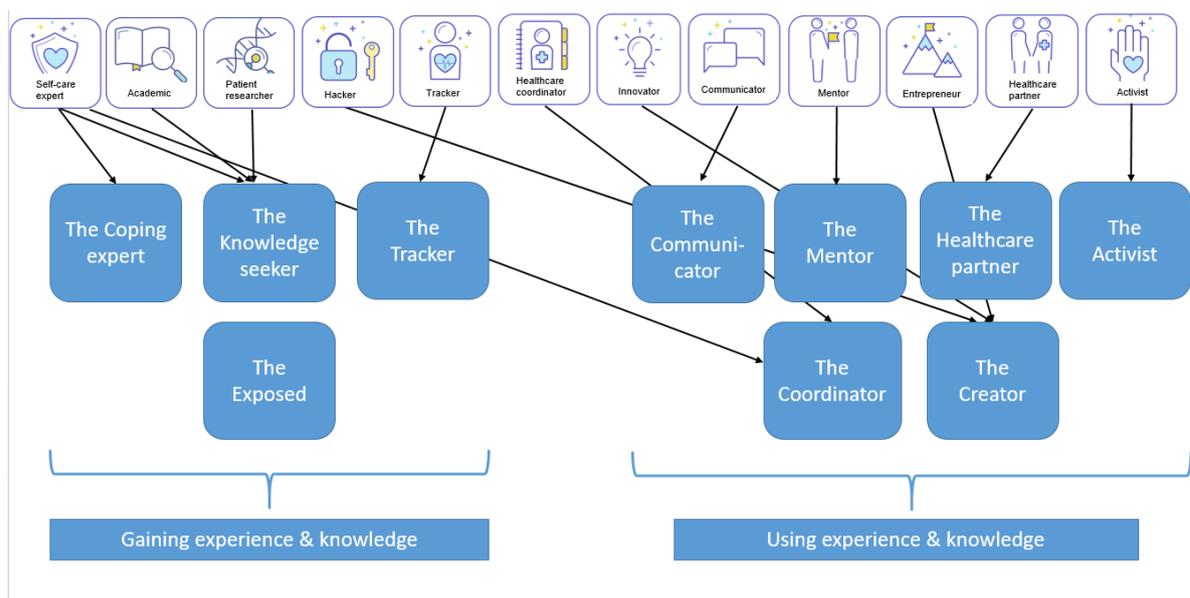


Figure 7. Comparing the framework of roles from the second generation of e-patients with a broader group of patients/informal caregivers, as result of dataset 2.

The alteration was mostly regarding different aspects of already existing roles, as well as one completely new role – *the exposed*. The strongest represented roles from the 12 fixed key concepts were *the self-care expert*, *the mentor* and *the communicator*, according to the participants’ first choice regarding how well the role fitted into their actions and behaviors (Figure 8). However, analyzing the focus groups made us realize that almost all categories were aspects of some form of self-care. Therefore was the self-care expert divided into *the coping expert*, *the knowledge seeker* and *the coordinator*. The knowledge seeker also consisted of the academic and the patient researcher. A modification was furthermore done regarding the hacker, the entrepreneur and the innovator, which became one role – *the creator*.

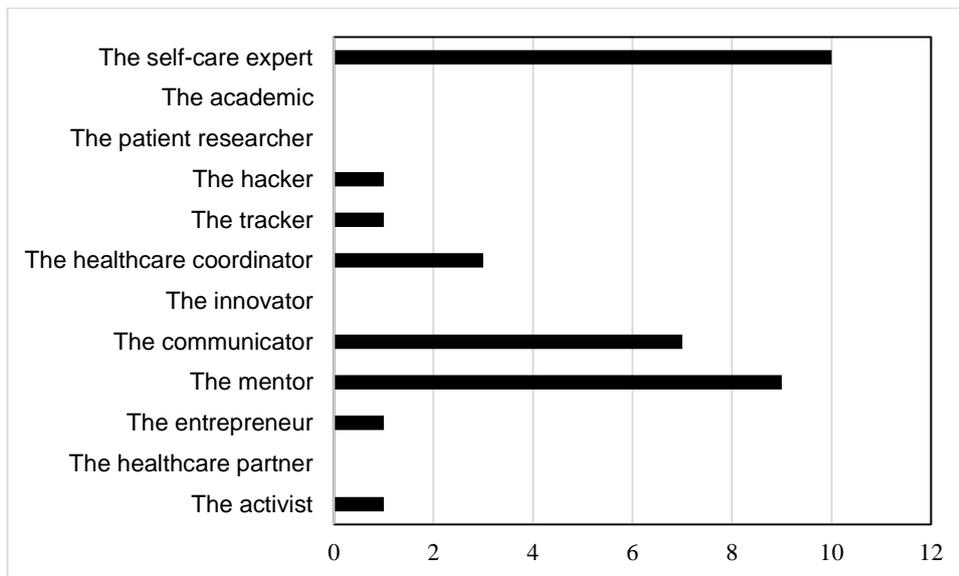


Figure 8. Roles represented by the participants' first choice.

### 5.3.2.1 Gaining experience and knowledge

Some of the roles were more represented depending on whether they were mutual with everyday activities or behaviors. Less represented were those roles which drained energy from the participants or whether the behaviors were forced upon them. Most represented were performing different coping strategies, as a *coping expert*, and to search for information, as a *knowledge seeker*, in order to gain experience and knowledge. However, it was also common to be the *exposed* as a patient. This was connected to how the participants recognized the existence of problems within their everyday life and worked to find a way to accept their situations. Through their journey they found proactive ways of restoring everyday life by dealing with stressors.

*It is a long journey – to accept my condition – and a grief to discover that you never again can do things you could do before.* (The exposed)

*My driving force is to remember that it is my responsibility to live my life the way I can, and not to focus on things I can't do.* (The coping expert)

*The physician rarely talks about the future. Then I push forward because I have found information about something I want to test. Then I think about those who are not as well informed, do they not get the same care as I do?* (The knowledge seeker)

Less represented within the data were behaviors of finding patterns and mapping side effects, medication and symptoms, as the *tracker*.

### 5.3.2.2 Using experience and knowledge

The most common behaviors and activities using experiences were to coordinate self-care and healthcare needs as a *coordinator*, to share gained knowledge as a *communicator*, and to inspire peers, as a *mentor*. When the participants shared their lived experience and knowledge, they

hoped for a change and increased acceptance from healthcare providers and within the society. Sharing their experiences with peers was a way of paying it forward – being a role model and finding solutions for needs of others than themselves.

*You need to be a project manager, in your own small way, so that you receive the healthcare and support you are entitled to, and should receive.* (The coordinator)

*When I was new with Parkinson disease, I met patients that were old, not being able to talk and sitting in a wheelchair – it was difficult to find a self-image there. Was this supposed to be me in the future? Therefore it is so valuable to be out there to tell a more true story about living with Parkinson.* (The communicator)

*I'm often interested in testing new things, but others may not be. At work, people with diabetes sometimes come to me to ask how they should manage their self-care when they are struggling. Then I can tell them what's out on the market and help out with that...* (The mentor)

Less represented were *the creators* of innovations, technical solutions and companies, as well as lobbying for a change at system level as *the activist*, and perform partnership with healthcare professionals, as *the healthcare partner*.

## 6 DISCUSSION

This thesis contributes to a better understanding of the second generation of e-patients and their experiences, actions and driving forces, as well as how far these are applicable to a broader group of active patients with chronic conditions and their informal caregivers. Here follows a discussion of the findings and of the methodology as well as implications for further research.

### 6.1 DISCUSSION OF THE FINDINGS

One of the most important finding in this thesis is that the second generation of e-patients showed a strong relatedness to healthcare professionals and peers. Learning experiences from performing self-care, using digital solutions and collaborating with their peers, the second generation report how they increased their perceived knowledge and skills. E-patients also report how they used their competence when finding new solutions for their own and others' needs. These innovations were described to serve their own autonomy as well as provided a feeling of satisfaction when helping others. All these actions spurred their driving forces and increased intrinsic motivation. It seemed to be a chronological development of actions, using exploratory behaviors at first to increase the competence, and influencing behaviors then to inspire and learn others. The analysis indicated different actions and behaviors of e-patients, as here are described as a framework of roles e-patients adopt when using role-specific competencies: *The Self-care expert*, *The Academic*, *The Patient researcher*, *The Hacker*, *The Tracker*, *The Healthcare Coordinator*, *The Innovator*, *The Communicator*, *The Mentor*, *The Entrepreneur*, *The Healthcare partner*, and *The Activist*. To understand if the behaviors and actions of e-patients are different than those of other persons with chronic conditions or their informal caregivers, we analyzed similarities and differences. Some similarities could be found, e.g. both e-patients and others appear to undergo a learning process using exploratory behaviors and/or gaining experience. All of the participants also experienced that they sometimes do not have a choice performing all these actions, since there seemed to be an external force. The major differences we found however were the high degree of creativity seen in the second generation of e-patients when using digital solutions, creating companies and innovations, searching for and producing their own research, compared to other patients/informal caregivers. Even though some roles were represented in both groups – there could be an alteration within the role. Whereas the broader group of patients gave a more balanced and reality-based story about living with their condition to the society, the focus for e-patients seemed to be to spread knowledge at a system level. The framework of roles for a broader group of patients/informal caregivers resulted in the following roles: *The Tracker*, *The Coping expert*, *The Knowledge seeker*, *The Exposed*, *The Coordinator*, *The Healthcare partner*, *The Communicator*, *The Mentor*, *The Creator*, and *The Activist*. Even though this broader group of patients/informal caregivers performed self-tracking, it was less common compared to e-patients. To further search for opinions and experiences regarding self-tracking, as one of e-patients' exploratory behaviors, we included PwP with experiences of tracking their health, side effects and symptoms in association with their medication. The results showed that it was important for PwP to understand these connections to be able to perform changes in the

medication if necessary. Three of the most common aspects of self-tracking were to track physical activity, timing of medication intake and type of medication. PwPs recognized how their condition varied over time, got a better understanding how to manage their PD, and could discuss their results with their physician. Nevertheless, many participants agreed on the need for more efficient data handling and better organizational structures in healthcare to receive PwPs' tracking-results. Further, participants mentioned the difficulty of knowing what and how to track without risking self-tracking to dominate their lives. Overall, enhanced decision-making regarding their self-care and in collaboration with healthcare was considered the main benefit of self-tracking.

Despite the opportunities provided by self-tracking and other CHI applications, such as better patient involvement and generating data for clinical decision making, there are also challenges. Concerns about the ethical implications and disempowering effects of self-tracking, when patients feel forced to focus on all negative aspects of their condition or being observed, are raised in the literature [46]. This was also a consideration from the participants in our study. However, one of them solved it by focusing on tracking her "feeling-well-time" instead. All of our participants had performed self-tracking on their own initiative, which could reduce the risk of feeling forced or observed. It is suggested that autonomy, solidarity and authenticity need to be detected in order to perform beneficial self-tracking [46], which could better be preserved through patients own initiative to track. Most of our participants tracked in their head (taking mental notes of different connections), however notes on paper were also used, as well as different technologies to make their tracking more objective. This was the same result as for patients with chronic conditions performing self-tracking in the US [69]. There is a vast selection of CHI applications for self-tracking on the market, with health and medical applications and wearable devices [69]. Why the use of CHI applications for self-tracking seemed rather low in our study, could be due to insufficiently addressed needs of the target group. CHI applications have in some cases not shown expected effectiveness, or considered being patient-centered enough, which could be an effect of not using participatory design and permitting the users being part of the development process [44, 47]. End user involvement in the design process is one way to reach patient engagement within society. Other ways of describing patient behaviors and engagement in the literature are different taxonomies, typologies and frameworks. Building on SDT, is a taxonomy of participation in healthcare service development that considers patients' behaviors. It shows different styles of patient participation according to their motivation; *non-participatory*, *restitution* (complaining to gain reimbursement), *social* (for social support and information), *volunteering* (to express support), *contributing* (to improve service functions) and *playful* (for the joy of performing the task), whereas *playful* is the only style leading to intrinsic motivation. The contribution from this work is to acknowledge the importance of experience-based participatory design to increase the health and well-being of patients [70].

E-patients can be both patients and informal caregivers [5], yet to some extent, they have different experiences, driving forces, and take different actions. We could see these differences in our results. Informal caregivers, for example, perceived the coordinator role as their most

important role. It was also this role most of them wished to let go. Some described it as something they have to do, whether they found it enjoyable, part of their interests, or if they were good at it or not. They had no choice. There are certainly more differences between patients and informal caregivers. However, we did not analyze these differences further as this was out of scope for this thesis. According to different e-patient typologies described in the literature, there could be a division between different types. *The accepting-, the informed-, the involved-, and the in-control-* e-patient is one e-patient typology. This typology describes how e-patients' empowerment level is connected to "the severity of their condition and their attitude toward their physician" (Ferguson T, 2007, p 6), which includes going from a medically passive to an autonomous role, with higher medical knowledge and control [5]. We did not see any alteration between different chronic conditions or their severity in our results. Nevertheless time since diagnosis could be an important factor for their behaviors. Another categorization according to Ferguson divides e-patients into *the well, the acutes* and *the chronics*, and how they use the Internet [5]. This division differentiates between persons with chronic conditions (using the Internet consistently every month), those with acute conditions (using the Internet every day) and the rest (using the Internet less consistently). Looking into the use of online communities, the chronics are the most active participants [5]. These typologies and categorizations are attempts to understand the diversity in online health resources and their usefulness. We would like to take it further when comparing literature from the beginning of this century – when the first generation of e-patients was described as patients or informal caregivers using online resources for seeking information and to be part of online communities [6]. During this time perspective, an evolution has taken place, much like the progression from the World Wide Web to Web 2.0 [22]. Going from static to dynamic processes, we see a development for the first generation of e-patients going from searching information online to themselves generating and sharing the information through experiences and gaining knowledge as early adopters or innovators. In tandem with the progressing digital environment, the second generation of e-patients has evolved [21].

There are several more frameworks or typologies trying to categorize and understand health- and healthcare resources. One of them is a framework from Canada that considers patients' everyday self-management and illustrates domains in relation to medical-, emotional- and role management [32,33]. This framework consists of:

- *Internal strategies* – coping, expressing sadness and grief, seeking comfort through beliefs
- *Activities strategies* – organizing routines and systems, using aids, engage in meaningful activities, acceptance, staying positive
- *Health behavior strategies* – mental exercise, diet, sleep hygiene, treatment management
- *Disease control strategies* – prevent, using complementary medicine
- *Social interaction strategies* – choosing situations for social interactions, facilitating interactions through controlling misunderstood symptoms, using social networks, exercise, use humor
- *Process strategies* – awareness, proactive, information-seeking, problem-solving and self-advocating

- *Resources strategies* – seeking and managing received support, healthcare needs, pacing and planning to conserve energy) [71].

These strategies show similarities with activities from both our frameworks developed in this thesis; the activist, the coordinator, the knowledge seeker, and mostly the coping expert. To cope with a life threatening or difficult situation is to handle stressors. This is done in different manners, either by avoiding difficult situations and threatening information – *blunting style* – or by taking part in these situations or information – *monitoring style* [72]. We do find both coping styles within the broader group of patients with chronic conditions and their informal caregivers. However, there is no indication of the second generation of e-patients avoiding threatening information in difficult situations, instead it seemed necessary for them to attend to these kinds of situations and information. To further understand the driving forces of the second generation of e-patients, intrinsic and extrinsic motivation provide two ways to understand active engagement and persons' behaviors. The inspiration for behaviors regarding the second generation of e-patients, originates from inside themselves and their strive to be self-aware [25,26,27]. By understanding the three psychological needs (autonomy, competence and relatedness) it is easier for healthcare professionals to evaluate which features will improve individual engagement [26]. It is important to be observant regarding autonomous motivation, since it could be either intrinsic or come from extrinsic sources. Being motivated through internal sources that align with a sense of self, is more long-lasting than being motivated through fear, pressure or external rewards. This is more of a controlled motivation, being forced by someone else rather than yourself [25,26,27]. Feeling involuntary autonomy – to not have a choice as described from several of the participants in this thesis – could be considered an external source, feeling forced to continue through having a personal importance and conscious valuing without any considerable interest or enjoy the task [25,26,27,70].

With an internal LOC and being in control over their lives could be perceived as the second generation of e-patients are conscious about their different choices regarding their behaviors and actions, and are derived from their experiences and skills [28]. It has also been noted that patients covet being in control and value their autonomy [73]. However, having a severe chronic condition tends to reduce the importance of seeking control or participation within self-care or healthcare contexts in order to make decisions. Salmon et al indicates from their research that often when a decision has been made, the patients felt as if they had no choice. Still, there is a value in receiving information to build relationships and maintaining hope [74]. Believing the second generation of e-patients to be role models with perceived better health through empowerment, could inhabit some risks, when engagement in one's health is realized as something a person can choose. It could be considered that those who choose not to be engaged regarding their self-care and collaboration with healthcare are to be blamed for meagre health. This increases the stigmatization and adds to the burden of treatment, and could lead to treatment based on lifestyle choices [46]. Tran et al describe a taxonomy of burden of treatment that visualizes the different burdens as *healthcare tasks imposed on patients*, *factors that exacerbate the burden of treatment*, and *consequences of healthcare tasks imposed on patients in their daily lives*. This framework provides us with a comprehensive understanding of the

consequences living with a chronic condition, and performing self-management [75]. A contribution to the burden of treatment is the burden of self-care and the possibility within the digital age, to use technologies for self-monitoring or other forms of self-care. Critics consider this as a way of eliciting patients to become more digital regarding their medical care and self-care [18]. So whether being engaged in self-care and in collaboration with healthcare is empowering or disempowering is rather debatable, and perhaps is patient empowerment not what the second generation of e-patients is aiming for [21].

## **6.2 METHODOLOGICAL CONSIDERATIONS**

We had no intention to explore how to change patient behaviors, and thus did not consider different behavioral change models. This research aimed to provide better insights into possible actions by patients/informal caregivers to be more active. We have included the positive aspects of being active and engaged in self-care and in collaboration with healthcare, as well as accounted for the negative aspects. We used SDT as a theoretical background to explain behaviors and motivation at individual level. However, it could have been possible to choose a social learning theory instead, looking into how persons organize their thinking [27].

Using exclusively a Swedish context for the samples could affect the generalizability of the three studies – being in the lead of digitalization and with a population of 95% considering themselves using the internet to some extent [56]. The Scandinavian countries are well known for their strong workers unions and societal focus on equality, resulting e.g. in the approach of participatory design [76], in which the end-users of IT-systems are given strong influence in the design process. This context may also give strength to e-patient movement. There is also a strong social safety net within the Swedish healthcare system, which enables and is indulgent for a movement such as e-patients [77]. This is why it makes it so interesting to perform these studies within a Swedish context.

As a researcher for this project, and being an e-patient myself, made it important to differentiate between the two roles, in order to counteract an arbitrary subjectivity throughout the research and to restore the reliability [48]. This was also considered when analysing the data, to provide a foundation for validity by discovering recurrent themes through the interviews [48].

Using an online survey in study II as a data collection tool and sampling frame could lead to selection bias and decreased generalizability, only reaching potential participants that used the Internet [50, 57]. In addition, it was not possible to calculate the response rate [50]. However, to collect an exploratory sample to generate new insights and models, a non-probability sampling [49] was performed, accepting the risk of not reaching all PwP within the study population. In our case, we wanted to reach PwP that performed self-tracking, and we could anticipate that these PwP were the same population using the Internet. However, there is still a digital divide in our society – despite the high rate of Internet users – which we needed to calculate for when conducting an online survey [56]. The focus was on collecting ideas instead of representability from the study population of PwP using self-tracking [57]. Since there was

a lack of standardized questionnaires concerning self-tracking for PwP, we developed our own, despite the absence of comparability [61].

The overall sampling process was convenience sampling [50,51], and as a result of that PD and Cancer were overrepresented, since two of the main authors for the sub-studies had connections within PD and Cancer. There were no samples within a clinical setting, which decreases the clinical relevance in this thesis. Still, that was an active choice to focus this research on patient participation – for sampling and within the three studies. The purposive sampling gave us a high degree of plausibility and validity, ensuring the participants were in key positions with great interest for the research as well as expert knowledge of the research topics [50]. The sampling process is important when comparing two groups, as was done within study III. However, within the broader group of active patients and their informal caregivers, as well as PwP within study II, it is not clear whether these samples include the second generation of e-patients or not. The inclusion criteria only stated active and engaged individuals, however no exclusion was made regarding the definition of e-patients.

### **6.3 FUTURE RESEARCH**

Examining the behaviors, motivations and actions of the second generation of e-patients provided us with a framework of roles. When comparing this framework with a broader group of active and engaged patients with chronic conditions and their informal caregivers, an alteration of the framework for e-patients occurred. Future research in relation to this could be;

- It could be relevant to compare patients as e-patients and informal caregivers as e-patient, what similarities and differences could arise within these different frameworks of roles?
- How meaningful are these two different frameworks for healthcare providers and professionals, looking into a system perspective? To increase the clinical relevance there is a possibility to go from an individual perspective towards a system perspective – how could the knowledge from individual self-care and meetings between healthcare professionals and patients/informal caregivers be relevant for the whole healthcare system? What possibilities and challenges could there be from a healthcare perspective?
- The second generation of e-patients could be a resource for the healthcare system and the public community over all. How do we find the right way to go, in order to make e-patients co-producers of solutions regarding health and healthcare?

## 7 CONCLUSION

The second generation of e-patients experienced that personal development and well-being are affected by how contextual factors either enhance or undermine psychological needs. To engage and achieve solutions for peers, family members and healthcare professionals open up for a strong relatedness. After gaining knowledge and competence from lived experiences and searching information through academic resources, the second generation of e-patients moved on to use digital solutions and create their own innovations. This gave the impression of a strong autonomy. Nevertheless, autonomy is not always intrinsic. All participants sometimes experienced involuntary aspects, since different social contexts expects them to be strong, active and engaged. This could increase the burden of decision making regarding self-care and within healthcare contexts. The broader group of active patients with chronic conditions and their informal caregivers have a slightly different focus, gaining experiences from being exposed and vulnerable, however still trying to solve their situations and problems through coping techniques and searching for information. To have a strong relatedness through engaging in others seemed to be the most important aspect of all the participants' driving forces. This thesis shows different levels of being an e-patient and how the movement is thriving towards generating own data, being early adopters of new solutions and evolves as innovators. In tandem with the progressing digital environment the second generation of e-patients will influence the future of participatory design within healthcare contexts as well as CHI applications. It is therefore important to follow and understand this development.

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