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Clinical self-tracking to improve knowing in practice:

designing self-experiments for Type 2 Diabetes care

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Cycle XXXIII

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Statement of contribution

This disclaimer is to state that the research reported in this thesis is primarily the work of the author and was undertaken as part of her doctoral research.

The work presented is part of a broader research pathway that involved the author and her colleagues during the years spent at the Fondazione Bruno Kessler. This path has involved the study of many of the multifaceted aspects of the social relations among the network of patients, associations, healthcare professionals and technology providers in the field of chronic illness, ageing and healthy lifestyle.

This research journey, culminating in the writing of this thesis, has resulted in the following publications, each of which has in some way influenced the work presented here:

- Fornasini, S., Dianti, M., Bacchiega, A., Forti, S. (2020) Promoting geocaching for active ageing: a qualitative study. *Journal of Medical Internet Research*
- Fornasini, S., Dianti, M., Bacchiega, A. (2020) Promuovere l'invecchiamento attivo in un centro diurno: un'esperienza di gamification. *Autonomie Locali e Servizi Sociali*
- Fornasini, S., Miele, F., & Piras, E. M. (2020). The Consequences of Type 1 Diabetes Onset On Family Life. An Integrative Review. Journal of Child and Family Studies, 1-17.
- Fornasini, S. (2019) Infrastructuring knowledge in practice: designing self-experiments for Type 2 Diabetes care. *Proceedings of The 7th International Conference on Infrastructures in Healthcare*
- Fornasini, S., Miele, F., Piras, E.M. (2019) La digitalizzazione dei processi organizzativi in sanità. Il caso della gestione dei farmaci oncologici. *Welfare e Ergonomia*
- Fornasini, S., Miele, F., & Piras, E. M. (2018). Maschilità e malattia cronica. Il caso dei padri con figli diabetici. *Rassegna Italiana di Sociologia*, 59(1), 51-76.
- Piras, E. M., Miele, F., & Fornasini, S. (2017). Infrastructuring primary prevention outside healthcare institutions: the governance of a Workplace Health Promotion program. In Infrahealth 2017 - *Proceedings of the 6th International Workshop on Infrastructure in Healthcare*

- Fornasini, S., Piras, E.M., & Miele, F. (2017). La sicurezza come pratica materiale di coordinamento. Il caso dell'introduzione di un sistema per la gestione della terapia oncologica. *Proceedings of the 6st STS Italia Conference*

The paper prototype presented in Chapter 5 was developed in collaboration with other researchers. The rest of the research work was conducted by the author.

Abstract

This thesis positions itself within the stream of research on self-tracking practices for the management of chronic illnesses. Self-care technologies, such as smartphones and many other mobile health devices, have led to the production of health data of patients outside institutional settings. This shift on the "personal" dimension of data has placed emphasis on self-knowledge practices supported by such technologies and on the concept of patient empowerment. Flanking a clinical trial conducted in north Italy aimed at quantifying the effectiveness and the acceptability of a self-tracking/remote-monitoring platform for type 1 and 2 diabetes patients, this work explores how a particular tool for self-tracking, the "personal experiment", fits in the process of knowledge of the patient with Type 2 Diabetes, exploring how the practice of learning to manage your own diabetes data is a complex activity that involves heterogeneous objects, actors and contexts.

The leading research questions in this work were: (1) How do the knowing processes triggered by personal experiments involve patients' with Type 2 Diabetes situated practices through their bodies, objects, technologies, contexts and relations? (2) How do personal experiments affect the empowerment and motivation of patients with Type 2 Diabetes to maintain a correct lifestyle? (3) How do personal experiments fit in the doctor-patient relationship, affecting existent educational practices and reconfiguring knowledge processes that involve patients with Type 2 Diabetes and their clinicians?

By adopting a knowing in practice perspective and a subsequent qualitative research methodologies such as observation, semi-structured interviews, focus groups and co-design workshops, it was possible, firstly, to design a paper prototype of the digital personal experiment, "the notebook"; secondly, considering the notebook as a knowledge artefact allowed to explore the processes through which patients with Type 2 Diabetes learn to manage their disease, observing learning as a situated and emergent activity that involves first and foremost the patient's body, the objects and the power relationship with their clinicians.

The main contributions of this thesis are on three different levels: first, analyzing self-knowledge of diabetes as a situated and emergent activity, it proposes to address the gap of studies on health literacy, which limit themselves to measuring what the patient learns as a result of the educational actions carried out by health professionals. Second, analyzing diabetes' self-knowledge as a process that involves the practical knowledge and reconfigures power

relationships between all actors involved, it aims to integrate studies on patient motivation and empowerment which conceive the doctor-patient reflections on patient's data as a well-defined moment that follows a structured script. The ultimate goal of the thesis is to provide guidance to designers to develop digital personal experiments that are less standardized and more practice-based.

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Preamble

This work is part of a wider research journey in which I've had the chance to work over the past few years, and which traces the trajectory of 10 years of studying the "making of diabetes". The investigation started to support the design of a Personal Health Record for people with diabetes and, over the years, it became an exploration of many of the multifaceted aspects of the social relations among the network of patients, associations, healthcare professionals and technology providers. In the past few years, I have worked with my colleagues on projects primarily related to the management of Type 1 Diabetes. This thesis aims to contribute to the results that have emerged during these years by proposing an initial exploration of the management of Type 2 Diabetes, a disease that is in some ways very different from the Type 1.

The starting point, as well as the key concept of this work, is the delegation of care by health care institutions to the patient, which has become increasingly widespread in recent years. This process has been favored by the spread of self-care technologies, such as smartphones and many other mobile health devices, which have led to the production of health data of patients outside institutional settings. This shift on the "personal" dimension of data has placed emphasis on self-knowledge practices supported by such technologies and on the concept of patient empowerment. Patients now have the opportunity to self-interpret their data through self-reflection, while clinicians typically take charge of disease education and the use of technologies (Oudshoorn, 2008; Anderson and Funnel, 2010). In numerous clinical settings, patients are required to keep track of parameters for various purposes (e.g. management, diagnosis) and in some cases, the objective of the patient–provider encounter itself is the analysis of self-tracked data. This collection specifically denotes the monitoring of data that can only be collected by patients themselves, sometimes also referred to as ‘observation of daily living’ (Brennan and Casper, 2015). Recently, studies on personal informatics systems supporting lifestyle-related diseases are becoming interested in the so-called “personal experiments" (Daskalova et al. 2016; Karkar et al. 2015; Lee et al. 2017; Kocielnik et al. 2018), a collection of data based on self-tracking but with a particular emphasis on self-interpretation of data through a structured self-reflection. The “experiment” can take place independently or in collaboration with health providers and usually requires three standardized phases: formulating a hypothesis (es. “does physical activity impact my glycemic index?”), testing the hypothesis (measuring glycemic index before and after doing physical activity) and examining the results of the study through reflection (Karkar et al. 2015; Lee et al. 2017). The main aim of a "personal experiment" is to educate and help the patient to understand firsthand the impact of his/her therapy on the management of the illness.

This thesis aims to analyze how the tool of the "personal experiment" fits in the process of knowledge of the patient with Type 2 Diabetes, exploring how the practice of learning to manage your own diabetes data is a complex activity that involves heterogeneous objects, actors and contexts. My work is flanking a clinical trial conducted in north Italy aimed at quantifying the effectiveness and the acceptability of a self-tracking/remote-monitoring platform for type 1 and 2 diabetes patients. The system includes a web interface for the doctor (medical dashboard) and a mobile interface for the patient (app). In particular, I followed the design, testing and implementation of a section of the app for the patients, that permits to set structured personal experiments on personal health data for patients with Type 2 Diabetes. In order to do this, I co-designed with clinicians and patients a paper-diary prototype for personal data collection during the experiment. Empirical data derives from a six-month field study, during which a group of Type 2 Diabetes patients, supervised by general practitioners and diabetologists, have been invited to collect on the paper prototype personal health data before and after a personal systematic physical activity.

The fil rouge that runs through the chapters moves back and forth along complementary perspectives and presents new insights on the ways personal experiments fit into the daily care practices of persons with Type 2 Diabetes affecting the processes of knowledge and management of their illness.

Each chapter aims to respond to one of the three research questions of my empirical work and is accompanied by a specific literature review that distinctively adds to a branch of the research on personal health data. In the last chapter I discuss some implications for the design of the “personal experiment” section of the app show. This modus operandi is the result of two distinct lines of reasoning: first, it allows me to focus on very specific topics, contributing to lines of enquiry and gaps in recent theoretical and empirical research; second, it helped me to think in terms of journal contributions, which are also the most common means through which knowledge can be disseminated to scientific audiences.

In the first chapter I discuss the motivations for this work, introduce the research questions and contributions of the thesis, explain the methodology adopted and the case study chosen, and outline the theoretical foundations of the thesis. The ways in which personal health data can foster patient education processes have been explored in different research areas. In the context of this work I will take in consideration the Science and Technology Studies (STS) with the "knowing in practice" perspective, that invites to dwell on the ways in which individuals learn their own ways of relating, of interacting with objects (technical and non-technical), of using one's own body and coming to share common ways of acting (Orlikoswsky, 2002; Nicolini et al., 2003; Gherardi, 2006). For each subsequent chapter I examine three branches of the knowing in practice perspective.

Chapter 2 makes use of the in-depth interviews with patients to analyse their practices of collection of data gathered during the experiments and to show the learning processes triggered by personal experiments, that involve the patient's body, objects, technologies, contexts and relations. I will consider Annmarie Mol's work, where she analyses the processes through which the diabetic patient learns to manage their disease, considering the management of diabetes as a situated activity (Mol, 2000; Mol and Law, 2004). I also will consider a sensemaking perspective in education science to explore the contrast between scientific and everyday thinking (Lave 1988; Godfrey-Smith 2003).

In chapter 3 I will explore the ways in which personal experiments, and in particular the final reflection on personal data, affect the ways in which participants try to maintain a correct lifestyle. Integrating work attributable to the knowing-in-practice perspective with the works of Deborah Lupton (Lupton 2013), I will show how motivating someone to take control of a chronic disease requires a unique skill set as well as more time than is typical in a standard health care visit, and it could imply aspects of surveillance and control. Illustrating what happens during the clinical encounter between patients and clinicians at the end of the experiments, I explore how the transfer of information from the health care professional to the person with diabetes represents only the beginning of a lifelong process leading to successful self-care and leading to a reconfiguration of power relationships between patients and clinicians.

Chapter 4 explores the ways in which personal experiments fit in the doctor-patient relationship, affecting existent educational practices. Through the analysis of the in-depth interview with clinicians and of the clinical encounters' observations, I discuss the concept of community of practices and mutual engagement of Lave and Wenger (1991). Following these authors, I will show how patients' and clinicians' actions are the product of prior negotiation and learning processes in which they link what they know with what they do not know to find meaning and form their actions, by exchanging mutual knowledge with each other. I also will explore the role of artefact in supporting knowledge-related processes and stimulating the reflexive thinking of participants regarding practicing and knowing (Turnbull 2003; Cabitza and Locoro 2014; Piras 2018).

Finally, chapter 5 illustrates some implications for design. I describe the process of co-design of the paper prototype of the personal experiment, during which I conducted two focus groups with clinicians and with diabetic patients, and a co-design workshop with diabetic patients to gather reactions to the self-experimentation process, to explore how self-experimentation fits with participant priorities and to design a first paper instrument. I use these data, alongside with the fieldwork results, to propose some suggestions for the design of a more advanced digital prototype of the TreC_Diabetes app.

In the conclusions, I summarise the most important findings of the manuscript, and I draw attention to the possible implications for patients with Type 2 Diabetes education processes, both during clinical encounters and outside healthcare settings, as well as for future research directions.

Chapter 1 – Introduction

This thesis explores the processes through which patients with T2D learn to manage their disease, considering learning as a situated and emergent activity that involves first and foremost the patient's body, the measurement objects and the therapies available to him or her, leading the individual to develop self-care skills and competencies.

This introductory chapter presents the motivations for this work, introduces the research questions and contributions of the thesis, explains the methodology adopted and the case study, and outlines the theoretical foundations of the thesis.

1.1 Context and thesis' contribution

Self-tracking for self-knowledge using digital technologies began to spread with experiments by North American computing engineers Gordon Bell, Steve Mann and others with the early versions of wearable digital technologies from the 1970s onwards (Mann, 2013; Mann & Ferenbok 2013). Since then, mobile digital devices have contributed to the ever more detailed measurement and monitoring of people's activities, bodies and behaviours in real time. In the healthcare field a number of digital health interfaces, such as health apps, platforms and wearable devices have spread to enable better management of one's health. New technologies such as health apps enable the constant generation and transmission of data, which can be used to monitor health and well-being parameters (Barrett et al., 2016; Lupton, 2016). This has also resulted in growth of the production of patient health data outside healthcare settings (Piras 2016; 2019). Data about, for example, heart rate, calorie intake, steps taken, or miles walked, are presented in more or less sophisticated ways to engender empowerment and behaviour change through constant self-surveillance (Lupton, 2014; Till, 2014; Ruckenstein, 2014). Patients can actively participate in the collection of their own data by improving their knowledge of their body and disease. In this way they can have more control over diseases that were previously seen as unmanageable or reliant on medical expertise (Lupton, 2016). Consequently, in the healthcare sector there has been a growing emphasis on self-knowledge practices supported by personal informatics systems, shifting the attention on the "personal" dimension of health data (Gherardi, Miele 2018). In numerous clinical settings, patients are required to keep track of parameters for various purposes (e.g. management, diagnosis) and in some cases, the objective of the patient–provider encounter itself is the analysis of self-tracked data. This collection specifically denotes the monitoring of data that can only be collected by patients themselves, sometimes also referred to as 'observation of daily living' (Brennan & Casper, 2015). Mobile and wearable digital devices have facilitated the ever more detailed measurement and monitoring of the body and everyday life in real time and the analysis, presentation and sharing of these data (Lupton 2014). The conventional approach driving self-tracking technologies in the field has been self-betterment through self-knowledge, potentially enabling the arising of self-discoveries, self-reflection, and triggering processes of behaviour change (Choe et al. 2014; Rapp et al. 2018). In recent years technologies for self-tracking have been expanded to include the so-called "lifestyle related diseases," including metabolic syndrome, obesity, cardiovascular disease and type 2 diabetes (Heymsfield & Wadden 2017; Arsenault & Després 2017; Van Ommen et al. 2018). This shifting has led to a growing interest in production of personal health data outside healthcare settings. From this perspective, self-tracking technologies can be employed as an intervention technique for behavior recording and producing a change in behaviour itself (Consolvo et al. 2008; Matthews & Doherty 2011; Rapp et al. 2018; Fogg 2009). A recent framework in behavioural science proposes that interventions can play one or more of nine functions in order to change behaviour; for example, interventions may seek to educate the target population of the need for change, persuade them by inducing positive or negative emotions around the behaviour, or train them in the skills needed to achieve change (Gardner et al. 2016; Michie & Prestwich, 2010; Michie, van Stralen, & West, 2011). Some studies have started to explore self-tracking in clinical contexts where patients and healthcare professionals collaboratively examine the data. For example, Mentis et al., (2017) examined collaboration between patients with Parkinson's disease and their clinicians around physical activity data from Fitbit devices. Ploderer et al., (2016) explored opportunities for stroke survivors and their therapists based on upper limb movement data. Finally, Smith et al. (2007) explored how people with diabetes and their doctors discuss diet and glucose levels tracked in daily life. Following this stream, some studies have been shifting the focus on self-experimentations or personal experiments, a collection of data based on self-tracking but with a particular emphasis on self- interpretation of data through a structured self-reflection

(Daskalova et al. 2016; Karkar et al. 2015; Lee et al. 2017; Kocielniket al. 2018). The “experiment” can take place independently or in collaboration with health providers and usually requires three standardized phases (fig.1): formulating a hypothesis (es. “does physical activity impact my glycemic index?”), testing the hypothesis (measuring glycemic index before and after doing physical activity) and examining the results of the study through reflection (Karkar et al. 2015; Lee et al. 2017). The hypothesis is testing using “paired testing” (Parkin et al. 2009; Greenwood et al. 2015), a process that includes defining independent variables (e.g., causes, triggers) and the dependent variables they may affect (e.g., symptoms, health outcomes). Technology for self-experimentation can be included in this process: traditional self-tracking methods, such as food journals or fitness trackers, may be adopted to collect data and test hypotheses. Patients can then use findings to target the most appropriate health behavior change to address their needs.

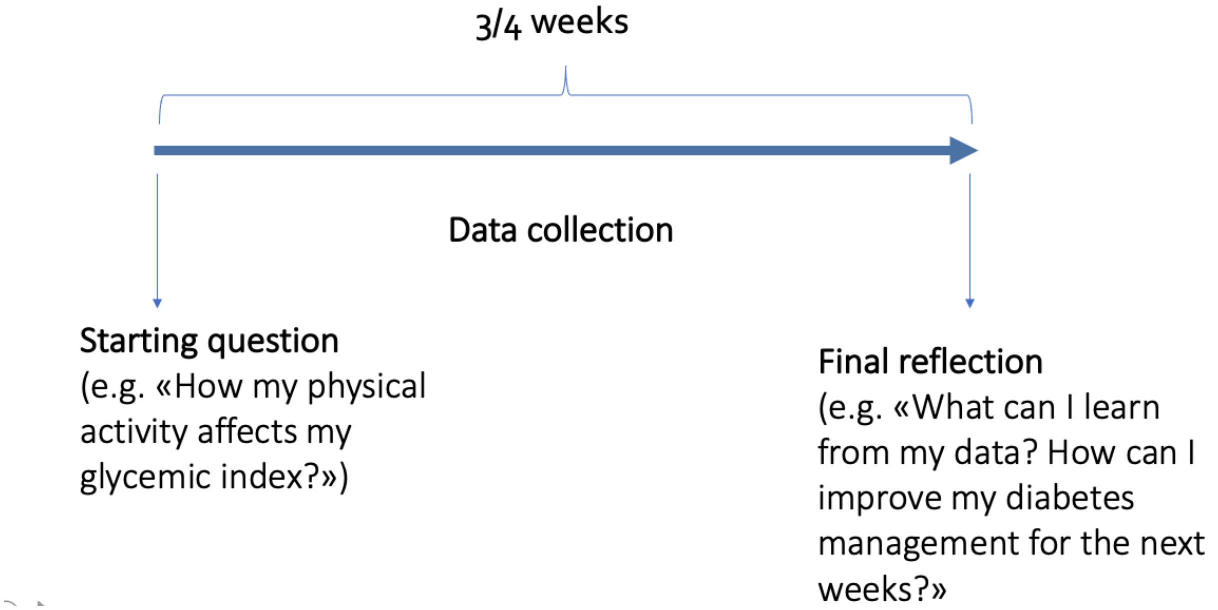


Fig. 1 Structure of a personal experiment

A key-concept of personal experiments is that of “self-reflection”: the patient is involved in both collection and reflection on the data at the end of the experiment. (Baumer et al. 2014; Li et al. 2010; Greenwood et al. 2015). Clinicians can play a significant role in the final reflection: they can encourage the person’s problem-solving skills by asking questions (e.g.: “Review the comments you made during the week. What can you learn from these notes?", or "What changes can you make next week? What would you like to learn?") helping them to reflect on their week. According to literature, reflecting on their data patients can increase their self-knowledge and formulate realistic behavior change goals (Lee et al. 2015; Kocielnik et al. 2018). Given the above, and on the basis of the studies reported in this section, my thesis aims to bring a new contribution to the debate on three fronts:

Type 2 Diabetes Management as a situated activity. Studies on health literacy, which have explored the learning of self-management skills in diabetic patients (Nutbeam, 2009; Piana et al., 2010; Redon et al., 2014) focuses on the risks that the poor ability of reading and managing clinical information poses to the health of patients (Schillinger et al., 2002; Powell et al., 2007; White et al., 2013) and on actions to prescribe and follow in order to improve that ability. These studies do not go in depth into the dynamics of learning, limiting themselves to measuring 'what' the patient learns as a result of the educational actions carried out by health and non-health professionals, and not providing useful tools to read in depth the processes of learning implemented by diabetic patients and medical and nursing staff.

My thesis aims to address this gap analyzing the management of T2D, and in this specific case the personal experiment, as a situated and emergent activity that involves first and foremost the patient's body, the measurement technologies and the therapies available to him or her, leading the individual to develop care skills and competencies (Mol, 2000; Mol and Law, 2004).

Type 2 Diabetes as a knowledge process. Although the emphasis of personal- experiments on the importance of self-experience, literature describes the process as strictly standardized and methodologically rigorous (Daskalova et al. 2017; Schroeder et al. 2019). Analysis on self-knowledge is limited to the "reflection" phase, conceived as a well-defined moment that follows a structured script. These approaches are especially focused on the development of persuasive systems and on the evaluation of behavioral and clinical outputs, but seeks to overshadow the broad processes and care practices through which, during the use of a technology, knowledge practices take place. The vast majority of technological interventions for diabetes self-management continue to focus on impacting behaviors, rather than on helping individuals make sense of and learn from personal data (Mamykina et al. 2015). My thesis aims to address this gap and provide insights to analyze self-knowledge as a process that involves the practical knowledge and the power relationships between all actors involved. I will also discuss how individuals make sense of their chronic disease using self-monitoring data through the theoretical lens of sensemaking. The ultimate goal is to provide guidance to designers in designing technologies that are less standardized and more practice-based.

Designing technologies to support knowledge processes in Type2 Diabetes management. In the fifth chapter I will presents the ways in which the analysis of the practices of use of a paper prototype - the notebook - can provide useful elements for designers to design a technology that takes into account the knowledge practices of all actors involved in the process of care, facilitating the articulation of users' knowledge and the sharing of expertise amongst users and between users and researchers. To achieve this goal, I will consider the qualitative methodology used in this thesis - based on observation and involvement of participants - as a co-design approach. My thesis proposes to discuss the limitations of clinical trials that do not take into account patients' daily care practices. The process of design and evaluation of self-care technology should not aim to "prove" that a certain technology is good enough for a medical or an economical perspective, as it happens with clinical trials. Differently, my thesis aims to address this gap by proposing that the evaluation process should rather have the purpose of improving the design of the technology from a practical perspective. Through a methodology based on the observation of users' practices, I will reflect on what a "good self care" is, stating that a good self care means also taking into account patients' tacit knowledge and sensemaking, considering the processes of empowering and disempowering between patients and clinicians, and observing the ways in which their mutual knowledge can influence the proper management of disease.

In the next paragraphs I will present the theoretical background of my PhD project, focused on studies which investigate how personal experiments go into the process of knowledge and management of type 2 Diabetes (T2D), affecting the daily care practices of patients and their relationship with providers.

1.2 Theoretical background

This thesis intends to answer the research questions exploring the knowing in practice perspective in diabetes studies. I will conceive the management of diabetes as a practical and emerging activity, not limiting the observation to technical actions, directly connected with care.

To do this, I will consider the knowing-in-practice theoretical framework (Cetina et al. 2005; Gherardi 2006; Nicolini 2007), which leads to extending the perpective to the ways in which, crossing different social and material contexts, patients with diabetes learn to attribute new meanings to the management of their disease.

Over the last 20 years, the so-called 'practice turn' (Cetina et al 2005) has involved different strands of the social sciences. The practice-based approach develops the assumption that phenomena such as knowledge, meaning, human activity, and sociality are aspects and effects of interconnected human practices (Cetina et al. 2005). They are not, therefore, just mere descriptions of what people do; they are meaning-making, identity forming, and order-producing activities (Chia & Holt 2006; Nicolini 2007). This approach addresses questions of how and why people do what they do, whether in everyday activities or professional settings. This interest in human practices is not a new phenomenon; philosophical roots of practice theory are found in works by Marx, Wittgenstein and Heidegger, with significant contributions also by Taylor, Bourdieu, Foucault and Giddens. From everyday practices in the home to practices within workplaces and organizations, those studies address research questions of relevance for numerous academic disciplines, including organizational and management studies (Nicolini 2007), consumption studies (Warde 2005; 2014), social anthropology (Shove et al. 2012), media studies (Bräuchler and Postill 2010) and political sciences (Jonas et al. 2017). These studies conceive the relationship between social and material as strongly interrelated. Fundamental is the concept of socio-material practice, "a relatively stable over time and socially recognized way of ordering heterogeneous elements in a coherent set" (Gherardi 2006). The distinctive feature of a practice-based approach is that its unit of analysis is 'practice', by which is meant 'a mode, relatively stable and socially recognised, of ordering heterogeneous elements into a coherent whole' (Gherardi 2006, p. 34). The knowing-in-practice perspective involves both individuals and the material context in which they learn common ways of relating, interacting with objects and technologies, using their own bodies and judging others' own work, arriving at to share common ways of acting (Orlikoswsky, 2002; Nicolini et al., 2003; Gherardi, 2006).

In this thesis, the primary interests are the relationship objects and knowledge, and between knowledge and practices. Regarding the relationship between objects and knowledge, the use of telemonitoring technologies in health care can be considered a practice produced, reproduced and interconnected through the everyday work of clinicians, patients, familiars, friends etc.

Drawing on these assumptions, several empirical studies have focused on the practices emerging around objects and technologies in health care, with special interest in the ICTs (Information and Communications Technologies) created to monitor the clinical status of chronically ill patients from a distance (Bruni et al. 2007; Gherardi 2010; Nicolini 2007, 2011; Piras, Miele 2019). Regarding the relationship between knowledge and practices, according to practice-based studies doing and knowing are indistinguishable (Gherardi 2010). During the reproduction of a practice, actors know about their social worlds and about other actors and, consequently, refine and redefine their ways of interacting. The conceptual lens of practice reveals how organised activities are sustained by a shared understanding among practitioners. (Piras, Miele 2019) This shared understanding does not depend on a rigid script, but rather on a shared 'feel for the game', the logic of practice (Bourdieu 1990), which allows a 'repetition without repetition' (Beguin & Clot 2004).

In the case study under analysis in this thesis I will focus on the practice of health data self-tracking through a paper prototype performed by clinicians and patients. This practice possesses some heterogeneous elements, such as the use of the object, the formal and informal rules associated with its use, the participants in the practice, the knowledge of diabetes needed to practice, etc. All these practices are interconnected and together constitute a texture of connected practices.

These topics will be explored in depth in each empirical chapter of the thesis in a theoretical background paragraph, in which I integrate work attributable to the knowing-in-practice perspective with stimuli from other related theories.

In chapter 2 I will consider Annmarie Mol's work and the processes through which the diabetic patient learns to manage their disease, considering the management of diabetes as a situated activity (Mol, 2000; Mol and Law, 2004). I also will consider a sensemaking perspective in education science to explore the contrast between scientific and everyday thinking (Lave 1988; Godfrey-Smith 2003). In chapter 3 I will integrate work attributable to the knowing-in-practice perspective with the works of Deborah Lupton, exploring how knowledge practices in health care lead to a reconfiguration of power relationships. In chapter 4 I will consider that the development of a practice requires dense and persistent mutual engagement between participants (Wenger, 1998). Thus I will explore the reconfiguration of mutual knowledge practices between patients and clinicians. I will also explore the role of artefact in supporting knowledge-related processes and stimulating the reflexive thinking of participants regarding practicing and knowing (Turnbull 2003; Cabitza and Locoro 2014; Piras 2018). In chapter 5 I will explore how knowing in practice perspective affects the design process of a health technology.

In the next paragraphs I will describe the three research questions that guided the empirical study.

1.3 Research questions

The case study presented will explore how personal experiments fit into the daily care practices of persons with type 2 Diabetes affecting the processes of knowledge of their illness.

The research questions leading the work were:

R.Q. 1: *How do the knowing processes triggered by personal experiments involve patients' with Type 2 Diabetes situated practices through their bodies, objects, technologies, contexts and relations?*

R.Q. 2: *How do personal experiments affect the empowerment and motivation of patients with Type 2 Diabetes to maintain a correct lifestyle?*

R.Q. 3: *How do personal experiments fit in the doctor-patient relationship, affecting existent educational practices and reconfiguring knowledge processes that involve patients with Type 2 Diabetes and their clinicians?*

By answering to the three research questions listed above, this thesis aims to fill knowledge gaps in the domain of health self-tracking design providing insights into three important elements to consider when designing a technology and that are related in different ways to how knowledge is developed: design technologies that take into account patients' situated and practice knowledge; design technologies that allow a degree of freedom of choice for the patient; design technologies that take into account the ways in which mutual knowledge exchanges between patients and clinicians can influence the proper management of disease. For this purpose, in chapter 5 I provide useful suggestions for the design of technology for self tracking that take into account the practical knowledge of users.

1.4 The case study

1.4.1 Type 2 Diabetes

Diabetes is one of the fastest growing global health emergencies of the 21st century. In 2019, it is estimated that 463 million people have diabetes and this number is projected to reach 578 million by 2030, and 700 million by 2045 (International Diabetes Federation, 2019). In Italy, the National Institute of Statistics (Istat) estimates that in 2016, people with diabetes are more than 3 million, or 5.3% of the entire population (Istat, 2017). Obesity and sedentariness are important risk factors for health in general, even more so for diabetic pathology. diabetic pathology. Among 45-64 year olds, the percentage of obese people suffering from diabetes is 28.9% for men and 32.8% for women (for non-diabetics, respectively 13.0% and 9.5%, respectively). In the same age group 47.5% of men and 64.2% of women with diabetes do not engage in any physical activity in their leisure time (Istat 2017).

This work will consider Type 2 Diabetes, a “genotype-environment interaction disease”, where the diabetic phenotype is expressed as a result of accumulated environmental pressures (wrong diet, too little physical exercise, disrupted sleep, and too much stress) in concert with genes that render individuals susceptible to the disease (Van Ommen et al. 2018). The chances of getting T2D increase with age and often occurs in combination with other symptoms and diseases such as overweight and cardiovascular diseases. T2D can remain unnoticed for several years without the patient experiencing the disease. Since it is mostly treated through a combination of medication and lifestyle changes, such as dieting and physical exercise, it must include the patient’s active participation in both the treatment and the preventive actions against further development of the disease. Type 2 diabetes patients’ engagement is regarded as a key factor to improve the quality and the sustainability of healthcare services (Carman et al. 2013). Previous studies have shown how an engaged patient is more likely motivated to act improved health behaviors, to have better clinical outcomes, to perceive a better quality of life, and to be more satisfied with their relationship with the healthcare system (Graffigna et al. 2014). To be a type 2 diabetic patient thus entails that you learn to be diabetic, and that you must continue to be so for the rest of your life (Maunsbach 1999). Hence, patient empowerment is central to the diabetic condition in order to enable diabetics to participate actively and rationally in their treatment (Danholt et al. 2004). Furthermore, empirical researches have demonstrated how patient engagement may contribute to a reduction of healthcare costs and to better economically sustainable organizational processes (LEee and Emanuel 2013). This active and co-creative role along with the process of care can also foster an integrated system of care and a fruitful collaboration and dialogue between the lay territory of reference for the patient and his/her reference healthcare provider, moving from the traditional passive role to the one of a real engaged patient in the design and delivery of healthcare services (Crawford 2002).

Within this context, a large number of studies explored the effectiveness of mHealth interventions in modifying type 2 diabetes patients' lifestyles, especially those related to dietary behaviors and physical activity, by facilitating diabetes self-management processes outside the clinical setting. mHealth interventions have shown clinical effectiveness in both the prevention and management of T2DM. Management based interventions have proven to be particularly successful at reducing haemoglobin A1c (HbA1c) levels amongst people with T2D (Cotter et al. 2014). Studies in this field focus, first of all, on how to promote patient's eHealth literacy, defined as the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem (Norman 2006), which becomes a priority to enhance the continuity of care. Secondly, other studies are focused on continuous monitoring of clinical parameters by mHealth and on the "on-demand" communication with the reference healthcare professionals (Jordan et al. 2008; Graffigna et al. 2016)

In the next section, I will describe the context of my case study, a mHealth project for the management of type 1 and type 2 diabetes.

1.4.2 TreC Diabetes

My PhD research project is flanking a clinical trial conducted in north Italy and aimed at quantifying the effectiveness and the acceptability of a self- tracking/remote-monitoring platform, named "TreC Diabetes", developed by the Digital Health lab of FBK, for type 1 and 2 diabetes patients. The system includes a web interface for the doctor (medical dashboard) and a mobile interface for the patient. The patient interface, a smartphone application (fig. 2), provides people with diabetes with a diary to keep track of relevant information (e.g. glucose levels, therapy, symptoms, diet) and some algorithm-based support for decision-making (i.e. a carbohydrate count, a bolus calculator, graphs, trend-tracking indexes).

Fig.2 The smartphone application for patients

The providers' interface, a web-based dashboard, enables doctors and nurses to remotely monitor patients' data through an algorithm-based alarm system triggered by specific events or recurring patterns in the patients' data. The web-based dashboard accessible by doctors was endowed with a system of rule-based alarms designed to send an alert to clinicians and/or patients in the presence of certain data or combinations of data and permits the doctor to activate or not activate the functions of the app, depending on the patient's needs. The app for the patient is prescribed by the doctor and supports the management of diabetes, partly through virtual coaching features, and partly by sharing data with the doctor. The virtual coaching intervention is preceded by a self-care profiling phase and a patient's lifestyles analysis. The main features of the app are a patient's diary, on-demand educational modules, micro learning activities, a virtual coach intervention to support lifestyle goals defined with clinician, a chat with other patients and a chat with clinicians. It is also expected the design and implementation of a digital support for the execution of personal experiments. The idea is that clinician could prescribe the experiment from his/her dashboard, “personal experiment” feature would support patients during the data collection -sending reminders and motivational messages- and at the end of the experiment provider would encourage patient’s reflection on their data asking them focused questions. The more long-term goal of the implementation of this feature is to design and implement a chatbot-based conversation that would permit patients to reflect independently on their data. In figure 3 can be seen as an early mock-up of a chatbot-based conversation in which the conversational agent guides the experiment through questions regarding the patient's physical activity and blood glucose values.

Ciao Gianni, bentrovato. Oggi è il primo giorno del nostro esperimento. Ricordati di misurare la glicemia prima e dopo l'attività fisica che svolgi.

inserisco i dati

e quali dati vuoi inserire?

attività fisica

attivitàò fisica

Indica la durata e il tipo di attività svolta

30 minuti

Ottimo!

inserisco i dati

e quali dati vuoi inserire?

glicemia

quale valore di glicemia stai per inserire?

Fig. 3 Early mock-up of a chatbot-based intervention

The whole implementation process (fig.4) includes also a preliminary phase during which personal experiments will be conducted using a paper prototype, which I will call *notebook* here, according to a co-design approach. My research lies in this phase of the process, the exploration of the requirements collections and analysis and the app design prototyping. The purpose was to investigate the knowledge-related practices and use of the paper prototype with the goal of offering hints for the design of the "personal experiment" app's future. Each practice was studied in its natural context through a qualitative design study mixing semi-structured interviews, artefact analyses and participant observation, which I will describe in the next paragraphs.

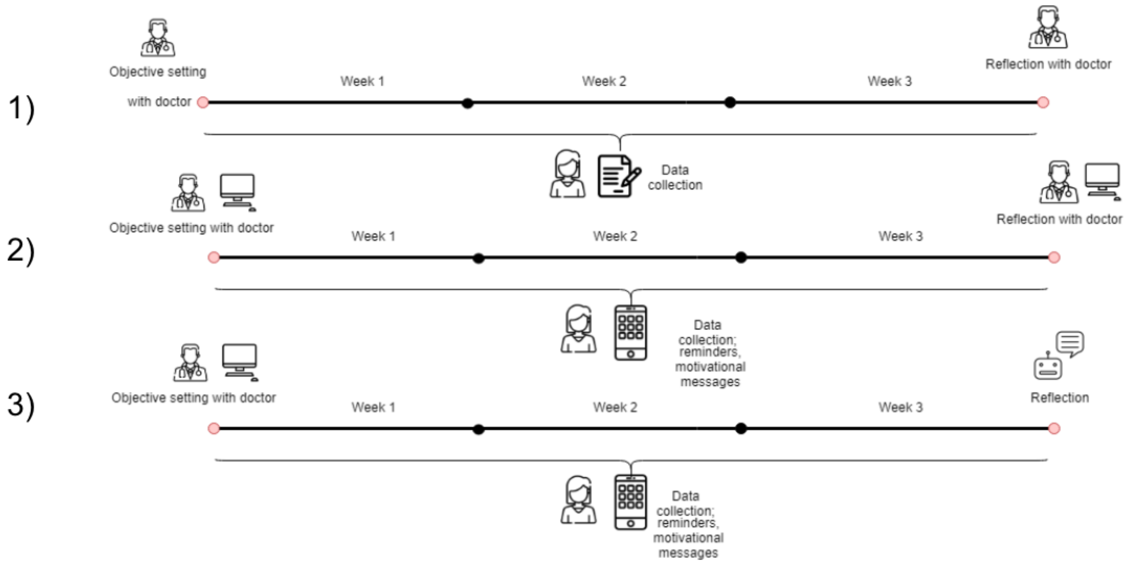


Fig. 4 TreC_Diabete Implementation Process

1. 5 Research process and methodology

I spent six months, from February to July 2019 in the field, studying the ways in which the paper prototype - the notebook - has become part of disease management practices.

Goffman (1989) identifies three main phases in conducting a qualitative research: the first concerns the researcher's getting into place, which means gaining access to the field; the second one concerns the actual observation of the research context, in which there is the possibility of acquiring data and "drawing" from the field (exploiting place). Finally, there is a phase that concerns getting out of the situation (getting out of place), therefore the return of the data and the presentation of the results to the organization of which we were guests. These three moments can also be identified in my research. The study was done through three research phases (fig.

5): exploring the field phase, understanding and designing phase, fieldwork and data analysis phase. The research techniques used were qualitative: conversational interviews, focus groups, workshops, ethnographic observation. For each phase of the research, the following actors were involved (fig. 6): in the exploratory phase, five key informants (three general practitioners and two diabetologists); in the understanding and designing phase, two associations of diabetic patients, the five key informants and the research group design team; in the fieldwork phase, thirty diabetic patients (Table 1), five general practitioners and three diabetologists were involved.

Demography		**Number of participants**
Age (in years)	50-70	16
	71-80	10
	Above 80	4
Gender	Male	16
	Female	14
Level of education	Primary school	5
	Secondary school	9
	Tertiary school	9
	Degree	7

Table 1 Demographics of study participants (diabetic patients)

Below I will describe the research techniques used for each phase.

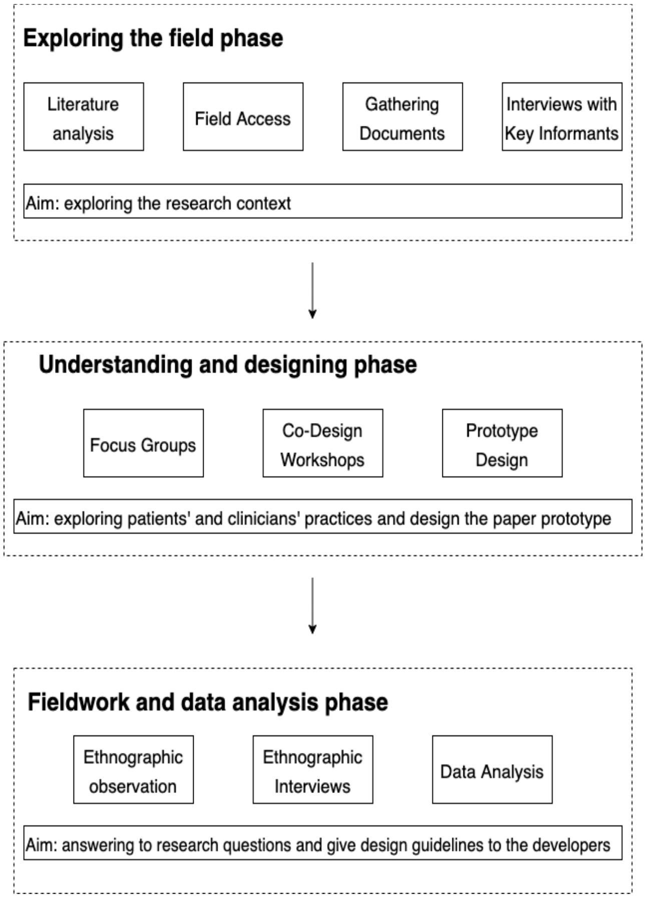


Fig. 5 Research process and methods

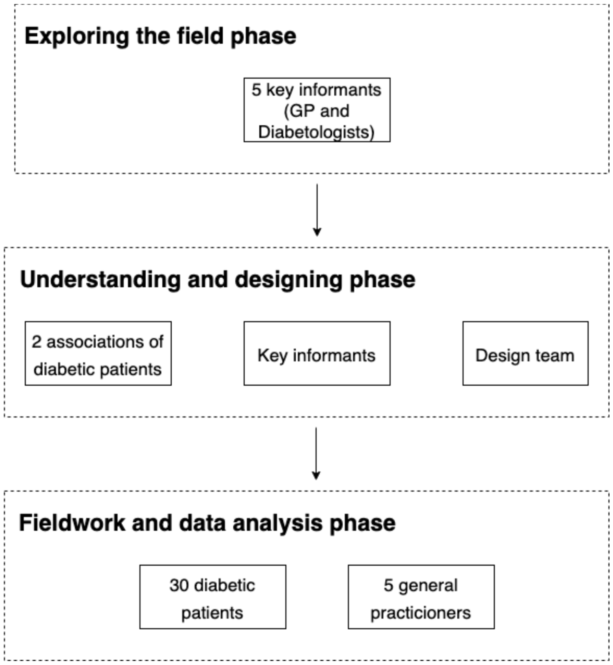


Fig.6 Actors involved for each phase

1.5.1Exploring the field phase

This first phase aimed to explore the research context before the empirical field study. The first step was to negotiate the field access, a period of stay at the general practitioners' studios. The access to the field phase is fundamental: this is the most delicate moment of the research, the one in which the researcher "knocks at the door" (Bruni, 2003) of the organization and waits in hope that it will be hopeful that it will be opened to him, although it is not taken for granted that this will happen. The term negotiation implies a question of trust: the researcher becomes the object of observation by the observed actors, who must decide whether and to what extent they can trust him/her (Cardano, 2003; Bruni et al. 2004). In my case, the access to the field was made easier by the fact that the seat of the school of general medicine is located in FBK premises, and the president of the school played the role of intermediary (Gobo, 2002) between me and the general practitioners involved.

Literature Analysis: before starting my research, I provided a critical assessment of the sources I have gathered and read surrounding the topic of self-tracking in Type 2 diabetes.

Gathering documents: Documents produced by organizations are not to be merely treated as representations (Cottle, 2007), nor are they simply the representation of the organization's practices and processes to employees and relevant audiences (Atkinson & Delamont 2010).

Documents themselves as material artefacts, linked into practices, and connected up with other entities in chains of reference (Latour, 1999). Therefore, during my stay in the field I collected various documents that concern the object of the research: organizational documents, company websites, photos and images regarding the activities and actors involved in the organizational process considered. Specifically, I analyzed documents already used by physicians to educate their patients about the management of type 2 diabetes. The analysis of these documents was useful to complete the reconstruction of the organizational form under consideration, to deepen the knowledge of some organizational practices, and to obtain information on the activities of some actors that it had not been possible to observe or interview (Walsh & Meyer 2006).

Discursive interviews with key informants: The discursive interview differs from the structured interview (which is characterized by a clear structure, precisely, between questions and answers) in that the interaction between interviewee and interviewer is determined in content, but the ways in which the interlocution takes shape, the words with which to ask the questions and those used to articulate a response, are not predetermined, but are defined in the course of the interaction (Cardano, 2011). I did my interviews both to key informants (general practitioners and diabetologists) during the exploring the field phase, in order to gather some preliminary information about the practices of T2 diabetes management and to build the structure of the personal experiment. During the interviews, I initially proposed a rather general topic of discussion through a descriptive question (Spradley, 1979), and then I entered more and more into detail, depending on the type of information I wanted to elicit from the conversation.

1.5.2 Understanding and designing phase

This second phase aimed to investigate the needs of patients and physicians and to design the paper prototype (the notebook), as well as to develop the structure of the personal experiment (timing and mode). In the next paragraphs I will describe the methods I used.

Focus group The focus group is a survey technique for social research based on discussion among a small group of people, in the presence of one or more moderators, focused on a topic that you want to investigate in depth (Corrao 2000: 25). It takes place as a "group interview" led by a moderator who, following a more or less structured track (grid), proposes "stimuli" to the participants. The stimuli can be verbal (direct questions, sentences, definitions, associations) or visual (photographs, drawings, cartoons, films). The characteristic, which is also the great value of the focus group, lies in the interaction that is created between the participants, an interaction that produces ideas to a much greater extent than a single interview, both in terms of quantity and quality of study. I involved my key informants in two focus groups to test the validity of the interview; often, in fact, what is considered important and salient for the researchers is not so for the interviewees, and it is their point of view that should be probed.

Co-design Workshop I did two co-design workshops involving an association of diabetic patients in order to explore their everyday practices of diabetes management and to supplement physician suggestions for the design of the notebook. During the workshops I used the value proposition canvas (fig. 7) to explore needs, gains and pains of participants.

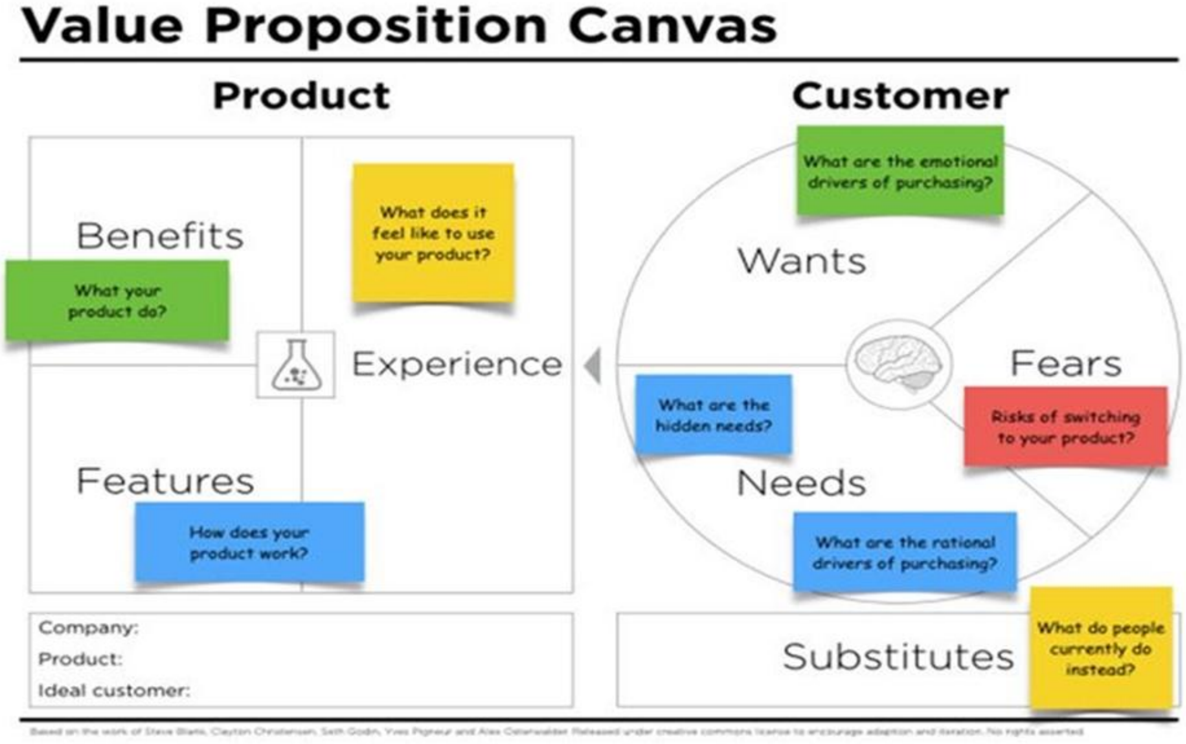


Fig. 7 Model of value proposition canvas

Osterwalder et al. define the value proposition as ‘the benefits customers can expect from your products and services’ (Osterwalder et al. 2014). Defining the value proposition during the development of eHealth technologies can be valuable in that it sheds light on important factors such as the purpose of the technology, i.e. the reason why the technology should be developed, and how it fits into daily practices of participants (Van Limburg et al. 2011). The value proposition goes beyond the technology’s relevant added value for end-users, but also includes how the technology meshes with the technological, organisational needs of users (Van Gemert-Pijnen et l. 2018)

The value proposition canvas has two sides (Osterwalder et al. 2014): (1) the customer or stakeholder profile, which fosters an understanding of the customer, in my case of the patients and (2) the value map, which shows how the product creates value for customers (the patients), i.e. how the values are translated into the design. Together, the customer profile and the value map make up the value proposition. Products that manage to fit together the customer profile and the value map have a higher chance of successful development and implementation, resulting in greater impact and improved uptake (Osterwalder et al. 2014). Based on the value map (fig. 8), the notebook for the personal experiment was created.

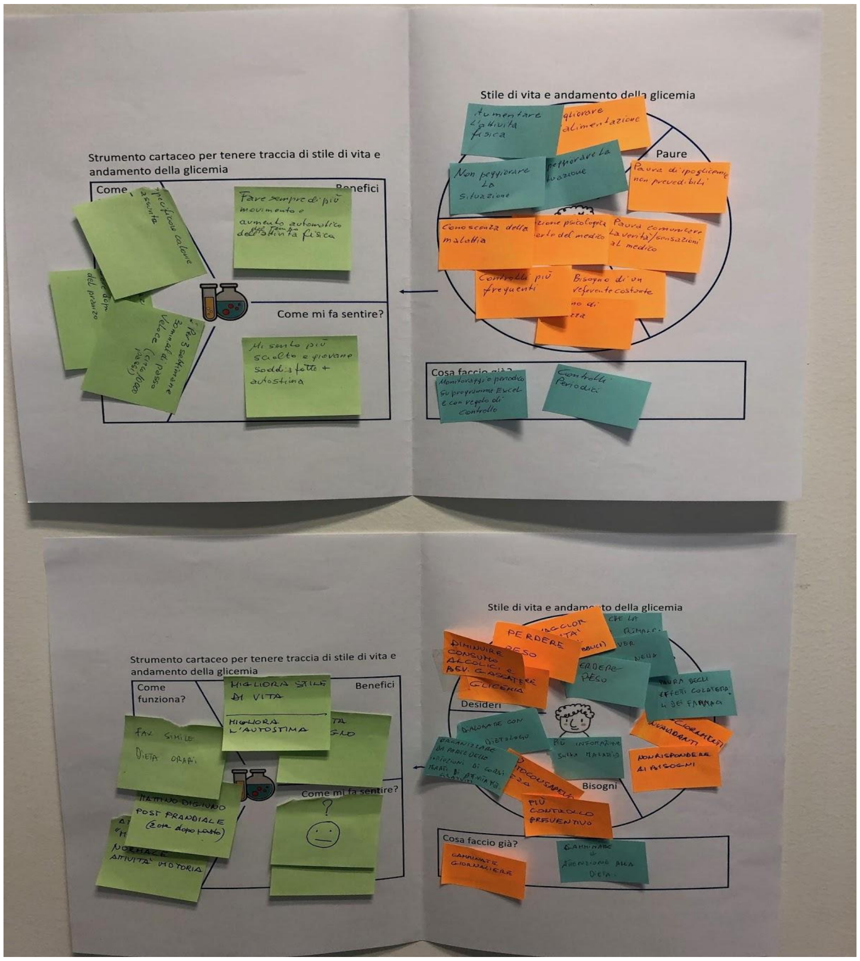


Fig. 8 Value proposition maps

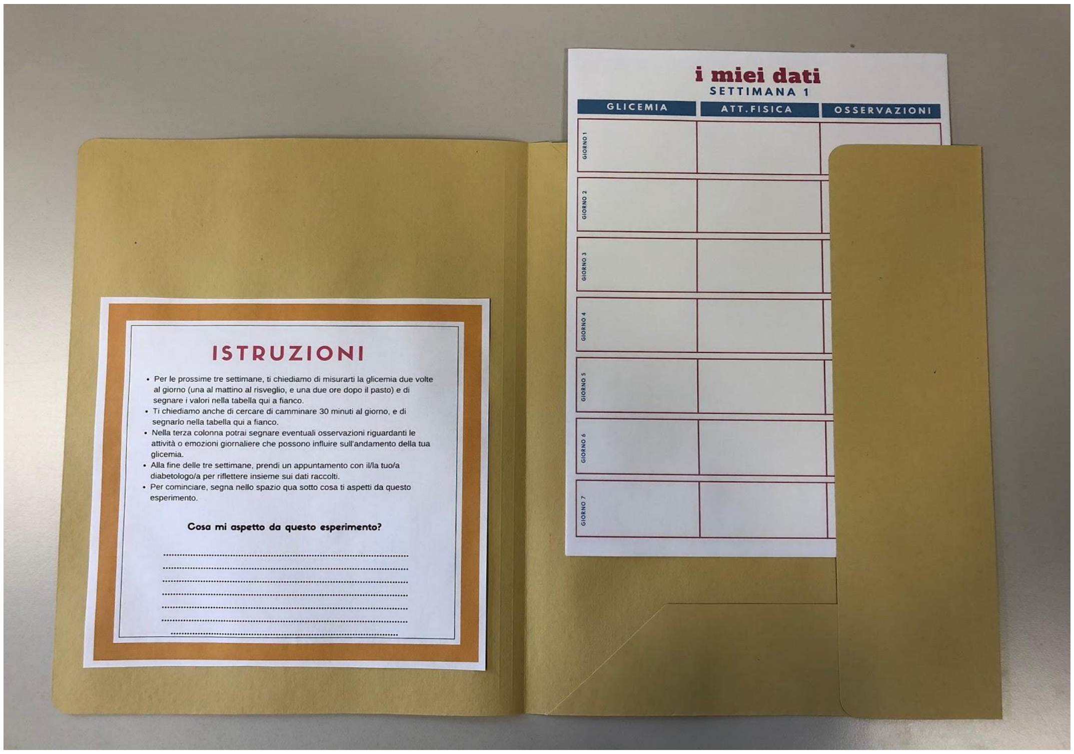
The notebook: a cultural probe

The notebook (fig. 9 and 10) and the structure of the personal experiment were created based on literature analysis, focus groups with physicians and workshops with patients. As stated in the instructions, for the next three weeks, we ask to the participants to measure their blood sugar twice a day (once in the morning, and once two hours after a meal) and mark their values in the twice a day (once in the morning, and once two hours after a meal) and write down the values in the table. During the first week, no physical activity was expected. During the second and third week, we ask to walk thirty minutes every day within 1/2 hour after the meal, for at least 2 km (4000 steps) and measure blood sugar immediately afterwards. For all three weeks, we ask participants to take note of the total steps they take during the day.

In the third column they can write down any comments about their daily activities or emotions that may affect their blood sugar. At the end of the three weeks, during a meeting with their doctor, patients would reflect on the data collected.

The notebook consists of a cardboard case in which three sheets are inserted (fig. 11), one for each week of the experiment. Each sheet has three columns: the first in which to mark the blood glucose values, the second in which to mark the minutes of physical activity performed, and the third in which to note any observations. Inside the case there is also a sheet with instructions for completion, and a space in which to note expectations about the experiment.

Fig. 9 The notebook



ISTRUZIONI

- Per le prossime tre settimane, ti chiediamo di misurarti la glicemia due volte al giorno (una al mattino al risveglio, e una due ore dopo il pasto) e di segnare i valori nella tabella qui a fianco.
- Ti chiediamo anche di cercare di camminare 30 minuti al giorno, e di segnarlo nella tabella qui a fianco.
- Nella terza colonna potrai segnare eventuali osservazioni riguardanti le attività o emozioni giornaliere che possono influire sull'andamento della tua glicemia.
- Alla fine delle tre settimane, prendi un appuntamento con il/la tuo/a diabetologo/a per riflettere insieme sui dati raccolti.
- Per cominciare, segna nello spazio qua sotto cosa ti aspetti da questo esperimento.

Cosa mi aspetto da questo esperimento?

....
....
....
....
....
....
....

i miei dati

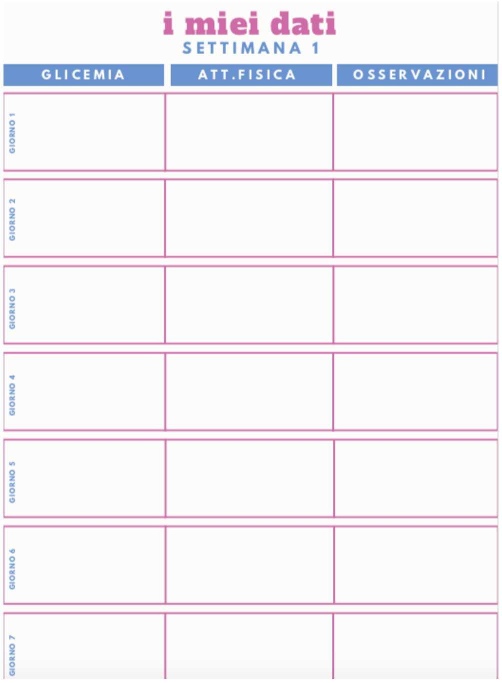
SETTIMANA 1

	GLICEMIA	ATT.FISICA	OSSERVAZIONI
GIORNO 1			
GIORNO 2			
GIORNO 3			
GIORNO 4			
GIORNO 5			
GIORNO 6			
GIORNO 7			

Fig. 10 The notebook

I considered the notebook as a cultural probe, a tool for sharing users' tacit knowledge in participatory design. Originally referred to as "cultural probes", this method was used in design contexts in which users were the subject of design interventions (rather than partners or participants). (van Woezik et al. 2016). Probes are self-documentation materials which can take a variety of forms from diaries, to cameras to maps or games, and through which users can document their everyday aspects of a task. The intention of using probes is literally to send a probe into the everyday life of people in order to collect information. The strength of this method is that the material is designed and produced for a specific project, for its participants and for their environment (Gaver et al. 1999). Usually, probes are sent to users with little guidance, completed individually and then returned to the designers/researchers (Van Gemert-Pijnen et al. 2018). The cultural probe method includes open-ended and evocative activities for participants to pursue in their own time to help narrate and depict their lives to researchers and technology designers (Wherton et al. 2012).

I used the notebooks in a participatory design context in order to identify social practices in which the use of notebooks emerged as knowledge artefacts that support knowledge-related processes, and discuss how far they can facilitate the articulation of users' knowledge and facilitate the sharing of expertise amongst users and between users and researchers.



i miei dati

SETTIMANA 1

	GLICEMIA	ATT.FISICA	OSSERVAZIONI
GIORNO 1			
GIORNO 2			
GIORNO 3			
GIORNO 4			
GIORNO 5			
GIORNO 6			
GIORNO 7			

Fig. 11 Weekly planner for the experiment

1.5.3 Fieldwork and data analysis phase

This third phase was intended to answer research questions observing participants while using the notebook, and to give design guidelines to the developers. Each patient was given a glucometer and a pedometer bracelet to keep track of their blood glucose readings and their physical activity. In the next paragraphs I will describe the methods I used.

Direct observation

During a direct observation, the researcher spends a certain amount of time observing the everyday life of groups of actors involved in a certain social event, process or phenomenon. In this case, the adjective "direct" indicates that the researcher, unlike in participant observation (Silverman, 1997; Cardano, 2011), although having interacted continuously with the research participants, was not directly involved in the performance of the activities observed.

I did my observations in general practitioners' offices observing the interaction between physicians and patients as they reflected on the data collected in the notebook. During my observations I took written notes that were anonymised in order to ensure participants' privacy and confidentiality. For patients and clinicians, I have either used pseudonyms or I have referred to their job title. I obtained informed consent from all my informants on an ongoing and dynamic basis including the future use of research data. For the interviews, I obtained written informed consent, with each informant receiving a copy of the consent form.

Ethnographic Interviews

Alongside participant observation, I conducted 30 semi-structured interviews with patients and clinicians involved. Semi-structured interviews (Spradley, 1979), are characterized as partially structured interviews, in most cases used to explore aspects and themes that emerged during the observation periods or to learn about activities that could not be directly observed. The interviews were taped, transcriptions were made from the recordings and informants and other identifying features were anonymised. Finally, interview data was subjected to discourse analysis and used to support the arguments I make in the following empirical chapters.

In the next paragraph I will deepen the process of analysis of the data

Data analysis

All empirical data have been explored through a template analysis (King and Brooks, 2016), a form of content analysis guided by the theoretical framework adopted. The goal of the analysis was to identify social practices in which the use of notebooks emerged as knowledge artefacts that support knowledge-related processes. The process of analysis followed three progressive coding steps (Charmaz, 2008; Tarozzi, 2008), aimed at bringing out theoretical concepts capable of providing a comprehensive and sufficiently abstract answer to the research questions:

- Initial encoding
- The focused encoding
- Theoretical encoding

Initial coding appears to be the first step in constructing a theory "anchored" as much as possible in the data collected, in which the researcher carefully reads the data collected, underlining the parts of the text (words, phrases, events) deemed interesting and significant to the initial research question. Following this approach, after having collected and transcribed the data of the first case, I first read all the material collected, underlining the parts considered significant and commenting on them with memos, in which I summarized with short sentences the content of the portions of text selected and commented on them with my notes and personal reflections. In a second moment I re-read the material related to the first case, this time starting to create the categories, still extremely descriptive and related to the characteristics of the first case.

On the basis of the first categories that emerged, I reflected on ways to saturate them (Morse, 1995), that is, to deepen them, broaden them and make them suitable for answering the research questions. Results from the analysis of the empirical data will be reported within chapters 2, 3, and 4.

Chapter 2 – Self-knowledge as situated practice

2.1 Introduction

As the number of people living with long-term conditions continues to increase and unprecedented pressures continue to be placed on available resources, the promotion of self-management is expected to lead to a number of benefits, including those related to a reduced burden on health services (Department of Health 2010). However, such benefits require what was described in a report of the World Health Organisation as a fundamental shift in the relations between professionals and those receiving care (Wallerstein 2006), such that patients are repositioned as experts and self-care options for chronic diseases is prioritised. In this regard, management of Type 2 Diabetes (T2D) requires accurate self-care behaviors, including dietary control, exercise, and in many cases frequent medication. Failure to follow treatment recommendations is reported as a serious and widespread problem in patients with T2D (Johnson 1992). Research on nonadherence in these patients commonly focuses on patient motivation, self-knowledge and psychological characteristics. In this chapter I explore how the failure of T2D patients to follow treatment recommendations reflects the complexities of adjusting diabetes management to the exigencies of everyday life. There are so many heterogeneous elements that can affect diabetes management: resource allocation, fears, pains etc. Their evaluation of patients' choices goes well beyond the clinical goal of achieving adequate glucose control, but instead regard multiple considerations that are intimately connected to the daily context of their lives. Modification and adaptation of clinical recommendations is not a radical or innovative behavior of only a few patients; it is a necessary aspect of any attempt to apply the principles of self-care to the particulars of daily life (Gorst et al. 2019). In this chapter, the empirical results that allowed me to answer the first research question are presented, related to how the knowing processes triggered by personal experiments involve patients' with T2D situated practices, their bodies, objects, technologies, contexts and relations. The purpose of this chapter is therefore to explore knowledge as a situated practice and its representation inscribed in artefacts, in this case the notebook. To fully explore the learning processes of diabetes management, I will also consider the concept of sensemaking (Lave 1988; Godfrey-Smith 2003) in order to examine how patients make sense of their disease, learning from direct experiences and interpreting new information.

2.2 Theoretical background

In the next paragraphs I will make an excursus of the theoretical background that I will consider: first the work of Annemarie Mol (2000), which considers the management of diabetes as a situated activity; secondly, studies concerning the role of sensemaking (Dervin, 2015; Weick et al. 2005) and the ability of individuals and their providers to make sense of the data collected through self-monitoring,

2.2.1 Diabetes management as situated activity

Knowledge is not what resides in a person's head or in books or in data banks. To know is to be capable of participating with the requisite competence in the complex web of relationships among people, material artifacts, and activities (Gherardi, 2001).The knowing-in-practice perspective invites us to dwell on the ways in which groups of individuals learn common ways of relating to each other, of interacting with objects, of using their own bodies and of judging the actions of others, coming to share common ways of acting (Orlikoswsky, 2002; Tsoukas, 2003; Nicolini et al., 2003; Gherardi, 2006). Knowing is practicing and participating; it is inextricably interwoven with the situated activities, or "to know is to be able to participate with the requisite competence in the complex web of relationships among people, material artefacts, and activities" (Gherardi, 2010, p. 35). Knowledge is embedded in social relations and emerges from mediations between groups; it can be contested, and it is situated and provisional (Blackler, 1995). From the perspective of knowing-in-practice, every "heterogeneous item", regardless of whether it is physical, participates in the knowing-related activities. According to the knowing-in-practice perspective, the concept of socio-material practice is "a relatively stable over time and socially recognized way of ordering heterogeneous elements into a coherent set" (Gherardi, 2006: 34). Thereby, to practice means to produce and reproduce an articulated set of ways of doing, involving both individuals and the material context in which they are acting, creating over time a relatively stable order in the daily life of a community of individuals. There is a close relationship between practices and knowledge: to practice is to know in practice, whether the subject is aware of it or not, knowledge in fact takes shape through the activity itself and not the other way around (Bruni and Gherardi 2010). From this point of view, knowledge is the emergent product of situated practices occurring in certain material contexts and involving heterogeneous technological objects and infrastructures. 'Situated' has a multiplicity of meanings (Gherardi, 2006), all of which are present when we consider the knowing process as embedded with the performance of a practice: the materiality of the knowing subject is primarily anchored in the body; knowing in practice articulates the emergent nature of knowledge from interactions; it is situated in language, because all expressions change their meanings according to the subject and the context of use; and it is situated in a physical context, because subjects actively engage with space and establish relations with it (Kirsh, 1995).

Annmarie Mol, a Dutch anthropologist and philosopher, has closely studied the processes through which the diabetic patient learns to manage his disease (Mol, 2000; Mol & Law, 2004). reminding us of the need to explore the bits of medicine that aren't about science. According to Mol, in the case of diabetes, knowing is a practice: it only becomes possible to talk about a certain blood sugar level only if someone's skin is pricked, a blood sample is taken, and its sugar level is measured (Mol & Law 2004). This usually used to happen in clinical contexts, where a technician would puncture a vein, collect some blood in a small tube, insert it in a machine and read the outcome. With the dissemination of diabetes self-care tools, this still happens, but it has been joined by another measurement practice. People with diabetes now can measure their own blood glucose, without the need to visit a doctor. They prick a finger-tip and squeeze a drop of blood onto a measurement stick. The stick is put into a slot in the machine and within a few seconds a number is displayed. Put like that it sounds easy, but measuring glycemia is a practice that requires a range of skills, attitudes, appropriate situations, etc. Pricking the finger may hurt, the number may take some while to appear – and so on (Mol & Law 2004). Consequently, in Mol's studies diabetes management is considered a situated activity involving heterogeneous elements: first and foremost, the patient's body and the technologies necessary for disease management. Through the measurement of blood glucose, the patient can change the meaning attributed to their body sensations, choosing what action to do or not to do (Mol, 2000; Mol e Law, 2004). In this sense, the patient learns through the exploration of their own body. In this perspective, there is no clear-cut distinction between knowing and practicing, or as Mol (2002) puts it, knowledge should not be conceived "as a set of statements about reality, but as a practice that interferes with other practices. Despite the fact that blood glucose measurement has specific and strict protocols that patients are required to follow, daily diabetes care often requires adapting to unexpected events, such as a fear of pricking your finger, technology that doesn't work, a mishap, etc. (Mol 2009). For this reason, according to Mol "...control is an illusion even if you master the tasks". People with diabetes learn that the amount of energy in the food they absorb should balance with the amount of energy they expend while their insulin dose should be adapted to both. But there are so many variables not accounted for that all too often the sums simply do not add up. However, much you count, your body cannot be counted on (Mol, 2009). Patient's body and technologies are mutually forged: on the one hand, the numerical values indicated by glucometers are a consequence of the sugar present in the patient's blood. As a result of the measurements, the patient can revise the meaning of his body sensations. The meaning attributed to their body sensations by taking or not taking certain activities aimed at managing glycemic (Miele, Piras 2016).

In the next paragraph I will explore the concept of sensemaking (Lave 1988; Godfrey-Smith 2003) which gives a different view on the process through which learning, and in particular, experiential learning is accomplished.

2.2.2 Sensemaking of diabetes

Most of behavioural theories which explore the design of technologies for facilitating self-management, among which the most used is the Transtheoretical Model of behavior change (Prochaska, Velicer 1997), focus on factors that motivate and regulate individuals' behaviors and on the psychosocial determinants of these behaviors; few explicitly examine how individuals make sense of their disease, learn from past experiences, interpret new information and develop mental models to inform their future choices. Perhaps as a result, the vast majority of technological interventions for diabetes self-management continue to focus on impacting behaviors, rather than on helping individuals make sense of and learn from collected personal data (Mamykina et al. 2015). As a part of understanding chronic conditions through personally generated data, establishing associations between outcome measures and contextual factors is one of the primary need of patients.

In this chapter I discuss how individuals make sense of their chronic disease using self-monitoring data through the theoretical lens of sensemaking. Sense-making describes a process of learning and producing knowledge that guides action decisions (Dervin, 2015; Weick, Sutcliffe, & Obstfeld, 2005). Although the term sensemaking has been commonly used as early as the 1980s in fields such as organizational research (Dervin, 1983), artificial intelligence (Klei et al. 2006), and symposia on decision making (Leedom, 2001), it has more recently become a fast-growing topic of science education research. The traditional view of science education draws a strict contrast between scientific thinking, characterized by rationality, precision, formality, detachment, and objectivity, and everyday thinking, characterized by improvisation, ambiguity, informality, engagement, and subjectivity (Warren et al. 2001). In the traditional perspective, everyday lived experiences and language are often perceived as incongruent with scientific thinking and as a source of educational problems. In contrast to this view, proponents of the sensemaking perspective in education argue that the kind of improvisational thinking and learning that happens in the context of mundane everyday life, which contrasts with how science is taught in schools, has many stark similarities with how science is actually practiced by scientists (Lave, 1988). In addition, the sensemaking perspective takes a different view on the process through which learning, and in particular, experimental learning is accomplished. Sensemaking is not just a crutch that human beings use because of our limited cognitive capacity; it is a highly adaptive response in the face of fundamental uncertainty of a complex dynamic world (McDaniel 2007). Sensemaking unfolds in a nonlinear fashion and is interactive and relational. Sensemaking is also "an issue of language, talk, and communication" (Weick et al. 2005). Through conversation, people make sense of their collective circumstances and of the events that affect them, and they create the basis for action to deal with those circumstances and events (Taylor & Robichaud 2004). Specifically, in the case of diabetes, individuals must re-examine such mundane everyday activities as grocery shopping, cooking and eating meals or participating in social gatherings, and adjust their practices to the new demands of diabetes self-management. They are called on to know their bodies better and more intensely, and to work to interpret these novel forms of information about themselves - to engage in data sensemaking (Lupton and Maslen 2017). Consequently, they experience frequent and multiple gaps in their understanding and their ability to select appropriate action and must make sense of the new situation in order to construct their new reality (Mamykina et al. 2015).

In this chapter, therefore, I will conceive diabetes management as a practical and emergent activity. In order to do this, the theoretical stimuli coming from the knowing-in-practice strand will be fundamental, which leads to extend the gaze to the ways in which, through different social and material contexts, people with diabetes learn to attribute new meanings to the management of their disease.

2.3 Methodology

This chapter was intended to answer to the first research question:

R.Q. 1: *How do the knowing processes triggered by personal experiments involve patients' with Type 2 Diabetes situated practices through their bodies, objects, technologies, contexts and relations?*

Thirty diabetic patients, five general practitioners and three diabetologists were involved. Each patient was given a glucometer and a pedometer bracelet to keep track of their blood glucose readings and their physical activity. The aim was to answer research question observing participants while using the notebook, and to give design guidelines to the developers. Each patient was given a glucometer and a pedometer bracelet to keep track of their blood glucose readings and their physical activity. I did direct observations in general practitioners' offices observing the interaction between physicians and patients as they reflected on the data collected in the notebook. During my observations I took written notes that were anonymised in order to ensure participants' privacy and confidentiality. Alongside participant observation, I conducted 30 semi-structured interviews with patients and clinicians involved.

2.4 Empirical results

2.4.1 Self-knowledge is much more than numbers

In this paragraph I will report a selection of excerpts from the interviews with patients at the end of their experiment. The first excerpt reports how compiling the notebook brings out knowledge that is not fixed, but mutable and interpretable through knowledge-related practices which involve heterogeneous actors and objects.

> I'm getting on well with it, I try to follow the chart and do the recommended physical activity...I feel better since I fill it out, I know I'm doing my homework well and the doctor will be happy...it's a joke (*laughs*)...the nice thing is that we used to hardly leave the house...now even my husband sometimes comes in the evening and looks at my booklet (*the notebook*)...he also started measuring how many steps he takes, and we go out together...we see that it makes us feel good… (Licia, patient)

The notebook is not only used to mark blood glucose values to learn their trend in relation to physical activity, as patients were told at the beginning of the experiment. The patient interviewed also uses the notebook to feel less "guilty" and to "do the homework" the doctor prescribed. In addition, the notebook is also consulted by other family members, in this case the husband, who consequently gets involved in the walks. In other cases, filling out the notebook is an "extra" practice that complements existing disease management practices:

> I have to say that I don't like the chart very much...ok, I fill it out, but at home I have a diary where I write down many more things...I am someone who likes to keep track of everything… I would like to write my autobiography (...) so I needed more space, so I fill in both the notebook and my diary, every night (...) on my diary I didn't write down my steps or even my blood sugar, I just wrote down how I felt, since I have diabetes...who knows, maybe when the experiment is over I will write down these things in my diary too… (Antonio, patient)

The person interviewed kept always track of his feelings, but never of data related to glycemia or physical activity. Filling out the notebook was therefore in addition to that of his personal diary, and the patient does not exclude the possibility of modifying this practice in the future, beginning to note in his diary also other data.

The next excerpt shows how, in some cases, patients modify the notebook by customizing it to their needs.

> I didn't know what I could mark (*on the notebook*)...for me it's important to know if I went out to eat or to a party...when I go to the dance class sometimes we eat something at the end, some savouries...the other day I was sick because a relative was diagnosed with a bad disease, and I know that blood sugar changes when I'm sick...so I marked these things too, because I think they are important… (Sandra, patient)

The excerpt shows how the artefact is shaped by the needs and personal daily occupations of each patient. There are some things that patients feel are important for their disease management even if they are not required by the doctor and the experiment. There are also some daily practices that patients don't want to give up, as the following excerpt demonstrates:

> I was a little skeptical and I still am...I'm not one who pays particular attention to what I eat, and I've never done much physical activity...I like to go for walks, but nothing much...these past few weeks I've been filling out the chart (*the notebook*) and it's true, I've been a little more careful about what I eat...maybe I've even walked a little more, but in the end I'm old, it's hard to change, for me...I have my own days and things to do… (Gianni, patient)

These first excerpts have shown that compiling the notebook requires patients to somewhat modify their behaviour (e.g. pay more attention to food and physical activity), but the actual unfolding of the practice and the inner structure of a day of disease management remain unaltered. In the next section I will describe how the practice of compiling the notebook has become embedded in patients' daily lives, influencing its timing or, vice versa, being influenced by its timing.

2.4.2 Self-knowledge is a matter of time (and weather)

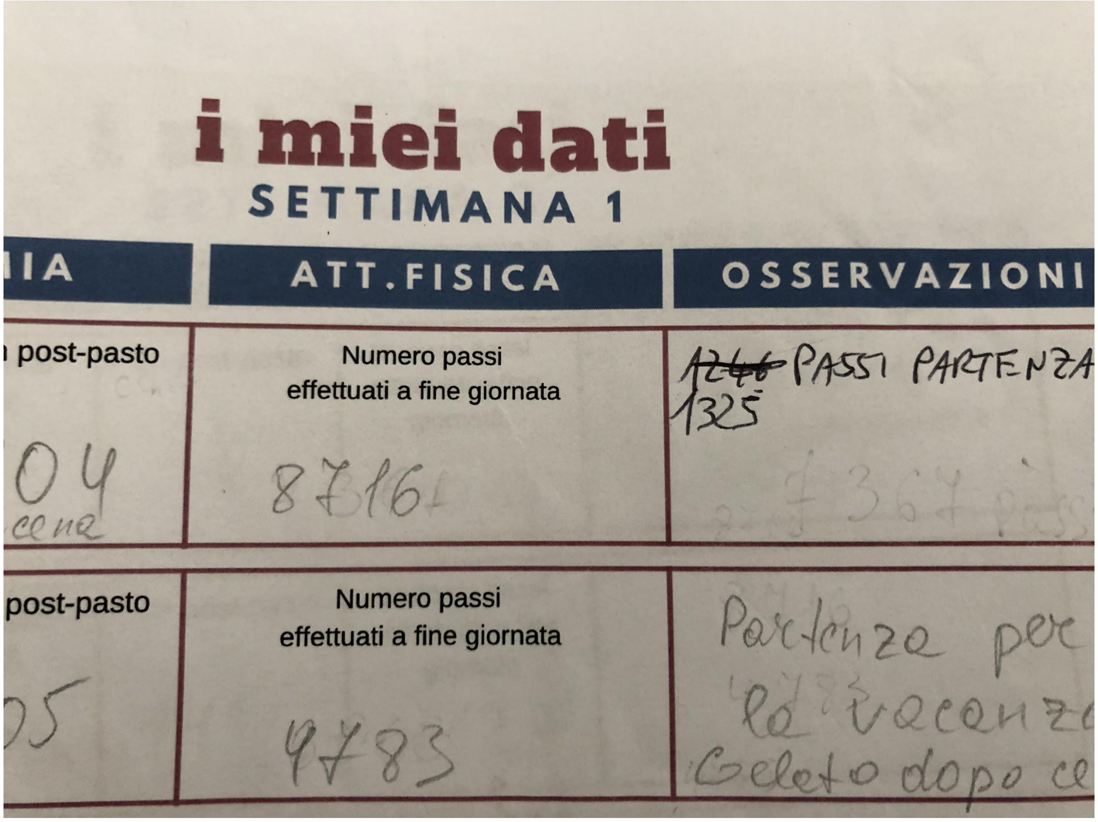
In this section we will look at care practices as a complex activity learned over time, occasionally coping with the unexpected.
In some cases, at the end of the two-week experiment, patients continue to monitor their own behavior:

> "I learned a lot... I had to know how to control myself... because since I did this experiment, I was able to learn that this is the way to do it... it helped me a lot, because I used to take things a bit "but yes, come on"... maybe because I’ve never kept track of my data... now that I know that I have to control myself, I want to do well... for my health above all (...) Since the end of the experiment I am realizing that I have to keep myself under control (...) Now even when I go to eat pizza I am careful, or I eat less at lunch... I always reflect on it..." (Marisa, patient, 68 years old, excerpt from interview)

However, the following excerpts highlight how control over the disease, and in this case compiling the notebook, could be temporary or partial: there is always something unexpected to deal with, or the purpose of learning something new.

> I'm surprised at how helpful it (the experiment) was...now that it's over, I'd like to keep tracking the data...I'd like to try something new, maybe taking notes on what I'm doing, or increasing my physical activity a bit.... (Mario, patient)

> ...at a certain point I had to stop the experiment because I was on vacation (*fig. 11*)...I wanted to take the notebook with me, but I forgot it...so I resumed it when I got back (Anna, patient)



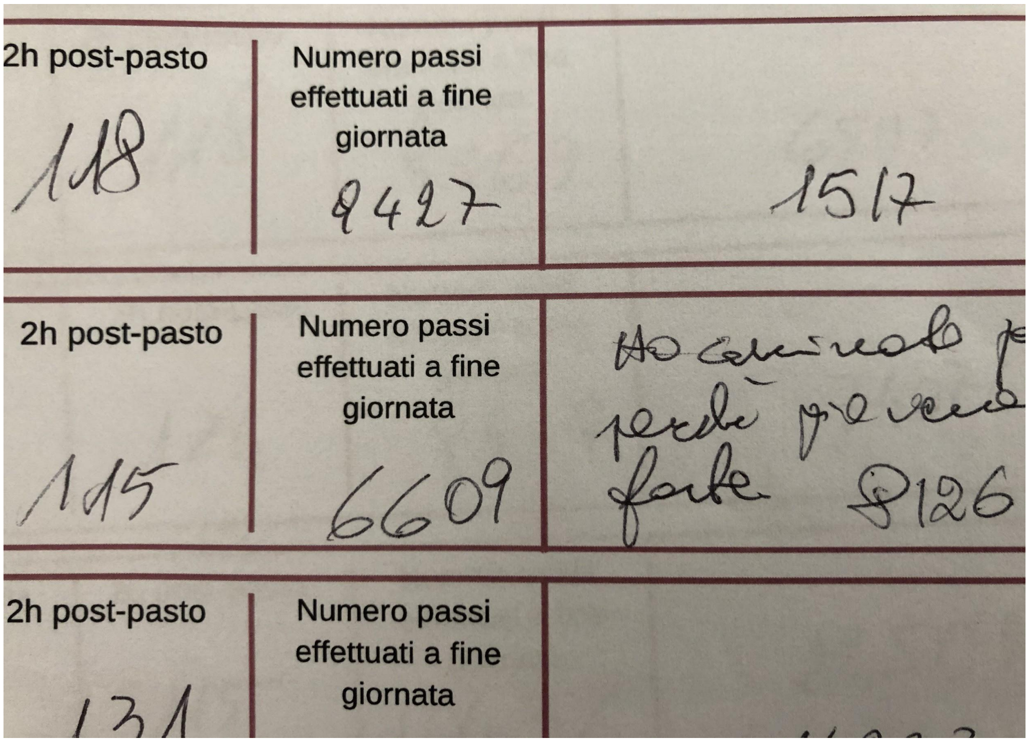
i miei dati

SETTIMANA 1

IA	ATT.FISICA	OSSERVAZIONI
post-pasto 04 cena	Numero passi effettuati a fine giornata 8716	~~1246~~ PASSI PARTENZA 1325
post-pasto 5	Numero passi effettuati a fine giornata 9783	Partenze per le vacanz Gelato dopo ce

Fig. 11 Here the patient marked that she had left for vacation (*from a notebook*)

The excerpts above demonstrate that in some cases the timing imposed by the experiment influenced those of the participants. In other cases, unforeseen events and exceptions determined the timing of the experiment. As in this last photograph (fig. 12), where the patient marked "I walked very little because it was raining hard." In this case, a weather-related aspect that the patient felt like reporting affected the success of the experiment:



2h post-pasto 118	Numero passi effettuati a fine giornata 9427	1517
2h post-pasto 115	Numero passi effettuati a fine giornata 6609	Ho camminato p perché pioveva forte 8126
2h post-pasto 131	Numero passi effettuati a fine giornata	

Fig. 12 (*from a notebook)*

In the next section, we will see how notebook completion is not only influenced by patients' daily disease management practices and personal timelines: for some participants, feelings such as stress and fear came into play during the experiment.

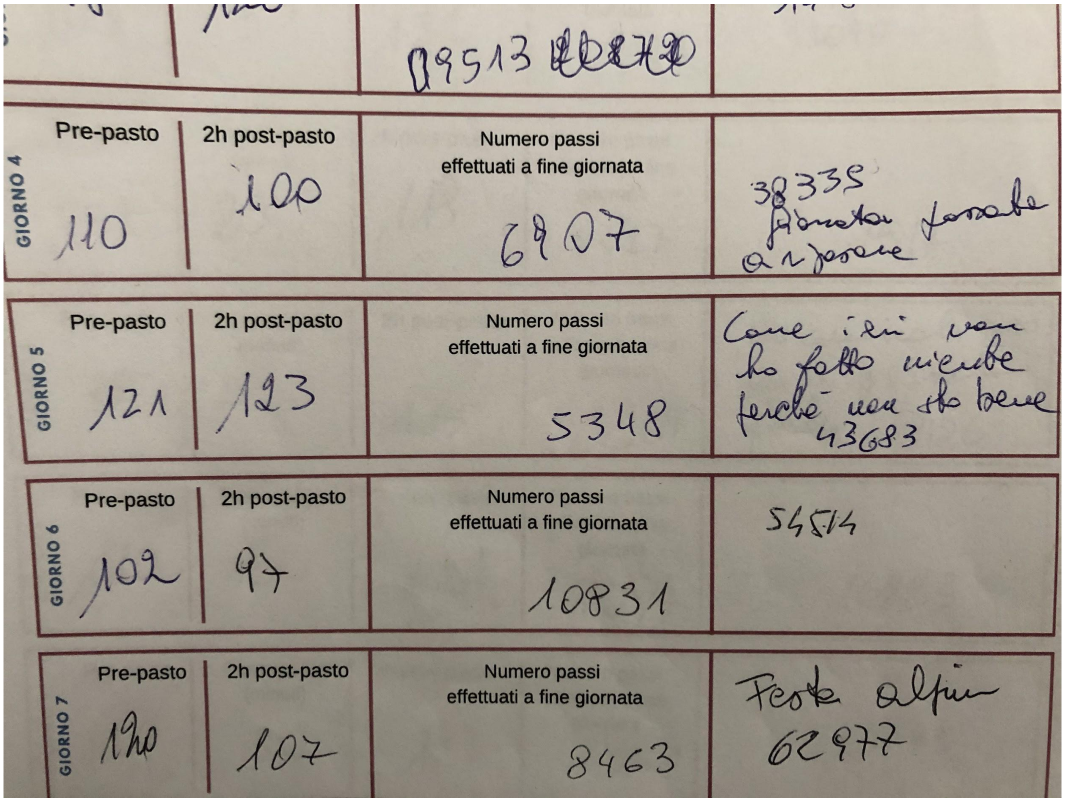
2.4.3 Self-knowledge may involve stress, pain and unexpected events

Glucose monitoring adds glycemic control benefit in self monitoring of blood glucose in patients with type 1 diabetes. With regard to patients with T2D , the emphasis of treatments is on a healthy lifestyle, but the data are less clear about the advantages of glucose monitoring. Physicians do not require daily measurements except in special cases. As a result, many patients with T2D have never had their blood sugar measured, and they did so for the first time during this experiment, as evidenced by the next excerpt:

> When he told me (the doctor) that I would have to prick myself, I got a little scared...not really scared, but I've never done it...so I was a little taken aback...at first I didn't know how to do it, I had to learn...my husband helped me...I didn't really know how to prick my finger, and it hurt a little anyway… (Anna, patient)

As the excerpt shows, blood glucose measurement involves also the self-inflicting of a little finger prick. Having never done it before, the lady therefore had to learn how to prick her finger, after several trials. She also expresses some fear in performing this task, and reports discomfort in her finger. For the first few days, measuring blood glucose becomes an anxious moment, but this is resolved with the passing of time. There is another aspect that emerges from the interviews and that concerns stress. In the management of diabetes, even when an individual does the same things everyday and eats the same thing at the very same time, blood glucose trend data may still differ. As highlighted in the next excerpt and photograph (fig 13), aspects like stress, other illnesses and hormones can have a role:

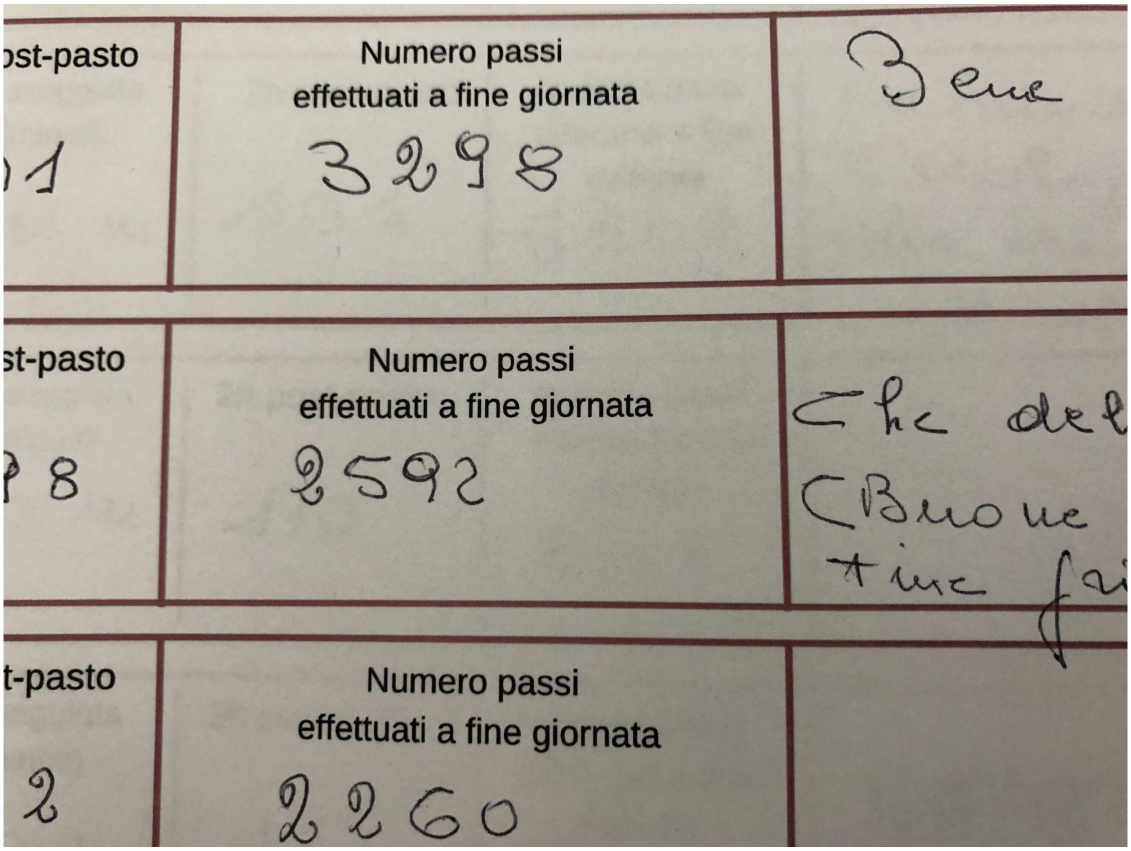
> Yes it's true, I scored 230 here...but I remember that day was a bad day, I got some bad news and I was nervous...I remember it because it was on the weekend...I scored 123 and I took a few steps, but I remember I wasn't well (Gina, patient)



			09513 ~~[illegible]~~	
GIORNO 4	Pre-pasto 110	2h post-pasto 100	Numero passi effettuati a fine giornata 6907	38335 Giornata passata a riposo
GIORNO 5	Pre-pasto 121	2h post-pasto 123	Numero passi effettuati a fine giornata 5348	Come ieri non ho fatto niente perché non sto bene 43683
GIORNO 6	Pre-pasto 102	2h post-pasto 97	Numero passi effettuati a fine giornata 10831	54514
GIORNO 7	Pre-pasto 120	2h post-pasto 107	Numero passi effettuati a fine giornata 8463	Festa alpini 62977

Fig. 13 Here the patient has made some notes in the notebook that do not directly concern blood glucose and physical activity, but rather other aspects of his daily life (one reads "day spent resting", and "like yesterday I did nothing because I am not well"). *(from a notebook)*

In the next photograph excerpt the patient expresses the role of emotions in conducting the experiment: at first the patient is happy with the progress of the experiment and writes "good", but then she marks "what a disappointment (good french fries)": here, although the patient was disappointed by the recorded figure, she consoled herself by eating some french fries.



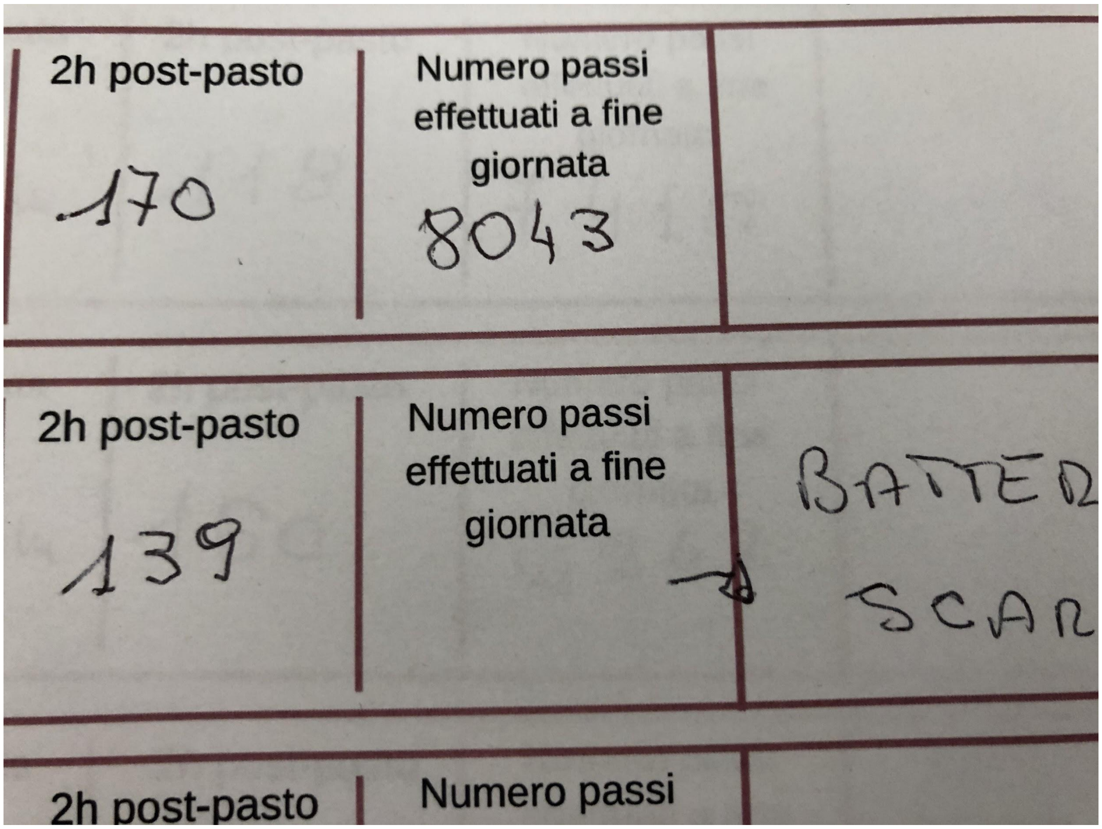
ost-pasto 11	Numero passi effettuati a fine giornata 3298	Bene
st-pasto 8	Numero passi effettuati a fine giornata 2592	Che del (Buone tine fr
t-pasto 2	Numero passi effettuati a fine giornata 2260	

Fig. 14 (*from a notebook*)

However, fear and stress aren't the only concerns that can get in the way of the experiment. There is also other elements that indirectly influences the mood of the participants in conducting the experiment:

> I don't think I will go ahead with the experiment...I never measure myself, I did it only in this case...and because the strips were given to me by the doctor...but

> they cost too much, I could never buy...how many are there?...three strips a day, multiply by seven...no, I wouldn't do it, if I didn't have to (Aldo, patient)


2h post-pasto
170
Numero passi effettuati a fine giornata
8043

2h post-pasto
139
Numero passi effettuati a fine giornata
BATTER
SCAR

2h post-pasto
Numero passi

Fig. 15 *(from a notebook)*

These two patients report, in words and through the notebook, two aspects regarding the daily management of diabetes and that may affect the experiment: on the one hand, the economic issue of the cost of blood glucose measurement strips; on the other hand, the patient in the fig. 15 scored "low battery": an aspect regarding the technology (in this case the pedometer) affected the performance

As we have seen in this paragraph, glucose measurement and counting steps is not only a matter of producing numbers. It has many more aspects, such as fear, stress, and economic issues.

2.4.4 Self-knowledge flanks medical knowledge

Patients with diabetes develop a form of practical knowledge that is not necessarily opposed to a medical one but derives from the need to appropriate and contextualize the standardized medical aspects of the disease. Some patients developed situated knowledge over time, as evident in the next excerpt:

> “The doctor told me to follow this diet...he explained to me why it is important, that my blood sugar will get better...but I have been regulating myself for years, even before coming to the doctor… I already had diabetes… So I do this, I follow the diet that the doctor gave me and I measure my blood sugar, but I already know that for example I can eat bread and so I eat it, nothing happens to me...in short, I don't follow everything well but I am fine with it… (Maria, paziente)

This patient had known he had diabetes for years, but had only recently been treated by his physician. Over the years, he has developed a situated knowledge of the progression of her diabetes (she knows that eating bread is not bad for her), so she is not willing to completely change her daily management of the disease. Other patients have developed personal ways of managing blood glucose:

> I know that if I eat more then my values go up...every time I eat pizza it's like this...the doctor told me that I have to walk, but I also know that if I stay calm and quiet, then I feel better...I've always known that...and so I do it this way...except for these weeks when I have walked… (Gina, patient)

Gina has experienced that if she stays relaxed after eating pizza, her blood sugar situation improves. The two-week experiment changed her way of dealing with the unexpected because she had to walk to observe any change in her blood glucose values.

Medical knowledge becomes inseparable from understanding of what happens to eating bread, having a calmed body, ecc. Moreover, the extract shows how following a medical prescription based on universal assumptions - in this case compiling the notebook - is too simplistic and fails to adapt to the complexity and uncertainties of daily life.

2.3.5 Self-knowledge entails new sensemaking

In the development of practical knowledge, learning to interpret bodily sensations is indeed an important aspect. Many of the patients recalled this aspect during interviews. In this paragraph

I will explore the ways in which they learn to attribute new meanings to the management of their illness, as can be extrapolated from the following excerpt:

> I looked at the diary (the notebook) and I said to myself "I knew it", when I feel so agitated it's because I have high values...I knew it but seeing it written down is different, it's another thing (...) every time I wrote a high value in the evening, it was because I was agitated...or because I ate heavily, but that's another story (*laughs*) (Aldo, patient)

The experiment turns out to be a key tool for patients to make sense of certain sensations as they learn to correlate their feelings with high and low glucose data on the notebook. While on the one hand the notebook imposes a medical perspective through the logic of monitoring and the emphasis on quantified values, on the other hand this logic is reappropriated and brought into relationship with aspects like making sense of a symptom, as the next excerpt shows:

> ...I remembered that I went to my nephew's house, that afternoon...I saw it because I marked that we had eaten pizza...then I understood why it went up so much (the glycemia)...because we had eaten pizza...it was useful to me because then I understood better how it works, why there are these values so high, sometimes (Maria, patient)

The next and last excerpt shed light on how sometimes patients recognize discrepancies between their expectations and between what they marked in the notebook:

> Here I don't understand what happened...(look at the notebook)...I thought it was going down here (the blood sugar), because usually when I walk a lot then it goes down...and instead...then I saw that it had happened the week before, then I thought maybe it's normal… (Aldo, patient)

This patient tries to recall similar past experiences that can make sense of what happened: first he tries to remember both experiences from before the experiment, then the notebook helps him remember what happened in the past days.

2.5 Discussion and conclusions

In this chapter I discussed various forms of lay expertise that people with diabetes develop in dealing with the daily practicalities of the disease: learn how to measure blood glucose, understanding one's own body, appropriating objects and producing lay data. As described in the previous chapter, the structure of the personal experiment, agreed with physicians and proposed to the participants, was rather schematic: they had to measure their blood sugar twice a day (once in the morning, and once two hours after a meal) and mark their values in the twice a day (once in the morning, and once two hours after a meal). We also ask them to walk thirty minutes every day within 1/2 hour after the meal, for at least 2 km (4000 steps) and measure blood sugar immediately afterwards. For all three weeks, we ask participants to take note of the total steps they take during the day. Excerpts presented in this chapter have shown how doing personal experiment does not mean diligently marking up your data in a table. Instead, compiling the notebook is a practice which combines heterogeneous elements: human actors, material artefacts, bodily sensations, memories and past experiences are mobilised to elicit practical knowledge (Gherardi, 2010).

We have seen that, in order to do the experiment, patients need to constantly compromise between heterogeneous aspects of their life. In doing their personal experiments they often need to act as experimenters with their own body and therapy, and in doing so, they develop a capacity of diagnosis and various forms of situated knowledge. A first element that emerges from the excerpts is that the practice of compiling the notebook does not strictly concern food, physical activity or glycemic index. Instead, patients need to integrate different elements such as stress, fears, contingencies of time, and even economical issues. Sometimes participants found it easier to make the necessary diet changes if they were supported by a member of the family, who may decide to do the experiment with them. Significant others provide the individual with support and encouragement (Wilkinson et al., 2014). The relationship between the experiment and participants' personal feelings is more complex than it seems. Sometimes, and for some people, feeling bad is sufficient reason to act, and measuring the glycemic index is simply unnecessary. But in other circumstances intro-sensing and measuring are thrown into contrast and the latter is advertised as being more accurate (Mol and Law 2004), improving self-knowledge of the disease. By producing ever more data, technologies for self-tracking may draw all the attention of clinicians and patients towards numbers, putting patients' feelings and sensations in the background. However, it may also happen that the notebook helps to increase patients’ physical self-awareness, encouraging one to better recognize the signals of one’s body. In the case of miniaturized blood sugar measurement devices both these effects, however divergent, occur (Mol 2000). Consequently, sometimes the results of the experiment might differ from what the doctor had expected: in everyday diabetes care, numbers are important but there are many other factors that determine the success of the experiment.

This reflection leads us to another element that emerged from the interviews, and that is how the patient's self-knowledge complements medical knowledge. Chronic care is not just a matter of attending medical prescriptions; instead, it is populated by a variety of heterogeneous elements. The interview excerpts reported demonstrate how diabetes loses its exclusively medical character and becomes difficult to reduce into one trajectory, one language or one perspective. Elements that are traditionally not taken into account by medical practices, such as individual feelings, uniqueness of circumstances, and unexpected events, are instead fundamental to knowledge of disease and to improving the development of systems for self-tracking. It becomes therefore fundamental to consider that patients' self-knowledge does not see the medical as separated from the non-medical: self-knowledge is instead hybrid. Disease, illness, objects, treatment and the practicalities of everyday life come together as a package, and we should study and deal with them in that way (Mol 2008). I will elaborate on this in the chapter 4 of this thesis.

A third reflection stimulated by the empirical work concerns the temporal dimension of self-knowledge. As patients' words highlight, awareness of one's own diabetes is a process that goes from "before", in which the patient did not measure blood sugar and had no awareness; to "now", in which measurements have become part of the practice of managing the disease; to "then", in which what has been learned seems to remain in daily routines. During this process, the patient encounters a series of contingencies that affect the daily management of the disease, shaping new trajectories on which self-knowledge develops. There is always something unexpected to deal with: an impromptu vacation, forgetting your notebook at home. In a recent literature review on the assessment of psychological distress in adults with type 2 diabetes mellitus through technologies (Bassi et al. 2021), authors emphasize how it is important to intensify efforts in the deployment of digital solutions for the accurate assessment of patients' psychological condition: effective programs for chronic disease management should combine relevant information systems, with constant follow-up and targeted self-management for patients. Stress and fear are elements that emerge from the interview excerpts presented in this chapter: the fear of pricking your finger and the stress of knowing if your blood sugar values have risen are also important elements to consider in the design of self-management interventions for patients with type 2 diabetes.

A final thought concerns the importance of sensemaking for diabetes self-knowledge. Little is known about how users actually engage with these kinds of devices and with the data they generate as part of their everyday lives, and to what extent these promises and imaginaries are realized, resisted, or re-interpreted. People are confronted with making sense of the information, deciding how valid or valuable it is, and deciding how best to incorporate their data into their lives. They are called on to know their bodies better and more intensely, and to work to interpret these novel forms of information about themselves to engage in data sensemaking (Lupton and Maslen 2017). In this chapter empirical data have shown how patients through the personal experiment learn to correlate their feelings with high and low glucose data on the notebook, making sense of their illness. While on the one hand the notebook imposes a medical perspective through the logic of monitoring and the emphasis on quantified values, on the other hand this logic is reappropriated by patients and brought into relationship with aspects like making sense of a symptom. When they see something unexpected regarding their data, patients try to recall similar past experiences that can make sense of what happened, and in this they are helped by the notebook. Sometimes, patients may fail to see connections between their new observations and past experiences or fail to integrate the new discoveries within their existing model. If every new observation is viewed as unique, an individual's perception of the disease will merely be a collection of disjointed facts rather than a comprehensive mental model where experiences are connected together in a series of inferences and explanations.

In conclusion, this chapter contributes to the debate concerning self-management in chronic illness, showing as knowing processes are intertwined with social and material aspects, involving patients and technologies of care, but also health professionals and relatives. The notebook is not a fixed object with immutable features; rather, it is an evolving artefact that accompanies the illness trajectory and serves different purposes (Piras 2017). Through the words of the interviewees we saw how diabetes care is a context where things that worked yesterday might not work today, and things that work for clinicians might not work or work in a different way for the patients. For this reason, it is important not to reduce diabetes to a mere matter of fixed numbers and timelines, but rather to listen to the patient's perspective, their feelings, senses and situated knowledge. This is because once a medical and standardized perspective is assumed, then lots of other things get fixed: the patient's subjective feelings, his tacit awareness of the disease, his fears, the unexpected events of everyday life, etc. Medical authoritative knowledge acquires its character from the scientific and objective nature of its disciplined constituents, separating the disease from the rest of patients' life. In this way, this kind of standardized knowledge acts as a barrier to the situated knowledge of the patients that characterize chronic care. We have seen that patients need to constantly compromise between heterogeneous aspects of their life, and sometimes they need to act as experimenters and reflective practitioners with their own body and therapy, and in doing so, they develop various forms of self-knowledge. To do this, they need to integrate and bring into a relationship different elements such as, for instance, certain physiological values to certain sensations, or plans, or uncertain circumstances. And sometimes the results might differ from the medical prescription. In this chapter we have also seen the ways in which human senses and objects interact and work together in sensemaking. Making sense is a continuous process in which there is back and forth between the layers of understanding gleaned from direct patient sensemaking and data collected through the notebook. Patients involved in the experiments work with objects and data to bring sensemaking capacities into being. The affordances of objects and data may facilitate these capacities, but may also hinder or subvert them so that human users' desires or needs are not realized in ways they expect (Lupton & Maslen 2018).

These considerations may be useful in improving medical practice and developing self-tracking strategies that are less based on numbers and more based on patient experience. Knowledge of patient's situated practice, emotions and daily contingencies, such as measure with family members the steps taken, go on vacation, join the dance class, be afraid to prick your finger etc., will provide the doctors with context as they collaborate with the individual to personalise a self-management based care. Self-care employs an embodied, practical knowledge that is very different from the abstract, rational model of patient knowledge. Knowledge is not something you have or acquire but something you do, and in a social, biographical and clinical context, that contains objects and other people as well as one's own body. An understanding of self-care as situated practice is key to effective medical support and may serve as a starting point from which to change standardized educational programs for patients with type 2 diabetes. Building from the epistemological starting point of knowledge as practical activity, "medicine should come to recognize that what it has to offer is not a knowledge of isolated bodies but a range of diagnostic and therapeutic interventions into lived bodies, and thus into people's daily lives" (Mol and Law 2004, p. 58).

Chapter 3 – Self-knowledge for motivation: from self-reflection to control

3.1 Introduction

Type 1 and type 2 diabetes are two very different diseases. While symptoms are common in patients with type 1 diabetes, diagnosis in someone with type 2 diabetes may be met with skepticism, as there are no significant symptoms until hyperglycemia[1] is well over the threshold of 180 mg/dL. Given the absence of symptoms, motivation to self-manage type 2 diabetes may not be very strong. Therefore, together with empowerment, patients' education is an essential element of self-management (Funnell & Anderson, 2004). Self-tracking technologies for health permit the generation of knowledge that will enable users to have more informed discussions with their healthcare practitioner, thus challenging what is presented as a traditionally asymmetrical relationship. In this chapter the empirical results that allowed to answer the second research question are presented. In the next paragraphs I will describe how personal experiments, and in particular the final reflection on personal data, affect the motivation of patients with Type 2 Diabetes to maintain a correct lifestyle. In order to explore these topics, I will explore how self tracking - and in this case the notebook - can be integrated in the system of practices and power relationships already existent between clinicians and patients with T2D, affecting their motivation.

3.2 Theoretical background

Starting from the studies that have analyzed the role of self tracking tools in motivating and

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[1] High levels of sugar, or glucose, in the blood. It occurs when the body does not produce or use enough insulin, which is a hormone that absorbs glucose into cells for use as energy. High blood sugar is a leading indicator of diabetes.

empowering patients, and continuing with the role that the figure of the physician can play in this process, I examine studies that have critically explored the transition from patient empowerment to health surveillance by clinicians.

3.2.1 Self tracking for motivation

Self-tracking devices have recently proliferated to help people manage their health and wellness by quantifying a great deal of health data. Individuals can be more involved in the management of their own health and will produce health information that can benefit clinical decision making and scientific research (Sharon 2017). Self-tracking for health is thus expected to play a key role in the move toward personalized healthcare, the model of preventive and participatory healthcare that is being envisioned as a solution to the crisis of public healthcare systems in the industrialized world (Norris 2012; Flores et al. 2013). It is argued that these technologies promote healthier behaviors by making these data visible to the users. In the context of wearable health-tracking devices, some studies have focused on the motivation related to the use of these devices and how the technology affects users' behavior (e.g., Consolvo et al., 2008; Munson & Consolvo, 2012; Gabrielli et al. 2017). These works feature self-tracking as a means for achieving behavioural change in target groups to achieve better health or other outcomes. This approach is referred to in computing science research as "persuasive computing", or using digital technologies to "nudge" people into behaviour change (Fogg 2009, 2010; Purpura et al., 2011). This is particularly evident in the patient self-care, health promotion and preventive medicine literature (Fritz et al., 2014; Li et al., 2010; Matthews & Doherty 2011; Rapp et al. 2018). Arguments for persuading people to self-track such bodily features as their body weight and physical activity level, and, in the case of patients with chronic illnesses, such aspects as blood glucose level and blood pressure, are becoming increasingly common. In this context, the analysis of personal data generated from self-tracking are represented as pedagogical and motivational, a means of encouraging self-reflection or emotional responses such as fear, guilt or shame that will then lead to the advocated behaviour changes. Self-monitoring is otherwise presented as a form of self-care that allows people with chronic conditions to reduce their interactions with healthcare providers and become "digitally engaged" (Lupton, 2013, 2014, 2016). Recently, in response to the overwhelmingly positive attention that self-tracking has received in the medical and public health literature, critical discussions of self-tracking for health have begun to emerge in the social sciences literature (e.g., Lupton 2012, 2013, 2014, 2016; Nafus and Sherman 2014; Ruckenstein & Pantzar 2017; Till 2014). Some studies indicate many such devices fail to deliver on health benefits in the long term. For example, a 2014 survey of thousands of adults in the United States revealed that more than half of the self-trackers no longer used their tracking devices, and a third of those stopped using the device within six months of receiving it (Ledger & McCaffrey, 2014). The authors provide one possible explanation, emphasizing that activity trackers can provide data but may not inspire many users to be active, and other motivators are needed. Another recent study shows that for some users, quantifying their bodies has become an addiction: much of their day revolves around self-tracking, and they would feel anxiety and discomfort if they were prevented from monitoring their bodies (Motyl 2020). Other studies (Gabriels, K., & Coeckelbergh 2019; Oravec 2020) articulate a number of concerns regarding the social, cultural, political, and ethical implications of self-tracking and the move toward more personalized healthcare. Others (van Velthoven & Powell, 2017; Leigh & Ashall-Payne 2019) highlight the fact that mHealth interventions in order to be successful need clear endorsement from the healthcare system (Graffigna 2016). In the context of this thesis, we will explore the latter case, and in the next paragraph I will delve into the literature about the role of clinicians in motivating patients with T2D in adopting self-tracking.

3.2.2 The role of healthcare professionals in self-tracking interventions

The reference healthcare professionals are the key actors, from the patients' perspective, that can legitimize the intervention process and can motivate T2D patients in being compliant with mHealth and eHealth (Newton et al. 2005; Leigh & Ashall-Payne 2019). This underlines the role of healthcare organizational and professional cultures in enhancing or inhibiting the effectiveness of mHealth and eHealth interventions in managing type 2 diabetes. In this paragraph, I explore the enabling role of healthcare professionals in the eHealth and mHealth interventions for type 2 diabetes. Literature shows how healthcare professionals should sustain type 2 diabetes patients' autonomy in care management and thus their motivation to adhere to the mHealth and eHealth intervention (Graffigna et al. 2016). However, depending on the type of self-tracking, the physician's role may be different. Deborah Lupton (2013) developed five distinctive modes of self-tracking that have emerged in recent times: private, communal, pushed, imposed and exploited (Lupton 2014). ‘Pushed self-tracking’ involves encouragement for people to monitor themselves from other agencies, while the mode of ‘communal self-tracking’ relies on people sharing their personal information with others. ‘Imposed self-tracking’ involves moving from encouragement to requiring people to collect or engage with data about themselves in situations in which they have little choice. The ‘exploited self-tracking’ mode represents the use of personal data by other actors and agencies for their own purposes, either overtly or covertly. Self-monitoring may be taken up more or less voluntarily, but in response to external encouragement or advocating rather than as a wholly self-generated and private initiative. In pushed self-tracking, those who are advocating others to engage in these practices are often interested in viewing or using participants’ personal data for their own purposes (Lupton 2016).

This mode of self-tracking is common in the healthcare sector, where providers persuade patients to keep track of certain health-related information. The practice of filling out the notebook which I describe in this thesis can be considered as a ‘pushed self-tracking’, referring to practices initiated in response to external encouragement of clinicians. However, what emerges from the empirical results of my work is that the transfer of information from the health care professional to the person with diabetes represents only the beginning of a lifelong process leading to successful self-care. The interesting thing is to analyze how this self tracking modality affects the patient’s role, fitting into a discourse of patient empowerment, producing both empowering and disciplinary effects. In the next paragraph I explore how literature about empowerment has focused on the different facets that physicians can have, and on the fine line between motivation and control in the management of a chronic illness

3.2.3 From patient’s empowerment to health surveillance

Empowerment has gained more and more prominence in healthcare: firstly, because its potential for improving cost-effectiveness of care, especially for people affected by chronic conditions (Lorig et al. 2009); secondly, as part of a move away from paternalism towards more collaborative models of healthcare delivery (McAllister et al. 2012). Within this process, the role of the patient is starting to shift from being a minimally informed advice recipient to an active participant, instigating collaborator, information sharer, peer leader and self-tracker engaged in participative medicine; a transition is underway from paternalistic health care to partnership models (Swan, 2009, p, 513). The rhetoric of "empowerment" appears first in the late 1970s and growing in popularity over-time (Calvès 2009; Morley and Floridi 2020). The concept of empowerment has been used within the field of health care in several ways, and has been emphasized in literature during the 1990s. According to Funnel and colleagues (1991), empowerment is "... the discovery and development of one's inherent capacity to be responsible for one's necessary to influence their own behavior and that of others to improve the quality of their lives". Literature reports a key role of health professionals in patient empowerment. In these studies, power does not come from the patients, it comes from health care professionals. Patients may become empowered via health education programmes (Feste, Andreson 1995), but also via their interactions with physicians (McKay et al 1990). What is missing from these conceptualizations of empowerment is recognition that the source of patients' empowerment may not be health care professionals.

Today, many definitions of patient empowerment exist, but essentially patient empowerment is about patients taking control or responsibility over their health, illness and treatment care, as well as the ability to participate in the consultation and decision-making process (Bridges et al. 2010). In the context of healthcare, the rhetoric of empowerment has been taken into account by studies that have explored the ways in which mHealth can be used to put individuals in control of their health (Lupton 2014; Rich and Miah 2014; Morley and Floridi 2020). Technology has proven to be extremely useful to patient empowerment not only as a tool to aid the empowerment process but also as a facilitator of learning about patient empowerment (Fumagalli et al. 2013). Many patient empowerment frameworks and models are designed, developed and implemented with the aid of various technologies (Calvillo et al. 2013). Another important point is the use of technology for collaboration among patients and providers (Lober & Flowers 2011). What is seen as revolutionary with the advent of mobile health is that it will allow ordinary people to take more control over their health. These developments have the potential to empower the most medicalised patients (Klawiter, 2008), or to reverse the roles between experts and lay groups (Novas and Rose, 2000, p.490). At the same time, the data that is generated is often portrayed as knowledge that will enable users to have more informed discussions with their healthcare practitioner, thus rectifying what is presented as a traditionally asymmetrical relationship. Eric Topol, for example, one of the leading advocates of digital health, views the democratization of medicine as the most significant impact of the use of mobile devices in healthcare. In his latest book, Topol (2015) describes the widespread integration of mobile health devices as medicine's Gutenberg moment, comparing the newfound control of patients over their care to the liberation of knowledge from the control of an elite class by the printing press.

The concept of patient empowerment has not gone unquestioned in critical studies of health. According to these studies, empowerment narratives have often been understood as strategies of contemporary health promotion that encourage individuals to view their health as a project to be managed in a way that aligns with medical regimes, thus extending the reach of medical power and control (Bunton and Burrows 1995). A proof of this paradigm shift is that the word 'control' is most widely used in recent self-management literature to describe disease control or patient autonomy and control (Robinson et al. 2008; Jones et al. 2013; Costello 2013). This debate has developed in a particularly interesting way in the studies in the context of self tracking for health. Mobile wireless devices that can collect patient's data anywhere and anytime and communicate it automatically to medical professionals seem to offer an unprecedented opportunity on the part of public health to monitor and discipline people's health and lifestyle behaviors. By tracking their health and interpreting their data in the light of population statistics, patients become subjects and objects of surveillance and epidemiological analysis at the same time (Samerski 2018). For Albrecht and Michael (2013), self tracking and surveillance are two sides of the same coin; but, because self-tracking has been promoted as an empowering technology that promises to make people healthier and happier, it has been more easily accepted than traditional surveillance technologies (Charitsis 2019). The sociologist of health Deborah Lupton, who has undertaken an extended critical analysis of mobile health and self-tracking technologies in the last few years, writes that the use of mHealth in health promotion extends the temporal nature of health surveillance, and allows for further refinements of the categorizing and identifying of risk factors and at-risk groups that are then deemed eligible for targeting (Lupton 2012). Health-related data may easily and frequently be collected from users' mobile devices each time they log on to the relevant app. Such devices thus offer an unprecedented opportunity to monitor and measure individuals' health-related habits. These technologies are now becoming used not only to facilitate medical supervision and monitoring of ill bodies, but into the realm of well bodies in the attempt to prevent illness and disease. Central to a critical analysis of the use of the new social media and mobile devices to promote health is a recognition of these technologies as part of 'surveillance society', a term used by some writers to denote the increasing ubiquity of surveillance technologies in everyday life, which are used to record, survey, monitor and discipline people (Lupton 2012). She writes: "The fastest growing and most controversial specific type of surveillance is that using the processing of personal data gathered from computerised devices 'for the purposes of care or control, to influence or manage persons and populations" (Lupton 2012). The digital data produced by these forms of surveillance serve to individuate users, distinguished from others and identified by a series of criteria and then behaviour analysed, to produce 'surveillance knowledge' (Lyon, 2010). Australian computer scientist Roger Clarke had proposed the term "dataveillance" to capture the idea of "surveillance by data" (Clarke 1988; Lyon 2010). Dataveillance frequently operates with the use of digital technologies and takes place at varying degrees of people's knowledge and consent. Individuals may voluntarily choose to engage in self-surveillance, for example, by using self-tracking devices and software (Albrechtslund & Lauritsen, 2013; Lyon 2010; Lupton, 2016). All of these forms of dataveillance contribute to what Lyon and Bauman (2013) refer to as 'liquid surveillance', or the dispersed and mobile watching of ourselves and each other facilitated by digital technologies that generates continuous flows of data about individuals. Once collected, these personal data tend to become part of the digital data economy, available for use by a variety of actors and agencies in ways that are often unknown to the people about whom this information relates (Kitchin & Lariault, 2014; Lupton, 2015). Self-tracking for health, in such accounts, is portrayed as a paradigmatic practice of contemporary surveillance society, as one of the many ubiquitous technologies used to monitor, measure, and record individuals' activities for purposes of disciplining and managing populations. Yet, while surveillance has traditionally been conceptualized as something externally imposed, as Lupton argues, self-tracking gives rise to even more complex forms of monitoring, blurring the boundaries between private and public surveillance.

In the next sections, I present methodology I used and empirical findings that highlight the relationship between patient's empowerment and physicians' control over patients through self-tracking, affecting participants' motivation.

3.3 Methodology

This chapter was intended to answer to the second research question:

R.Q. 2: *How do personal experiments affect the empowerment and motivation of patients with Type 2 Diabetes to maintain a correct lifestyle?*

Thirty diabetic patients, five general practitioners and three diabetologists were involved. Each patient was given a glucometer and a pedometer bracelet to keep track of their blood glucose readings and their physical activity. The aim was to answer research question observing participants while using the notebook, and to give design guidelines to the developers. Each patient was given a glucometer and a pedometer bracelet to keep track of their blood glucose readings and their physical activity. I did direct observations in general practitioners' offices observing the interaction between physicians and patients as they reflected on the data collected in the notebook. During my observations I took written notes that were anonymised in order to ensure participants' privacy and confidentiality. Alongside participant observation, I conducted 30 semi-structured interviews with patients and clinicians involved.

3.4 Empirical results

In order to answer the research question described above, thirty diabetic patients and five general practitioners and three diabetologists were interviewed. The power relationship between patients and clinicians configures itself in more or less subtle ways in all interviews with patients and often emerges during clinical encounters. As described in the next paragraphs, physician authority is developed across heterogeneous practices and contexts, and often takes the form of control over patient behavior.

3.4.1 Clinician's authority inside and outside the clinical context

The excerpts reported within this paragraph show how there are several ways through which the doctor can exert control over their patients' diabetes. This authority is exercised both inside and outside the institutional health context.

Inside their studios, general practitioners exercised authority on patient’s knowledge over patients primarily through education and instruction directing the patient to control the disease through changing their behaviour.

> We try to do all we can to explain what they have to do...it's difficult, because they are of a certain age, many of them didn't even move before...it's hard to convince them, but we do what we can… I also wrote the rules (*to conduct the experiment)* on a sheet of paper, so he (*the patient*) can remember it... (Doctor)

This doctor chronicles their commitment to explaining to patients how important it is to maintain a healthy lifestyle, and giving them recommendations in doing the personal experiment. They affect patient education both through the management of the rules for the personal experiment and through the same notebook used by the patient. As is evident from the next excerpt, the notebook is viewed by physicians as a tool through which to educate the patient:

> “In my opinion Gianni (*the patient)* has understood more in these weeks...before he never measured up… Now I think he has learned something, you can see it from the way he writes, even from what he tells...it could certainly serve to teach him to behave better…” (Sandro, doctor)

The excerpts above describe some occasions when doctors have been able to exercise their authority on patients’ knowledge within an institutional context - in these cases their medical studios - where the roles of the physician and the patient are usually well defined. The delivery of the notebook to the patients took place in all cases during a typical doctor-patient consultation, in which the doctor first checked the progress of the patient's data on the computer and asked general questions about the progress of diabetes; then he showed the operation of the notebook, explained the rules necessary for conducting the experiment, and the patients asked questions regarding these rules.

The next excerpt highlights how the physician's authority goes beyond institutional boundaries and is also exercised in other contexts:

> Gianni: “I know that I have to be careful, that I have to walk more....
> Doctor: “I always tell him...then I meet you at the bar instead…”
> Gianni: yes, it's a small town, I can't escape even my doctor, he keeps an eye on me...(*laughter*)” (Gianni, patient)

The small-town-context facilitates close acquaintances between the physician and his patients, and most importantly there are opportunities for physician-patient encounters outside the institutional setting. On such occasions, while the physician may have more insight into the patient, he has additional opportunities to exercise authority in an informal, non-institutionalized manner. However, there is a more subtle way in which physician control over the patient can break out of institutional boundaries, as we can see within the next excerpts:

> “...the other night I got home and wanted to get on the couch...I'm retired but I still have busy days, you know, the grandkids...but then I saw the notebook on the table and remembered that I needed to jot down data (...) the doctor is watching me, I know! (*laughs*) now I can't escape him anymore....” (Anna, patient)

> “...it's convenient, because I know that now they have to do it (*have a healthy behavior*), if they have to fill the notebook then I can have some more data to check...we have to see if then they do it, some I trust, but others...there are good ones and less good ones…” (Andrea, doctor)

The excerpts highlight how the notebook allows the physician to cross the boundaries of the patient's everyday home life and also exert control over his or her daily disease management practices. As is evident, patients report feeling "watched" by the physician and unable to "escape" from him. Through such metaphors, patients emphasize the sense of control that patients feel, even by filling out the notebook.

As can be seen from the excerpts above, the final reflection on the data shows us how the notebook becomes from an educational tool, an instrument through which to exercise a kind of authority over the patient. In both cases, the doctor's oversight role of patient knowledge is clear.

3.4.2 Empowerment vs self-discipline

In the previous paragraph, we saw how patients feel controlled by the physician through the practice of filling out the notebook. In this paragraph, we will see how filling out the notebook can yield ambivalent results regarding patients' self-discipline and knowledge of their own disease.

> I feel much more confident since I have this (*the notebook*)...I can check the values better...before I didn't, I didn't know them (*the data about glycemic index*)...I see now that if I take steps, the numbers (*notes about blood sugar*) are low...before I didn't realize it, I felt maybe better but didn't know, I wasn't sure...
> (Giada, patient)

> Before, I never used to measure my blood sugar...now, with this thing here (*participating in the study*), I am forced to measure myself...I thought I was doing well, because when I eat less I feel much better, I can feel it...but you see here (*he indicates high values on the notebook*), here I was afraid, because I don't understand why...then it's better not to know, at this point... (Aldo, patient)

The excerpts above show that when patients believe that better knowledge of their bodies is achieved through the notebook, they feel as if they are more in control, and this leads to greater security and reassurance. However, if the data they produce suggest that their health is suffering, or if these data conflict with their self-knowledge of illness, may be afraid and even prefer not to know.

> I was actually getting used to writing here (*in the notebook*)...see, I was also marking birthdays, here I was at my sister-in-law's birthday and had a piece of cake...it was like having a personal journal, for a while… (Anna, patient)

> When he told me (*the doctor*) that I would have to prick myself, I got a little scared...not really scared, but I've never done it...so I was a little taken aback...at first I didn't know how to do it, I had to learn...my husband helped me...I didn't really know how to prick my finger, and it hurt a little anyway… (Anna, patient)

Whereas some of the interviewees consider the notebook as a “personal diary”, on which they can also mark personal events in a free way, others describe it as something they don't like, that they are afraid of. They disliked having to prick their finger constantly to elicit the blood for the test, and feeling ashamed, anxious, helpless or frustrated by seeing the data on the notebook that were not in the normal range.

3.4.4 Motivation and control through warning and downplaying

According to physicians involved in the study, motivation to maintain a proper lifestyle is very important for a patient with type 2 diabetes. During an interview, one of the doctors told me: “*There are some patients who are more motivated than others...when the motivation is there, it's easier to get more exercise or eat better....*”. In particular, during the final reflection in clinical encounters, the data in the notebook were used as the primary indicator of successful disease control. During reflection, data regarding blood glucose are considered evidence that the experiment is going well:

> Physician: you can tell very well from these numbers...I see here that you've been taking a lot of steps all week, right?
> Patient: yes, I have been in the mountains all week....
> Physician: so you see, this is proof that if you follow the directions, then your blood sugar gets better...in fact, the week before you didn't do the number of steps we agreed on, you were less good...and you see that the values are all off…

If the data are not good, it means that the patient did not follow the instructions correctly, and is therefore considered "less good". With "less good" patients, it may happen that the strategy to motivate them is to scare them a little by explaining to them what the consequences of incorrect behaviors in diabetes management can be.

> With some patients you have to be tougher...maybe they have more difficulty in following the diet, in exercising...then you have to scare them a bit, I tell them that if they go on like this, it can end badly...it's the only thing that can motivate them, in these cases (Doctor)

Education and instruction, and in some cases scaring patients, appeared to be the key strategies adopted by clinicians to motivate patients. However, in other cases the strategy used is that of humor and downplaying:

> Patient: (*reads the notebook*) ...I didn't walk much because it was raining hard...and another day because I was putting down concrete and I couldn't just leave it there..."
> Doctor: "I told you it was forbidden to put down cement…(*addressing the interviewer*) he is renovating his house and wants to be a builder, this one" (doctor-patient encounter)

In this case, the physician knows that his patient is remodeling his home, and that he occasionally claims to participate in the work by "putting down the concrete". The intimate knowledge that the doctor has towards his patients legitimizes him to often use humor to "scold" the patient.

3.4.5 Motivation over time

In some cases, patients' words highlight what their care practices were before they began the experiment, and how they changed over the course of the experiment. Nineteen out of thirty patients say they will continue to maintain what they learned during the weeks of blood glucose monitoring, as this excerpt highlights :

> "I learned a lot... I had to know how to control myself... because since I did this experiment, I was able to learn that this is the way to do it... it helped me a lot, because I used to take things a bit "but yes, come on"...

> maybe because I’ve never kept track of my data... now that I know that I have to control myself, I want to do well... for my health above all (...) Since the end of the experiment I am realizing that I have to keep myself under control (...) Now even when I go to eat pizza I am careful, or I eat less at lunch... I always reflect on it..." (Marisa, patient, 68 years old, excerpt from interview)

In six cases, patients recall past events regarding the management of their diabetes, as reported in the next excerpt:

> One day I was feeling really bored, I didn't feel like going out...then I remembered this thing (the experiment)...then I went to look at the chart, backwards...I saw that the times I had walked it went better...I was reminded of when I went three days to Rome, last year, that I walked a lot and I always felt good...then I decided to go out and I did well… (Alda, patient)

In this case, the patient was enticed to get out and walk both by the data marked on the notebook the week before, but also by the memory of an outing last year, during which the patient felt particularly good.

Some other patients felt compelled to do the experiment. The fact that the experiment was time-limited meant that patients felt "controlled" for the duration of the experiment. But once the experiment was over, these patients felt free to return to their lives and their way of managing the disease.

> Doctor: Now that the experiment is over he feels relieved, he has one less thing to do...
>
> Patient: Now I don't have the obligation anymore, I'm going to sit on the couch…

The excerpts shown demonstrate how motivation is not solely a matter of data influencing the patient at that exact moment: the good intention to "keep oneself under control" can be protracted in time, as we have seen in the first case; or, remembering a past well-being can be a good reason to go out for a walk; again, the motivation can be strictly limited to the period of the experiment, during which the patient has felt "under control", and after which he feels he can regain his freedom.

3.5 Discussion and conclusions

In this chapter, the role of personal experiments in empowering and motivating patients has been examined in depth. As we have seen, self-tracking through the notebook affects the reconfiguration of the caring practice and the empowerment of the patients: in the words of cultural anthropologist Sherry Ortner, to speak about practice is to speak about empowerment or disempowerment or about power in the making (Ortner, 1984). At first, self-tracking seems to have an obvious and exclusive positive effect: patients are actively involved in their own care process within their own homes. However, interviews highlighted how self-tracking constitutes a specific disciplinary regime that both empowers and dis-empowers the patients. Within this ongoing process of empowering and disempowering, three key concepts that characterize doctor-patient relationships can be identified.

A first concept regards the correlation between empowerment and control. Self-tracking tends to place emphasis on the potential for the ‘empowerment’ of lay people offered by technologies and the importance of ‘taking responsibility’ for one’s health. The idea that collecting data on oneself is a primary means by which good health can be established and maintained is dominant in discourses of self-tracking (Lupton 2013). The concept of control is central to both patients' and physicians' words. However, the term control has many meanings, some are similar between physicians and patients, others are different. As we saw in the first part of this chapter, traditional models of practice tend to position the clinician as an expert and in a position of authority over the patient. This work confirms that trend, showing how clinicians attempt to control patient behaviour (aiming to lead to disease control) primarily through education and motivation. The delivery of the notebook to the patients took place in all cases during a typical doctor-patient consultation, in which the doctor first checked the progress of the patient's data on the computer and asked general questions about the progress of diabetes; then he showed the operation of the notebook, explained the rules necessary for conducting the experiment, and the patients asked questions regarding these rules. The interviews report an initial way in which physicians influence their patients' knowledge of the disease, that is provide the necessary information and clear recommendations to patients in doing the personal experiment. They affect patient education both through the management of the rules for the personal experiment and through the same notebook used by the patient. So, on the one hand the compilation of the notebook becomes part of the institutional practices of education to the disease, integrating perfectly within the doctor-patient encounter. On the other hand, informal ways in which physicians can contribute to the motivation of their patients have been highlighted. For example, meeting them and "keeping an eye on them" at the local bar. But there is another way to reach the patient in his daily life and keep him under control, and it is through the notebook, which enters the patients' homes and allows the doctor to have an "indiscreet" eye in their daily life. From this it follows that for physicians, to have control does not refer only to blood glucose control, as most of the studies about diabetes self-management report instead (Robinson et al. 2008; Costello 2013). Contrary, it concerns the entire sphere of patients' daily practices, which can be controlled and influenced thanks to the sharing of the spatial context in which care takes place, and thanks to the tool of the notebook, which allows the doctor to extend control outside the confines of his own studios. As the results shown so far indicate, patients’ empowerment is a process and not an end state, and the process of empowerment does not mean achieving unidirectional knowledge. If on the one hand, the experiment and the notebook offer the conditions for the patients to become active agents in the management of their condition, it also offers the clinicians a new opportunity for exposing the rhetoric of empowerment without actually fully enacting it in practice.

For patients instead, control has two facets: on the one hand, self-control, which means being able to regulate physical activity, diet and glycemic index. Users are ideal-type responsible citizens who possess the economic and motivational capacity to engage in self-surveillance via self-tracking instruments. As one advocate of self-tracking in preventive medicine put it, using these technologies represents a paradigm shift from ‘My health is the responsibility of my physician’ to ‘My health is my responsibility, and I have the tools to manage it’ (Swan 2012, p. 108; Lupton 2013). On the other hand, the control they feel the physician has over their behavior by filling out the notebook. Most patients surveyed report feeling "checked" by having to mark their data on the notebook. In this case, control also leads to a feeling of security: knowing that a walk can affect blood glucose data, and seeing on the notebook that these improve, makes them feel reassured. If, on the other hand, the data are not aligned with their self-knowledge, and do not meet their expectations, patients prefer not to know what is going on so as not to worry. In addition, some patients did not feel comfortable conducting the experiment, partly because of the fear of pricking their finger, which they had never done before, and partly because of the fear of seeing blood glucose data out of the appropriate range. These results confirm how some patients do experience significant health benefits from self-tracking, claiming that they feel more in control of their health and bodies. However, other users find self-tracking too onerous, find the devices inconvenient, unfashionable or uncomfortable to wear or that the apps are not compatible with their smartphones. Engaging in self-tracking led patients to become overly focused on their health and to experience feelings of failure, anxiety or self-hatred (Lupton 2013)

A second concept that emerges from the empirical data concerns what it means to be a “good patient”. The two conceptions of control which we have seen above lead to different conceptions of what it means to failure to complete the experiment. Self-tracking encourages people to think about their bodies and themselves through numbers. For physicians, the notebook is a trace of the self-management activities performed by patients. Therefore, it provides a tool to assess their adherence to therapy and evaluate the learning process. Adherence to therapy is evident in their blood glucose values, which they can then keep under control. Therefore, for clinicians seeing bad glycemic data means that the patient was not "good" at carrying out the experiment. In this way the notebook embodies the asymmetric patient-provider relationship, is an object of accountability, “ that is simultaneously a resource for participants in organising their own activities, and a regime created elsewhere, to which their activities are accountable” (Suchman, 2011, p. 28; Piras 2017). Even for some patients, marking "good data" in the notebook means that they have "behaved well" (often towards the doctor). For Lupton, the implication of the ‘self knowledge through numbers’ motto is that ‘self-knowledge’ as it is accomplished via self-tracking and the production of ‘numbers’ is a worthy goal for individuals to aspire to. The more we know about ourselves and our bodies, the more productive, wealthier, wiser, healthier, emotionally stable and so on we can be. It is assumed that the production of such hard/objective data is the best way of assessing and representing the value of one’s life and that better ‘self-knowledge’ will result (Lupton 2013). However, for patients, it's not just about the numbers:

achieving self-control over their own blood glucose, and thus over their daily disease management practices, is a matter of compromising and adapting the new lifestyle to their daily habits.

A third concept that empirical findings demonstrate is that there are some elements of reflection that do not relate to rigid, preset patterns. Consequently, motivating a patient during final reflection means bringing into play knowledge that goes beyond professional knowledge, and relates to a more intimate knowledge of the patient. Lupton (1997) suggests the importance of acknowledging the personal experiences of individuals, including the embodied and affective dimension of illness, and how their interaction with experts is part of their ceaseless construction and reconstruction of subjectivity. Health care incorporates the use of several kinds of tangible and quite prosaic consumables: drugs, vaccines, lotions, bandages, ointments and so on. The major component of health care, however, is more intangible, involving body work and affective exchanges and outcomes. Thus, for example, the physical examination involves the doctor looking at and touching the patient, using her or his knowledge to search for signs of illness to make a diagnosis. The touch of the doctor and the way she or he interacts with the patient, the doctor's tone of voice, the manner, the words chosen, are all central to the "consumption" experience, as is how the patient "feels" during and after the encounter (Lupton 1997).

The excerpts from the interviews demonstrate how doctors use strategies such as a sense of humor and fright, to stimulate the patient to maintain a proper lifestyle. The intimate knowledge of the patient, the little contest and the notebook allows the physicians to cross the boundaries of the patient's everyday home life and also exert control over his or her daily disease management practices. This confirms the importance that doctors provide us not only with medical expertise and knowledge, but with emotional comfort, concern and empathy towards our suffering and personalized care. The privileged representation of the patient as the reflexive, autonomous consumer simply fails to recognize the often unconscious, unarticulated dependence that patients may have on doctors. This representation also tends to take up the mind/body separation in its valorizing of rational thought over affective and embodied response (Lupton 1997).

In conclusion, the empirical results discussed in this chapter report the various facets that the concepts of motivation, empowerment and control can have. Health care is traditionally hierarchical and, especially in the paternalistic model, professionals have the authority. The data show how this authority can take heterogeneous forms, influencing patient knowledge in different ways. Here, the concepts of "patient empowerment" and "patient motivation" are multifaceted, and go beyond the simple numerical compilation of notebook tables. This implies that what is important in designing strategies for motivating patients to maintain a healthy lifestyle is to take into account the reconfiguration of the mutual relationships between different practices and what consequences these changes had for the identity and power position of the actors involved.

Chapter 4 – Mutual learning in care practices

4.1 Introduction

In this chapter, the empirical results that allowed me to answer the third research question are presented. In particular, it is described how personal experiments fit in the doctor-patient relationship, affecting existent educational practices and reconfiguring clinicians' roles. The first chapter of this thesis addressed the ways in which the notebook goes into disease management practices, and how it is shaped by patients' situated knowledge. In this chapter we will see how the so-called "experiential" knowledge of patients and the "scientific" knowledge of physicians intersect with each other in diabetes care.

In order to explore these topics, following an overview of how the doctor-patient relationship and care models have changed over the years, firstly I will consider the concept of mutual engagement of Leave and Wenger; secondly, I will consider the notebook as a knowledge artefact, exploring specific socio-material practices through which knowledge is iteratively produced, mobilised, tested and refined: consultation in the surgery and the daily use of the diary. Knowledge artefacts for chronic care management offer an interesting opportunity to analyse the multifaceted interplay of cooperation, tensions, contradictions and conflicts in the patient-provider relationship (Piras 2018)

4.2 Theoretical background

Chapter three reviewed the literature regarding the role that the figure of the physician can play in the process of collecting health data. In this chapter we will go deeper in exploring how the physician-patient relationship has developed over the years, influencing the processes of knowledge for chronically ill patients. Next, I will explore the role of knowledge artefacts in this process, and how they can foster knowledge exchange among the actors involved in care practices.

4.2.1 The negotiation of knowledge between clinicians and patients

The paternalistic approach to healthcare, where health professionals make all of the decisions with little or no input from the patient, has evolved over the past 20 years towards a patient-centered care model that aims to personalize care according to individual patients' needs, values, and experiences (Oates et al. 2000). Historically, studies have explored heterogeneous models of the relationship between doctor and patient (Emanuel and Emanuel, 1992). The different models have been developed over time in accordance with new approaches to conducting health care, for example, shared decision making (Charles et al. 1997) and patient-centered approaches (Mead and Bower 2000). This thesis specifically addresses the relationship between patients with diabetes and general practitioners. From the 1930s, studies show how general practitioners are increasingly focused on establishing a good relationship with their patients, and how this can lead to better patient compliance with the hope that the doctor-patient relationship itself would act as a therapy (Armstrong 1982).

Until the 1960s it was possible to observe a strongly doctor-centred model of the clinical encounter. In those years, the epistemological authority of medical knowledge and practice, paternalistically embodied in the doctor, was given as unproblematic, and 'relationships' through which the doctor knew the patient could legitimately be assumed to be longstanding (McWhinney 1985)

From the late 1960s, the doctor-centered model of the clinical encounter started to be strongly criticized. Patients began to expect to be seen as more than the passive objects of clinical knowledge, and to demand to be treated as 'whole persons', as part of a political shift which began with the critique of medicalization (Conrad and Schneider 1980) and extended to include a holistic impulse that connected ill-health with a wider pattern of social relations and contexts (May 1992). The basis of these studies is the work of the Polish historian of science Ludwig Fleck, "Genesis and development of a scientific fact" (1935), in which he develops the idea that medical knowledge is the outcome of a collective process of interaction and communication amongst distinct "thought collectives". Thought collectives comprise an esoteric centre made up of scientific specialists, and an exoteric circumference composed of both educated and uneducated lay persons (Fleck 1936: 106). In other words, for Fleck, medical facts are established by means of the exchange and circulation of ideas and practical experience between specialists, general practitioners and patients (Lowy 1988: 144-5). This is consistent with the view from, for example, actor-network theory in sociology of scientific knowledge (Latour 1987), which proposes that facts are generated by a process of mutual ordering and validation between overlapping networks of scientists and surrounding social groups (Arksey 1994). In the last few years, as the changing roles in the doctor-patient relationship suggest, patient participation in health care, including decision making, is increasingly emphasized. Patient participation has been described as the attempt to increase the patient's capacity to think critically and make autonomous, informed decisions (Anderson and Funnell 2010; Stewart et al. 2000; Carman et al. 2013). This shift occurred because within medicine itself there was a move towards enrolling the patient into the consultation in ways that reduced the growing strain on the epistemological authority of medical knowledge that seems to have become more evident as a result of wider shifts in its social production and organisation during this period (Lupton 1994).

In particular, chronically ill patients develop experiential knowledge that goes alongside the scientific knowledge of healthcare professionals. Health care decisions are based on two complementary forms of knowledge: the scientific knowledge of health professionals and the patient's own experiential knowledge. Patients' experiential knowledge and competencies, developed through their illness experience, must be recognized as a positive and complementary contribution to health care. Patients make decisions with regard to their own care based on their experiential knowledge, just as healthcare professionals apply their clinical and scientific expertise. Patients' ability to establish meaningful interactions with professionals depends on their capacity to communicate their experiential knowledge (Coulter, Ellins 2007). The lived experience of coping with a disease each day entails not only complying with medical recommendations, but also developing a more nuanced understanding of bodily sensations and their relationships with measurable parameters. Practicing self-management, patients and carers develop a lay expertise that can complement medical knowledge, but it is not reducible to it (Pols, 2013; Piras 2017).

In the 70's an increasing number of studies (Tuckett et al. 1985; Neighbour 1987) began to explore the form and content of doctor-patient encounters, in which a negotiation between the scientific and objective knowledge of the doctor, and the personal and subjective knowledge of the patient takes place. In order to explore how patients' and physicians' knowledge shapes each other within the physician-patient relationship, it will consider Leave and Wenger's (1991) concept of mutual engagement. Knowledge is not something that people possess in their heads; rather, it is something that people do together (Gergen, 1985: 270; Gherardi 2008). Lave and Wenger (1991) assumed that our actions are the product of prior negotiation and learning processes in which we link what we know with what we do not know to find meaning and form our actions. Thus, the process comes naturally in all the activities in which we engage in everyday life. Such learning is an informal, situational and ongoing process that occurs while we pursue different goals in life (Lave & Wenger, 1991; Wenger, 1998). For a practice to develop between several individuals, a mutual engagement is negotiated and learned by the participants while they pursue the same goal (Wenger, 1998). Therefore, the development of a practice requires dense and persistent mutual engagement between participants (Wenger, 1998) who consequently must include each other in what matters (p. 74), i.e., they must engage and respond to each other's actions and establish relationships based on the mutuality of interaction (Wenger, 1998, p. 137). According to Wenger (1998), everything that makes mutual engagement possible, e.g., information, instrumental aspects, the atmosphere, private talk, and even sharing of candies, is essential. By analysing empirical data based on the concept of mutual engagement, in the empirical paragraph of this chapter I will identify in the interactions between patients and clinicians the emergence of the type of mutuality Wenger (1998) describes as fundamental in practices. In the next paragraph I will describe the role of the notebook in such a mutuality, exploring how it is specifically created to support the knowledge-oriented processes.

4.2.2 The role of artefacts to support knowledge-related processes

Diabetic patients are encouraged to track continually, in a systematic way, blood glucose levels, dietary intake, activity level, and insulin dose if applicable for use in guiding appropriate care decisions. In order to keep track of this large amount of data, the patient with diabetes typically uses a variety of artifacts such as diaries, glucose meters, self tracking apps etc, which support knowledge-related processes. A peculiar kind of artifact that relates to the management of diabetes are "logbooks", which have a longstanding tradition in diabetes management, and their history is intertwined with glucometers, patient education and self-management practices. The availability of affordable and easy-to-use glucometers, in the market since the early 1980s, has allowed providers to delegate the measurement of blood sugar levels to patients and carers, establishing a regime of clinical self-tracking (Piras and Miele, 2017); this is a form of pushed self-tracking (Lupton, 2014) in which patients are required to interpret data and report to providers. The early glucometer models did not have a memory to store data, and the patients were required to keep a logbook to be shown at consultations. As glucometers evolved and were endowed with data-storage capabilities, logbooks' primary function became promoting awareness and stimulating the reflective activities needed to better understand the evolution of the disease. The use of logbooks is generally associated with the perceived need to find patterns, make sense of inexplicable glucose level values or re-establish the regime after a period of scarce control (Piras 2018).

With regard to logbooks for T2D patients, there are a lot of differences in their amount of consumption of medications, their blood glucose response to medications, and occurrence of side effects during the treatment process Therefore, each diabetic patient has his/her own characteristics and the treatment process should be personalized for him/her (Mannino and Sesti 2012). The logbook of type 2 diabetic patients should include at least blood glucose level, physical activity, daily meal and consumed medications (Glasgow et al. 2009). Literature reports that using the logbook helps patients share their own treatment by recording their conditions and effectively managing their disease, and this results in better management of T2D and boosts the quality of caring provided for the patients (Karter et al. 2001; Schwedes et al. 2002; Martin et al. 2006). By observing their blood glucose patterns, the patients can monitor blood glucose fluctuations during physical activity, and of food or special medications. Meanwhile, by observing the logbook, physicians can monitor their patients' full conditions and make proper decisions on their treatment. In addition, determining the dose of medication using the logbook is achieved with a higher level of accuracy by the physicians and thus response to treatment will be more effective (Moghaddasi 2020).

Traditionally, the recording of such patient experience data has occurred in paper-based diaries. For this reason, it is still in the design of diabetes that the logbook is implemented using a 'notebook' metaphor because patients are already used to this kind of object to manage their blood glucose measurements (Bellazzi et al. 2002; Kerkenbush and Lasome 2003; Mathiesen et al 2017). The "notebook" is a typical knowledge artifact in the field of health: notebooks are artefacts that support the knowledge-related processes (Cabitza et al., 2014) of doctors, patients and caregivers. The notebook accompanies the patients for relevant parts of their experience with the disease and are used in different contexts, and can be defined as a "knowledge artefact" (Piras 2018), an expression whose meaning depends on what connotation is attributed to the word "knowledge". As noted by Cabitza and Locoro (2014) we can identify two poles of a continuum, a realistic and a processual perspective, where the former considers knowledge as the representation of a piece of reality, while the latter focuses on knowing that emerges in situated interactions (Turnbull, 2003). Knowledge artefacts are not reification or containers of knowledge; rather, they are resources to be mobilised for specific activities, such as interpreting a glycaemic pattern. A practice-based approach emphasises that artefacts are to be studied not by considering them per se, but rather by assessing them as technologies-in-practice, attending to the routine use practitioners make of them in conjunction with any other resource available in everyday situated activity (Orlikowski, 2000). While ontological distinctions cannot be made between all artefacts involved in the unfolding of the practice, there are good reasons to adopt knowledge artefacts as a privileged vantage point to analyse knowing-in-practice. Considered by practitioners as the repositories of knowledge, they often occupy a pivotal position in mediating social interactions. Knowledge artefacts can be considered traces or vestiges of the practices to be explored when the actual practices cannot be directly observed. Moreover, they can be used as props to stimulate the reflexive thinking of practitioners regarding practicing and knowing, thereby making their way of reasoning accessible to researchers (Piras 2018).

4.3 Methodology

This chapter was intended to answer to the third research question:

R.Q. 3: *How do personal experiments fit in the doctor-patient relationship, affecting existent educational practices and reconfiguring knowledge processes that involve patients with Type 2 Diabetes and their clinicians?*

Thirty diabetic patients, five general practitioners and three diabetologists were involved. Each patient was given a glucometer and a pedometer bracelet to keep track of their blood glucose readings and their physical activity. The aim was to answer research question observing participants while using the notebook, and to give design guidelines to the developers. Each patient was given a glucometer and a pedometer bracelet to keep track of their blood glucose readings and their physical activity. I did direct observations in general practitioners' offices observing the interaction between physicians and patients as they reflected on the data collected in the notebook. During my observations I took written notes that were anonymised in order to ensure participants’ privacy and confidentiality. Alongside participant observation, I conducted 30 semi-structured interviews with patients and clinicians involved.

4.4 Empirical results

In the next paragraphs I will describe how the notebook becomes an object through which the doctor's knowledge and the patient's knowledge are exchanged, becoming mutual knowledge. After describing the ways in which patients gain a more objective and scientific understanding of the disease, and how in turn physicians gain insight into their patients' diabetes management practices, I will show how the notebook fosters mutual engagement and knowledge exchange between physician and patient.

4.4.1 Patients acquiring medical knowledge…

Having diabetes is a learning process in which patients are continually engaged in learning practices. This process may involve, first, adapting one's diabetes management practices to what is required by the physician. Usually, after the onset of diabetes, the doctor recommends that patients get more physical activity and eat a proper diet. Some doctors hand out a chart with dietary guidelines. In the most severe cases-which, however, were not included in the group of patients involved in this study-a once-a-day blood glucose measurement is also prescribed. The "prescription" of the personal experiment was integrated during a typical follow-up visit, in which the doctor keeps an eye on the patient's weight and asks him or her to tell how the diet and physical activity are going.

Second, learning how to manage diabetes may mean acquiring medical know-how about one's disease, familiarizing oneself with the scientific and objective knowledge.

Most of the patients involved in the experiment have had diabetes for many years. Therefore, they have gained independence from their doctor for a long time, and are used to managing themselves, as evidenced by the words of patients.

> I was not used to see this data...in the end I have been regulating my diet for years, I have been paying attention to it...for me it was a bit too much, it is not necessary to know how my blood sugar is doing, I am not used to it...in the end it is fine as I have always done (Andrea, patient)
>
> But yes, I did it because I was asked...if he (the doctor) asks me to do it I will definitely do it, we've known each other for years (laughter)...but I'm not sure I'll do it again...I'm a very active person already, I don't need to know how much I'm moving… (Anna, patient)
>
> I found out I have diabetes many years ago now...I know perfectly well what I have to do, what I should or should not eat...I think I have learned everything by now (Gianni, patient)

These excerpts show how some patients feel that they already know their diabetes very well and feel to know how to best manage it. In these cases, the personal experiment is felt to be one more thing, not necessary for disease management. Data collected do not appear to increase diabetes self-knowledge especially for people later in life who feel they "have nothing left to learn”. As for the patient of the second excerpt, participating in the experiment was a sort of "favor" that she did to her doctor because she has known him for many years.

However, the interviews highlight that, in some cases, participating in the experiment has led to the acquisition of a new form of knowledge and management of their diabetes:

> I had never been asked to measure my blood sugar...I thought it wasn't needed...instead I participated in this (to the experiment) and I did it… It was interesting to understand the numbers, it was helpful (...) I saw that when I go out to eat, most of the time it goes up… before I didn't know, I wasn't paying

> attention...I realized that if it (glycemic index) goes up that much, it means something is wrong… (Fabio, patient)

Before being involved in the personal experiment, many of the patients had never had their blood glucose measured. Now they had the opportunity to observe "scientific" data that they would never have known otherwise. Participating in the experiment and filling out the notebook meant that they gained a new form of knowledge, and that they understood the meaning of the data by connecting it to their daily actions.

> Now I have to be careful...I mark every day, I watch how the numbers go up and how they go down...you have to be very precise, it's an experiment… (Antonio, patient)

In this case, the patient took the experiment very seriously, behaving like a professional and becoming a sort of scientist, being accurate when measuring and efficiently writing down the numbers on the notebook. In other cases, some patients implement strategies to gain scientific knowledge of their disease, as the next excerpt highlights:

> Ever since I was told (*that she has diabetes*), I've been researching...I've been looking on the internet, because I like to know things (...) I don't want to be one of those people who get treatment and don't even know why.... (Giulia, patient)

In some instances, this kind of scientific knowledge can be obtained directly from the doctor during the reflection on data. During clinical encounters, patients have a lot of questions to ask the doctor: sometimes they are questions aimed at learning more about their diabetes, sometimes they are questions about the personal experiment.

> Every time I come here I ask him (*the doctor)* how is it going, what does this mean, what does that mean...I prefer that he tells me things, that he doesn't hide them from me… (Aldo, patient)

> I'm glad because I understood something more...I put my mind to it and I understood what all those numbers mean...with the chart it was easy, now I understand better when the doctor speaks to me...maybe without this chart (*the calendar of the personal experiment*) I would have never put myself to try to understand... (Sandra, patient)

In summary, the excerpts above revealed how some patients feel they already have enough knowledge to better manage their diabetes. In other cases, patients are constantly learning about their illness - either independently through their own means, or by involving their physician - acquiring more scientific and objective knowledge that are generally considered to be the prerogative of health professionals. The notebook is a tool through which patients have the impression of acquiring a more specific knowledge of their disease and of being able to better interpret the words of their doctors.

4.4.2 ...and clinicians acquiring patients' knowledge

> Interviewer: "Anything that has particularly changed since the onset of diabetes?"
> Patient: "No... I was always caught up in other thoughts...the doctor knows them very well...."

In the previous chapter we have seen how patients gain a type of "scientific" knowledge that is in addition to their practical knowledge of the disease. In this section we will see, conversely, the ways in which physicians were able to supplement their knowledge of their patients' disease. Most physicians involved in the study have a fairly intimate contextual knowledge of their patients, as can be deduced from the excerpt that opens this paragraph. This is because the research setting consists of small towns where most of the inhabitants know each other. An example of the close relationship between physicians and their patients is this excerpt from an interview with a doctor:

> "If there is a good relationship between me and the patient, I try to get them to tell me what their lifestyle is (...) it is very difficult to change their habits (...) if I know

> their lifestyle, as in the last case we saw, this person is particularly sensitive, she realized that she was really sick and she got in line...but it's not always like that...I am thinking of an overweight, hypertensive, diabetic person, whose wife is obese...how do you can change the lifestyle of those two people whose only purpose in life is nutrition? (...) There are some people with whom there is a great feeling...also for family reasons, there is a good relationship there (...) I am a general practitioner, and here in the little villages you know the lifestyle of people not only because of what they tell you, but because you see them ... you participate in community life, you catch them at the pub ..." (Marco, doctor)

The excerpt testifies to the influence that in-depth patient knowledge can have in treating lifestyle diseases. In this case, the context in which the physician-patient relationship develops is critical. It is a context in which the knowledge of the patient and his lifestyle is facilitated by the close ties of friendship and family and by the common places in which relationships can be strengthened. In the following excerpt, looking at the data in the notebook, the physician notices that data is missing, and feels "obliged" to justify the patient to the interviewer:

> Doctor: I see here that you didn't write....
> Patient: ah yes, here I didn't make it in time, I was away with the volunteers....
> Doctor: ...because he is a volunteer of the White Star, so last wednesday he was on duty (explains to the interviewer)
> (...)
> Doctor: so I see it went well with the food....
> Patient: It's all right, my wife has also gone on a diet...
> Doctor: I know...I'm moving in with you too, maybe I'll lose a few pounds…

The reflection between physician and patient on the data collected testifies to an intimate knowledge of the physician towards the patient. The physician knows the reasons why the patient's experiment may have suffered setbacks. The physician has such a familiarity with the patient that he allows himself to joke and suggest that the patient and his wife move in. In the next section we will see how the notebook and the reflection on the experiment allow a mutual exchange of knowledge "in real time" between patients and doctors.

4.4.3 Patients and clinicians assess mutual knowledge

In the previous sections, I have described the ways in which different types of knowledge, the more scientific and objective knowledge of physicians, and the more subjective and situated knowledge of patients, are often the subject of interchange between those involved in the interaction. Below I will present excerpts reporting the final reflections on the data collected from patients that occur during the encounter with their physician.

> Doctor: "Let's see how the data went... (*opens the booklet and looks at the data*)... did it seems to help?"
> Patient: "It helped because I felt controlled ..."
> Doctor: "But in your opinion was it more useful for diet or exercise?
> Patient: "...for both...see here (*indicates data)* I saw that I had eaten pizza..."
> Doctor: "...yes, you can see that here the blood sugar has risen..."
> Patient: "But you see here (*indicates the last line*) we went to the mountains and it went better..."
> Doctor: "yes, it (*glycemic index*) came down here... and you can also see that you took many steps... it's important, but the diet is important too, some foods are heavy..."
> Patient: "Oh yes, I saw... “
> (Excerpt from field notes, final reflection)

This excerpt highlights how mutual knowledge between patient and physician is built during the conversational exchange that occurs while the notebook was consulted. The doctor tends to refer to the numerical data and bring the patient's attention back to those, while the patient explains events in his or her daily life and how they might have affected the data.

The next excerpts highlight how, through reflection on the notebook, the clinician not only focuses on the objective data of blood glucose and steps, but can gain a deeper understanding of the patient and their feelings and experiences:

> Doctor: ...here I see you've been walking a lot...and your blood sugar is down....
> Patient: yes, that was a good week...as you can see, here it was bad...
> Doctor: strange, here you walked...
> Patient: yes, but I have not been well...it is not a good period, sometimes I am not well...
> Doctor: so that must be why...or maybe it was the pizza? I see you marked pizza here....
> Patient: no, pizza doesn't do anything to me usually…
> (Excerpt from a doctor-patient reflection)

In this case, the physician is almost surprised to see certain data on the notebook: even though the patient has walked, the data is not good. At this point, it is the patient who has to explain that she has not been very well during that time, and this may have affected the data. The patient also knows that usually eating pizza does not affect his blood sugar trend.

The next excerpt describes an episode in which the patient manages to avoid starting a drug therapy thanks to his lifestyle: even in the probability that the doctor already had this certainty, it was important for the patient to feel that he had contributed with his actions to his treatment plan:

> Physician: you can tell from the data that your blood sugar is doing better...see here? (points to the data on the notebook) How did it go down? And you've been walking a lot....
> Patient: yes, I have been working on it...I didn't think I would....
> Physician: we were supposed to start therapy...but at this point we can try to wait a little while....
> Patient: really? Well, I'm surprised...
> Physician: it's all thanks to you....

> Patient: glad it worked out....
> (excerpt from a doctor-patient reflection)

By reflecting on the data collected, the physician knows that the patient may not change her treatment; the patient is amazed and proud that she has helped change her health in some way, which she did not think she was capable of doing.

As we have seen so far, the notebook provides material support for learning and knowing. The use of knowledge artefacts not only allows providers to collect some knowledge about blood glucose data, but also facilitates their gathering of knowledge about the patients. The notebook is therefore placed in a context in which it can go to strengthen the in-depth knowledge that doctors have of the everyday life of patients, and patients can reflect on their blood glucose trends with the guidance of their doctor. During the reflection on the notebook, an interchange occurs between these two types of knowledge; where the patient has doubts regarding scientific knowledge, these can be ironed out by the physician; conversely, the patient's situated and contextual knowledge contributes to forming physicians’ knowledge of their patients.

4.5 Discussion and Conclusions

As we have seen in the first paragraphs of this chapter, the establishment of a regime of clinical self-tracking has changed the hierarchal patient-provider relationship, transforming it into a more symmetrical collaboration (Piras and Miele, 2017). Cooperation among these actors and over time is made possible with the use of several technologies, logbooks among them, which have all become constitutive parts of a “system of fragmented knowledge” (Bruni et al., 2007). The knowing-in-practice requires tinkering with information contained in the logbook, its symbols the discursive representation of home practices and bodily sensation and the measurements performed both at home and in the surgery (Piras 2017).

In a study on health literacy and patients with chronic illness, Edwards and colleagues (2012) find that “patients with a long-term condition can develop health literacy skills over time and put these skills into practice in becoming more active in healthcare consultations”. As patients' words highlight, they dedicate much effort to know about their disease and to become accustomed to self-managing their condition. This self-educational aspect includes asking your doctor for information, or finding out for yourself through a variety of means. This form of sharing knowledge specifically involves medical information, such as how much physical activity is necessary, what can be the side effects of diabetes, what is best to eat, etc.

The excerpts reported testify how having diabetes is a learning process in which patients are continually engaged in learning practices. This process may involve, first, adapting one's diabetes management practices to what is required by the physician. Second, it may mean acquiring medical know-how about one's disease, familiarizing oneself with the scientific and objective knowledge. Most of the patients involved in the experiment have had diabetes for many years. They have therefore gained independence from their doctor. Before being involved in the personal experiment, many of the patients had never had their blood glucose measured. Participating in the experiment and filling out the notebook meant that they gained a new form of knowledge. In this case, the patient took the experiment very seriously, behaving like a professional and becoming a sort of laboratory technician, being accurate when measuring and properly writing down the numbers. In other cases, some patients implement strategies to gain scientific knowledge, while others feel they already have enough knowledge to better manage their diabetes.

In summary, patients are constantly learning about their illness - either independently through their own means, or by involving their physician - acquiring more scientific and objective knowledge that are generally considered to be the prerogative of health professionals. The notebook is a tool through which patients have the impression of acquiring a more specific knowledge of their disease and of being able to better interpret the words of clinicians.

The empirical results reported also highlight the ways in which patients develop a more "scientific" knowledge about their disease; it is also important for physicians to develop an intimate knowledge of patients, which goes beyond their objective knowledge about the clinical data of the disease. In this respect, Karen Fairhurst and Carl May (2001) distinguished “knowing the patient” from “knowing about the patient”. The former refers to the formulation and validation of hypotheses through the analysis of the available clinical data, while the latter is an inductive process of becoming familiar with the patients with a view to understanding their behaviour, habits, preferences and way of thinking. Empirical interview data describe the process of "knowing about the patient" approach, a patient-centered care which McWhinney

(1989) describes as one where “the physician tries to enter the patient's world, to see the illness through the patient's eyes”. From the interviewee's words, emerge the importance of the general practitioner's tacit and experiential knowledge: the long time relationship with the patient and his/her family are part of the knowledge of vital importance in the care relationship. In the case of lifestyle diseases, knowing a patient's lifestyle means knowing his family history, his everyday life and, perhaps, meeting him in the village and having a chat. The territorial dimension of the care experience emerges here, the figure of the general practitioner strictly inserted in a local context that allows the development of an articulated network of knowledge and relationships. Most physicians involved in the study have a fairly intimate contextual knowledge of their patients, as can be deduced from the excerpt that opens this paragraph. This is because the research setting consists of small towns where most of the inhabitants know each other. The reflection between physician and patient on the data collected testifies to an intimate knowledge of the physician towards the patient. The physician knows the reasons why the patient's experiment may have suffered setbacks. The physician has such a familiarity with the patient that he allows himself to joke and suggest that the patient and his wife move in. When observing the data collected from the patient, physicians do not focus solely on the numbers regarding blood glucose trends, but rather supplement this data with the contextual and in-depth knowledge they have of their patients and their daily diabetes management practices. The interaction mediated by knowledge artefacts allows clinicians to evaluate patients’ understanding of the formal knowledge (e.g. rules and protocols) and its skillful adaptation to other sources of (tacit) knowledge, such as bodily sensations and experience, which are relevant for the self-management of the disease (Greenhalgh et al., 2011; Piras 2017).

So far we have seen how a clinical knowledge of patients and a more contextual and subjective knowledge of physicians have developed over time, in a process involving heterogeneous practices, objects and actors. What is interesting, however, is to observe the role of reflection on the data during the doctor-patient encounter at the end of the experiment. Reflecting on the notebook promotes a form of knowledge sharing among the actors involved. On this occasion, the exchange of mutual knowledge between doctor and patient takes place in real time, and this exchange is supported by the knowledge artifact that is the notebook. The reflection on the data allowed to highlight the effect of lifestyle on blood glucose trends: these are data that the patient can observe autonomously, but that acquire a complete sense within the doctor-patient interaction, and vice-versa. The knowledge artefact becomes the point of convergence of the embodied knowledge of symptoms of patients and doctors with the reflective understanding based on numbers and other hints. ‘Non-numerical’ information often tends to be disregarded or overlooked by doctors who want their patient to just keep track of numbers. Instead, during the reflection, actors involved develop a shared understanding of diabetes, and they become able to translate bodily feelings into numbers and vice versa (Piras 2017). Reflection on the notebook requires dense and persistent mutual engagement between participants (Wenger, 1998) who consequently must include each other in what matters (p. 74), i.e., they must engage and respond to each other’s actions and establish relationships based on the mutuality of interaction (Wenger, 1998, p. 137). In conclusion, the notebook permits the participants of the experiment to record their knowledge and their personal perspective on their experience; reflecting on these data permits patients and doctors to share their knowledge and experience each other.

Chapter 5 – Conclusions and implications for design

This concluding chapter presents the ways in which the analysis of the practices of use of a paper prototype - the notebook - can provide useful elements for designers to design a technology that takes into account the knowledge practices of all actors involved in the process of care, facilitating the articulation of users' knowledge and the sharing of expertise amongst users and between users and researchers.
At the end of this chapter I will illustrate the limitations of the study and the future directions of the research work presented.

5.1 Introduction

The research work presented in this manuscript was motivated by the interest to investigate how a particular tool for self-tracking, the "personal experiment", fits in the process of knowledge of the patient with Type 2 Diabetes, exploring how the practice of learning to manage your own diabetes data is a complex activity that involves heterogeneous objects, actors and contexts.
The three research questions that made it possible to achieve these results were (1) How do the knowing processes triggered by personal experiments involve patients' with Type 2 Diabetes situated practices through their bodies, objects, technologies, contexts and relations? (2) How do personal experiments affect the empowerment and motivation of patients with Type 2 Diabetes to maintain a correct lifestyle? (3) How do personal experiments fit in the doctor-patient relationship, affecting existent educational practices and reconfiguring knowledge processes that involve patients with Type 2 Diabetes and their clinicians?
By adopting a knowing-in-practice perspective and a subsequent qualitative research methodologies such as observation, semi-structured interviews, focus groups and co-design workshops, this research was based on two assumptions: i) self-knowledge of diabetes is a situated and emergent activity. Thus, empirical results addressed the gap of studies on health literacy, which limit themselves to measuring what the patient learns as a result of the educational actions carried out by health professionals. ii) diabetes' self-knowledge is a process that involves the practical knowledge and reconfigures power relationships between all actors involved. Thus, the thesis integrated studies on patient motivation and empowerment which conceive the doctor-patient reflections on patient's data as a well-defined moment that follows

a structured script. Each of these contributions has been discussed in the conclusions of previous chapters through the answers to the research questions.

The ultimate goal of the thesis is to provide guidance to designers to develop digital personal experiments that are less standardized and more practice-based. To achieve this goal, we can consider the qualitative methodology used in this thesis - based on observation and involvement of participants - as a co-design approach. Co-design is based on the involvement of potential users in the design process with the purpose of helping, on the one hand, designers to gain insights from participants' knowledge and, on the other hand, participants reflect on their current practices, thus fostering empowerment towards a possible change and making the design process more democratic (Vines et al., 2013). In the next paragraphs I will describe how participant knowledge can contribute to the design of a more advanced digital prototype of the TreC_Diabetes app.

5.2 Implications for design

Co-design research approaches involve developing an idea and creating a way of executing it, involving iterative processes of problem-solving and improvements (Bergman et al. 2007). Most involve participants engaging with design artefacts that are used to challenge standard ways of thinking and provoke new ideas. These artefacts may include making maps, scenarios, flow diagrams, stories, diaries, prototypes, videos, drawings, engaging in card sorting tasks, developing personas (user archetypes) and many other methods (Jarke and Gerhard 2018). Social researchers interested in mundane practices can use participatory design research methods to identify how people incorporate objects or services into their everyday routines (Kjærsgaard et al. 2016). In the context of this thesis, the notebook was used as a design artefact with a critical perspective, identifying users' needs and practices and attempting to imagine alternative possibilities and futures rather than generating solutions (Kimbell 2012; Jarke and Gerhard 2018).

Clinicians and patients were invited during the focus groups and the co-design workshops to explore the possible solutions that a "personal experiment" approach could provide to patients' and clinicians' needs. The result was the design and construction of the notebook. The evaluation of this paper prototype was conducted 'in the wild' (Rogers, 2011), during the observation of the clinical encounters and through the interviews with participants. This allowed for consideration of users' knowledge practices and to foster participatory sense-making and appropriation by potential users (Kuutti and Bannon, 2014).

During the evaluation it was observed how the notebook and the knowledge processes have evolved together over the course of the study. The notebook can facilitate the sharing of users' tacit knowledge (i) highlighting individual participants' perspectives, (ii) re-configuring the relationships of power between actors involved and (iii) by enabling participants to take each other's perspective and sharing mutual knowledge. In the next sections, each of these contributions will be explained in detail.

5.2.1 Individual users' perspective

The results of this work confirm those studies that report the importance of tacit knowledge in the clinical domain. Researchers have shown that clinical practitioners draw on tacit knowledge to address health problems (Smith et al. 2003; Yoshioka-Maeda et al 2006), or to complement technical expertise during the delivery of healthcare (Smith et al. 2003; Kothari et al. 2012). Regarding tacit knowledge and design, in their article about contemporary participatory design challenges, Bjögvinsson et al. (2012) argue that a type of values that strategically guided Participatory Design might be the importance of making participants' tacit knowledge come into play in the design process - "not just their formal and explicit competencies, but those practical and diverse skills that are fundamental to the making of things as objects or artifacts" (Bjögvinsson et al. 2012). Artefacts play a binding role in how people create shared knowledge together, in action (Suchman 2007). As every person has different bodies, experiences and skills, interpretations greatly vary amongst different people. Therefore, a rich respectful exchange of perspectives is necessary to reach participatory sensemaking; people influence each other's individual sensemaking and generate meaning in social interaction (Jaasma et al 2017; Jaegher H, Di Paolo 2007).

Taking into account patients' tacit knowledge and sensemaking, allows us to provide some useful suggestions for the design of the new digital prototype.

First, we have seen that in doing their personal experiments, patients often need to act as experimenters with their own body and therapy, and in doing so, they develop a capacity of diagnosis and various forms of situated knowledge. The practice of compiling the notebook does not strictly concern food, physical activity or glycemic index. Sometimes the results of the experiment might differ from what the doctor had expected: in everyday diabetes care, numbers are important but there are many other factors that determine the success of the experiment. This is also evidenced by the fact that all participants used the third column of the notebook to mark information beyond the numerical data regarding blood glucose and amount of physical activity. Here, a new digital prototype could take into account patients' tacit knowledge, supporting them in recording observations regarding their diabetes in a less standardized and more free-form manner. For example, they may have the ability to take notes about elements such as stress, fears, contingencies of time, and even economical issues.

Second, a patient's self-knowledge complements medical knowledge. Elements that are traditionally not taken into account by medical practices, such as individual feelings, uniqueness of circumstances, and unexpected events, are instead fundamental to increase knowledge of a disease and to improving the development of systems for self-tracking. It becomes therefore fundamental to consider that patients' self-knowledge does not see the medical knowledge as separated from the non-medical: self-knowledge is instead hybrid. Here, a new digital prototype could develop innovative ways to enable the integration of medical knowledge with patient practical knowledge.

Third, during the development of patients' awareness about their diabetes, the patient encounters a series of contingencies that affect the daily management of the disease, shaping new trajectories on which self-knowledge develops. There is always something unexpected to deal with: an impromptu vacation, forgetting your notebook at home. It is important to intensify efforts in the deployment of digital solutions for the accurate assessment of patients' psychological condition. Through personal experiments, patients learn to correlate their feelings with high and low glucose data on the notebook, making sense of their illness. Here, a new tool could mark and deal with unexpected events, also by providing tools to support and guide patients to make sense of their fears and uncertainties about managing their diabetes. New tools can help individuals to not only review relevant records from the past, but also to identify possible patterns and correlations (Mamykina 2015).

In conclusion, knowledge is not something static or a stable disposition, but something that is continuously produced and reproduced in everyday practice (Orlikowski 2006). The tacit knowing of users is of particular interest in participatory design processes and the articulation of this knowledge could be facilitated through digital technology. Designing self-tracking technology for diabetes management therefore means paying attention to tacit knowledge and experiential learning of patients.

5.2.2 Reconfiguring power relationships by design

The empirical results of the third chapter of this work confirm what Lucy Suchman stated in an article about practice-based design of Information Systems (2002): there is an intimate relationship between the materialities of human activity - settings, artifacts, and technologies - and the politics of authoritative knowledge (Suchman & Jordan, 1988). Technological innovation in healthcare contexts can lead to the perpetuation, but also modification, of physician authoritative knowledge.

This research highlights how, at first, self-tracking seems to have an obvious and exclusive positive effect: patients are actively involved in their own care process within their own homes. However, interviews show how self-tracking constitutes a specific disciplinary regime that both empowers and dis-empowers the patients. Within this ongoing process of empowering and disempowering, three key concepts that characterize doctor-patient relationships and that could influence the design process can be identified.

First, *clinicians are in a position of authority over the patient*. This work shows how clinicians attempt to control patient behaviour (aiming to lead to disease control) primarily through education and motivation. They explained the rules necessary for conducting the experiment, and the patients feel compelled to follow the rules. The interviews reported an initial way in which physicians influence their patients' knowledge of the disease, that is provide the necessary information and clear recommendations to patients in doing the personal experiment. They affect patient education both through the management of the rules for the personal experiment and through the same notebook used by the patient. Clinicians' control concerns the entire sphere of patients' daily practices, which can be controlled and influenced thanks to the sharing of the spatial context in which care takes place, and thanks to the tool of the notebook, which allows the doctor to extend control outside the confines of his own studios. Here, a new tool could have less standardized indications for patients and allow the user more freedom to set their own rules. Doing so could reduce the link between the coercive function of the tool and the user's motivation to follow a particular lifestyle.

Second: *patients feel the physician has control over their behavior*. Most patients surveyed report feeling "checked" by having to mark their data on the notebook. In this case, control also leads to a feeling of security: knowing that a walk can affect blood glucose data, and seeing on the notebook that these improve, makes them feel reassured. If, on the other hand, the data are not aligned with their self-knowledge, and do not meet their expectations, patients prefer not to know what is going on so as not to worry. In addition, some patients did not feel comfortable conducting the experiment, partly because of the fear of pricking their finger, which they had never done before, and partly because of the fear of seeing blood glucose data out of the appropriate range. Here, a new tool could educate the patient on how to prick their finger in the correct manner and reassure them if their blood glucose data does not match their expectations. Third: *the intimate knowledge physicians have of their patients plays a key role in motivation*. The intimate knowledge of the patient, the little contest and the use of the notebook allows the physicians to cross the boundaries of the patient's everyday home life and also exert motivation over his or her daily disease management practices. This confirms the importance that doctors provide us not only with medical expertise and knowledge, but with emotional comfort, concern and empathy towards our suffering and personalized care. Here, a new digital prototype could take into account the reconfiguration of the mutual relationships between different practices and what consequences these changes had for the identity and power position of the actors involved. In conclusion, the adoption and implementation of co-design in public services requires critical approaches to both organisational processes and to design practice. When applied in the institutional healthcare setting, participatory design approaches acquire a distinct political dimension by seeking to re-configure the relationships of power between citizens and public services (Donetto et al. 2015)

5.2.3 Learning from mutual learning: design and users' mutual engagement

Mutual learning processes have a long research tradition in Participatory Design projects (Bødker 1988; Bratteteig 1997; Kensing and Greenbaum 2013). Typically, this refers to mutual learning between users and designers. A process of mutual learning for both designers and users can enable participants to envisage future technologies and the practices in which they can be embedded (Greenbaum and Kyng, 1991; Simonsen and Robertson 2013; Robertson et al. 2014).

In the design of healthcare services, patients and clinicians are called to share their form of expertise and participate in the design process from the idea generation stage (Sanders & Stappers, 2008; Donetto et al. 2015). In design science this is part of a major shift towards a new role for designers where “the practice of designing is not exclusive to professional designers” anymore (Carr et al., 2009; Donetto et al.2015).

Here I would like to invite consideration of a further facet of the concept, which I will call "learning from mutual learning"; that is, stressing the importance of the mutual learning aspect between physicians and patients in the design of technologies for health care. In doing so, I will report three concepts regarding mutual learning that emerged from the analysis of empirical data and I will describe how they may influence the design of a new prototype.

First, *patients are constantly learning about their illness*. They acquire more scientific and objective knowledge that are generally considered to be the prerogative of health professionals. The notebook is a tool through which patients have the impression of acquiring a more specific knowledge of their disease and of being able to better interpret the words of clinicians.

Second, *doctors integrate their scientific knowledge with their contextual knowledge*. When observing the data collected from the patient, physicians do not focus solely on the numbers regarding blood glucose trends, but rather supplement this data with the contextual and in-depth knowledge they have of their patients and their daily diabetes management practices.

Finally, *reflection on health data implies an exchange of knowledge between doctor and patient*. As we have seen, reflecting on the notebook promotes a form of knowledge sharing among the actors involved. The knowledge artefact becomes the point of convergence of the embodied knowledge of symptoms of patients and doctors with the reflective understanding based on numbers and other hints. Given these premises, learning from mutual learning is made possible by the use of the notebook, that allows participants to perform and share their knowledge and makes that knowledge knowable to researchers and designers. One way to think about participatory design is to understand design artifacts, such as mock-ups or prototypes, as “boundary objects” binding different stakeholders together. These objects are viewed differently, for example by different professions, and allow them to communicate (Bjögvinsson et al. 2012; Jarke and Gerhard 2018). Here, designing a new digital prototype could mean exploring the ways in which boundary objects enable collaboration between different actor groups, and whether and how knowledge may be shared across different groups of experts or communities of practice (Jarke and Gerhard 2018). A notebook as a boundary object could enable the articulation of users' tacit knowing and focus on collaboration and knowledge sharing between patients and clinicians, facilitating the design of a technology that enables heterogeneous knowledge sharing among users.

5.3 Discussion and Conclusions

In this thesis I have described some forms of tacit knowledge that become fundamental to self-care practices, and that can transform the way we view chronic disease, and in particular type 2 diabetes, and the technologies for its management. As we have seen, knowledge is not something static, but something that is continuously produced and reproduced in everyday practice. Orlikowski (2006) argues that "everyday practices and the knowledge generated as a result is deeply bound up in the material forms, artifacts, spaces, and infrastructures through which humans act" (ibid). Therefore, when a knowledge artifact is placed in the patients' home environment, a multitude of different appropriations of technology in which patient empowerment takes heterogeneous forms emerges. Embedded in the everyday practices of patients, or inserted within the encounter between doctor and patient, the notebook has allowed, on the one hand, the articulation of patients' self-care practices; however, on the other hand, it has led to a redefinition of their interactions and power relations with physicians. This confirms that artefact and technologies are never used as designers expect; the notebook can be considered as a fluid object that is "adaptable, flexible and responsive" to the context (de Laet and Mol, 2000). This leads us to question the role of design and evaluation of self-tracking technologies. Design that supports the patient should be hybrid and equally support the different voices in play, even if this may mean bringing to the surface their inherent conflicts and differences (Storni 2013). Instead of considering the artefacts per se, we should consider them as technologies-in-practice and notice how the interaction between the users of notebooks shapes different practices (Orlikowski, 2000; Piras 2018). Therefore, through a methodology based on the observation of users' practices, this work highlights the importance of the socio-material practices and the tacit knowledge through which knowledge is iteratively produced. Thus, the contribution of this thesis to the design of a new prototype for self-tracking of Type 2 diabetes can be summarized as follows:

1. *Practice-based methodology can help to design technologies that take into account situated knowledge and patient practice knowledge, avoiding "pushed self-tracking";*
2. *Practice-based methodology can help limit the design of elements that may foster a sense of coercion on the part of the patient;*
3. *Practice-based methodology can help design technologies that take into account the importance of medical knowledge as well as patient knowledge, exploiting the ways in which such mutual knowledge can influence the proper management of disease.*

In conclusion, I would like to propose a last more general reflection on the contribution that this work can make within the research process of the TreC_Diabetes app and, more in general, within the state-of-the-art literature about design of self-tracking technologies. In chapter 3 we reflected on what it means to be “a good patient”, learning that this concept can have heterogeneous facets. Here I would like to propose a broader reflection concerning what “good care” is, what does it bring, what does it require, and how should we go about achieving it. Annemarie Mol (2006) asks this question in an interesting article on health care research as a form of self-reflection. She argues that these days, the most prominent way of handling the question of whether care is good enough is to seek evidence for its quality (Mol 2006). Researchers try to contribute by finding evidence that some therapy, some intervention or other, some procedure, is effective and has the desired effects. This research style arose in the ’50s and ’60s of the 20th century in the context of the extensive growth of the possibilities of pharmaceutical intervention. Clinical trials were gradually established, and pharmaceutical companies had first to seek evidence for the effectiveness of their pharmaceuticals by means of solid research before they were allowed to put them on the market. Clinical trials might be able to prove or disprove therapeutic claims, and however strong their credentials when it comes to seeking evidence, they have their limits when it comes to ensuring good care (Mol 2006).

The work presented in this thesis is intended to be an example of how the question of what good care is cannot be answered with the use of clinical trials alone or, as we have seen in the case analyzed, through a table for personal experiment; to be a "good patient" and to make a "good self care" does not only mean to respect some standardized rules, to try to keep the ranges of blood glucose values under control, to make a certain amount of physical activity per day. As articulated by Mol, “we cannot tell what good care is: not easily, not in general, not in a grand gesture. It has to be established closer to home: in day-by-day health care practice - in day-by-day life" (Mol 2006). Through a methodology based on the observation of users' practices, this work has shown that a "good self-care" means also taking into account patients' tacit knowledge and sensemaking, considering the processes of empowering and disempowering between patients and clinicians, and observing the ways in which their mutual knowledge can influence the proper management of disease. The question that arises here is: how to contribute to good care with research? I would like to relate these concepts to the process of designing a technology for self care, suggesting that not all health care research should be structured as if it were meant to convince outsiders of the quality of existing care, going beyond technological deterministic methods. According to Mol (2006), "there should be a genre of research that seeks to contribute to clinical work. The point of such research would not be proving practices right—or wrong. The more interesting and appropriate thing to do is to try to contribute to improving them" (p.411). As stated by Storni (2013) the question here is whether the evaluation of health and self-care technology should aim to "prove" that a certain technology is good enough for a medical or an economical perspective or, differently, to "improve" it from a practical perspective. In health care research, medical evidence may well serve a function, but not always and everywhere, and technological processes can have the specific purpose to evaluate and create room for reflecting together on what can be improved. They can be tools for self-care but also probes for its constant and open-ended redesign (Storni 2013).

5.4 Limitations and future work

The work presented in this thesis presents some limitations, which are meant to be addressed with future works. In the following paragraphs, the limitations are listed according to the contributions of the thesis.

A first limitation of the study is the lack of a collection of pre and post study data: analyzing the amount of steps taken by older people before and after participating in the project could provide statistics on the role that the personal experiment may have played in changing the care practices of patients with diabetes from a more quantitative perspective (number of steps taken, blood glucose trends).

Regarding the framework, another possible limitation of this work is that it is based on the analysis of data collected with the involvement of general practitioners. Future studies might consider involving hospital settings and diabetes departments to compare different care practices.

This ties into a third limitation, which relates to the notebook prototype; its future developments may allow its evaluation in other environments, like in the hospitals, in order to verify its usefulness and acceptability also in that context.

Finally, a long-term study to investigate adoption of the new digital prototype, and not only the initial acceptance would be required. The objective could be to propose the digital prototype developed also thanks to the suggestions of this work on an extended territory involving the entire healthcare system.

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