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ORIGINAL ARTICLE

Design challenges for ubiquitous and personal computing in chronic disease care and patient empowerment: a case study rethinking diabetes self-monitoring

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Abstract This paper aims to raise issues concerning the design of self-care technology, which supports an increasing number of individuals' chronic disease in everyday life. It discusses the results of an ethnographic study that exposes the intricacies and practicalities of managing diabetes in everyday life, and informs the patient-centric design of a diabetes journaling tool. It also sheds light on some everyday chronic self-care practices and suggests how to re-think some of the assumptions and connotations of the current medical model and the traditional role of the patient, which is not always fully appreciated in the design of ubiquitous and personal technologies for the patient. In particular, the analysis covers: the open-ended and uncertain nature of chronic care, the wide inter- and intra-variability of patients' conditions and attitudes towards the disease, and the need for more symmetrical interactions and consultations with medical experts. These findings informed the design of a proof of concept called Tag-it-Yourself (TiY), a mobile journaling tool that enables the personalisation of self-monitoring practices. A final discussion on the actual use of the TiY tool is also offered along with general implications for the design of self-care technologies and an outline of future directions for research in this area.

Keywords Self-care · Chronic disease · Patient empowerment · Self-monitoring · Diabetes

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1 Introduction and background

This research is concerned with the growing impact of chronic disease in our society and discusses emerging challenges for the design of information and communications technology (ICT) and ubiquitous technologies to be used by the patient in support of everyday chronic care practices.[1] There is a growing concern about the changes that health care systems in Western countries are currently undergoing. An ageing population and an 'epidemic' of chronic diseases (especially diabetes and cardiovascular diseases)[2] challenge the traditional organisation of health care delivery that is already struggling with costs and a lack of specialised personnel. In this context, some of the key challenges are as follows: shifting to outpatient care; prevention and wellness [1]; and spreading the notion of self-care, personalisation and patient empowerment. The idea of redistributing health care practices back to the citizens

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[1] The case study reported on and discussed in this paper was part of the FutureComm project (funded by the Irish HEA PRTLI Cycle 4—http://futurecomm.tssg.org), which investigates the future of Internet technologies in various domains including health care. Within this large research frame, part of the effort has been dedicated to enlightening some of the issues around the growing area of self-care, especially in chronic disease, and to reflect on the future role of design and technology.

[2] The World Health Organization (WHO) estimated that in 2000, there were 86,000 cases of diabetes in the Republic of Ireland. This figure is expected to rise to 1,57,000 by 2030. Globally, the WHO counted more than 170 million diabetics in 2000 with an expectation of that figure reaching 360 million in 2030. If current trends persist, it is estimated that as many as one in three adults will have diabetes by the year 2050. The Daily Finance also reports that diabetes is also becoming a global problem, not necessarily associated with Western society lifestyle. In some countries, such as China or India, it will become an epidemic (http://www.dailyfinance.com/story/investing/diabetes-big-pharma-gears-up/19816863/).

and their community, especially in chronic disease, generates understandable interest and is becoming increasingly popular, as it seems to represent an almost natural answer to some of the emerging problems [2–5]. In this context, the enabling role of ubiquitous and mobile ICT appears to be crucial. Indeed, we are already witnessing an unprecedented 'migration' of medical information and technology from traditional clinical settings (clinics, hospitals, laboratories and universities) and expert users, to domestic environments (mobile care, home care) and lay users. Medical information is increasingly available to everyone who can access the Internet [6, 7], and the diffusion of self-monitoring devices,[3] health applications, health-related social networks, and home- and tele-care projects [8] is growing fast.

This research acknowledges the current changes in the *geographies of care*, namely the transfer of care from formal and clinically controlled settings, such as hospitals and institutions, towards informal settings such as homes [9]. It is argued that understanding this shift is the key to informing the design of new ubiquitous ICT that will empower individuals and support everyday self-care practices outside hospitals and clinics. In particular, this paper argues that as self-care practices and technology become more ubiquitous, especially in relation to the explosion of chronic disease, some of the assumptions and connotations of the current medical model might become problematic and fail to empower patients, support everyday self-care practices and, ultimately, improve health outcomes. The problem is that, historically, the natural environment for the research, design and evaluation of medical technology and interventions has been the clinical setting with the expert user [10, 11]. This traditional clinical perspective has its roots in an acute disease-centric model that is based on the scientific method, the episodic nature of care, the emphasis on measurement, the asymmetry in the doctor–patient relationship and so on.[4] Through the analysis and discussion of a case study on diabetes,[5] this paper raises issues about the unreflective and uncritical application of some of these assumptions in the design of support technologies for chronic self-care and discusses a proof of concept that explores a different set of design principles and values.

The qualitative investigations highlighted inadequacies with the predominant clinical approach to chronic care and the need for a more holistic approach. They underlined the need to understand the disease not only as a biomedical condition but also as a complex lifestyle issue. In particular, this paper discusses: how the patient has to compromise between different aspects of the disease; the complex intra- and inter-variability of individual patients (their actual health status, their lay expertise, and their attitude towards the disease); and the potential conflicts and tensions that can emerge when a clinical perspective is imposed on affected individuals.

With these general issues in mind, a prototype was developed to explore new ways to improve, complement, integrate and perhaps even dispute, the dominant biomedical model and its intrinsically reductionist approach. Entitled Tag-it-Yourself (TiY), the prototype was designed to support the viewpoint of the patient and to enable the personalisation of self-monitoring practices. It also represents a means of empowering patients by supporting the development of lay expertise (traditionally silenced or of secondary importance) and by making the patient's voice heard, thus potentially improving collaboration and learning.

This paper is organised as follows. The literature review in the next section positions my research in the context of studies conducted in the field of human–computer interaction (HCI), health informatics and participatory design that have already started to shed light on everyday care away from the attention of medical experts, especially in relation to chronic disease (with an emphasis on diabetes studies). These studies represent an important, yet not mainstream, contribution to an understanding of the

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[3] MINTEL (a global product and market analysis agency) research shows that sales of self-diagnostics in the UK have grown by 40 % since 2000 and will rise by a further 38 % by 2010. Sales of blood pressure monitors have almost doubled in value from 2002 to 2004. The number of adults monitoring their blood pressure has increased by 250 % from 1999 to 2008. Manufacturers' revenues from medical devices will reach over $5 billion by 2011. Looking to the future, MINTEL predicts a staggering 60 % increase in the market of blood pressure, blood glucose and body fat measuring kits by 2012, with sales expected to reach £158 million, as growing awareness of health issues fuel sales of self-diagnostics. www.marketresearchworld.net/index.php?option=com_content&task=view&id=400&Itemid=48.

[4] See Storni and Bannon [12] for a critique of a disease-centric model towards patient-centric health infrastructure (2011). One of the key propositions of their work concerns the way in which, paradoxically, the call for self-care technology in the interests of patient empowerment can ultimately lead to new and more sophisticated forms of enrolment and the disciplining of patients within a traditional medical

Footnote 4 continued
model that, especially in the context of chronic disease, fails to fully acknowledge the patient's agency and perspective, and complicates rather than facilitates the establishment of an empowered patient.

[5] Diabetes was selected for a series of reasons: first of all, the diffusion of this non-communicable disease is quickly growing throughout society (not only in Western countries, but also globally); the disease is chronic and its management is very challenging as it requires a great deal of effort from the patient and, often, from a series of informal care givers; finally, its management involves a series of pieces of equipment and technological support for self-measuring, self-monitoring and self-medicating, thus providing an interesting case to study the role of technological mediation in chronic self-care. In this sense, it should be noted that although some of the considerations in this paper pertain to diabetes self-management, the general arguments have the potential to be extended to chronic self-care in general.

patient's perspective as well as the role of technology in supporting it. Section 3 discusses the case study on diabetes. Section 4 describes the development of the TiY prototype, which addresses some of the issues that emerged from the case study and raises implications to reflect on regarding the future role of design and technology in chronic self-care. Although the TiY prototype aimed to simply present a possible scenario to re-think the traditional clinical perspective in this area, this paper also reports on the iterative process of design and evaluation that was used in order to have the patient's concerns heard. The direction of future research is discussed at the end.

2 Literature review: design and technology in self-care and patient empowerment

As already mentioned, research and development of medical technology is typically undertaken from the perspective of the medical expert [10, 13] and benefits from a wealth of studies on the impact of technology in clinical practice and settings [11, 14]. However, demographic changes and the non-sustainability of the traditional model draw attention to new ways of empowering the patient to actively participate in the management of their disease. This has been evidenced by the explosion of assistive, ubiquitous, self-, home and mobile care technology [15, 16]; the explosion of medical information [6] and health-related online communities concerned with knowledge sharing [17]; and the changing role of the patient in disease management [7], which is central to this research. In the field of ICT, research on health and medical informatics is often concerned with health information systems and patient health records [18]. These systems and records are designed with a strong emphasis on ownership, privacy and accessibility of patient data [19] and with little focus on communication issues [20], the doctor–patient relationship [21], the implications of the 'invisible' work required by the patient [22, 23] and its impact on their lives [8]. One exception is represented by the work of Ma et al. [24] who discussed an approach for diabetics that placed education and a personalised approach centre stage. They describe a Violet Technology system where patient-specific diabetes information profiles (DIPs) are used to improve patients' literacy as well as their communication and interactions with health professionals.

Important contributions have also begun to emerge from design research, in particular from those traditions that are specifically concerned with the notion of participation, such as the Scandinavian tradition of participatory design [25]. For instance, Ballegaard et al. [26] stress the importance of designing self-care technology by paying special attention to aspects of everyday life; by developing patient expertise; and by involving patients in the identification of problems, the development of concepts and the evaluation of proposed solutions (limited to the design of evaluation studies, see also [27]). Similarly, Axelrod et al. [15] underline the need to understand new domestic environments as they represent a new set of challenges for the design of assistive technology. Extending this research, Aarhus and Ballegaard [2] show how home care and self-management can be seen as a complex negotiation of boundaries (e.g. medical/non-medical, public/private), and they discuss design implications for home care solutions and participatory research. Mamykina et al. [28, 29] argued for a shift away from the design of tools for decision making and towards the design of support tools for sense making by putting the patient's reflections and understanding at the centre of the empowerment agenda. It is suggested that technology supporting self-care in chronic disease should enable flexible usage, the negotiation of actions, as well as the formation of new proactive patients in chronic diseases [30]. In the same area, Smith et al. [31] emphasise the usefulness of multimedia to support understanding and communication with other caregivers, while Preuveneers et al. [32] elaborate on the idea of using mobile technology in diabetes self-management. Kanstrup et al. [33] argue for a more holistic approach (entitled Design for more) where the community of informal caregivers has to be carefully understood and taken into account in the design process. Storni [27] discusses multiple forms of appropriation in patients' self-monitoring practices and argues for more explicit reflection on the role of design and technology and, in particular, aspects that are often circumscribed in the traditional medical model and uncritically extended to patients and their lives. Prior to this, Orel [34] discussed the role of what he called self-vital technology and anticipated a series of issues, such as the need to look at patients as proactive experimenters.

These studies were highly influential on my research and helped to clarify the aforementioned differences between the new emerging patient settings and the current/traditional ones. They also represented a starting point from which to assess the appropriate design implications for ubiquitous and personal technological support. They all refer to an increasing awareness of issues of patient engagement, participation and empowerment in self-care, as well as acknowledge the key role of technology in supporting and enabling, but also potentially hindering, self-care.

Even though the language of patient empowerment is often associated with self-care initiatives, and despite the growing evidence that more participatory approaches to chronic disease improve health outcomes and patients' feelings of empowerment,[6] the needs of self-care patients and their carers, as well as the settings in which self-care occurs, are rarely investigated [8, 34]. Moreover, their implications on the design of self-care technologies are among the most neglected by manufacturers [34] who are already running towards new emerging market niches and in doing so they run the risk of limiting real patient empowerment and of silencing patients' voices and concerns.[7] Indeed, mainstream self-, home and mobile care technologies continue to privilege a clinical perspective.

3 Case study: methods and settings

In order to investigate self-care practices and the patient's perspective in dealing with diabetes, I decided to join a diabetes type 1 support group and to attend all of their meetings. This gave me an insight into the diversity of patients' concerns and perspectives, and provided access for deepening the investigation through in-depth semi-structured interviews (see [40] for more about this investigation), home visits and, latterly, participatory design workshops aimed at exploring design possibilities and testing prototypes.

3.1 Methodology

An approach aimed at emphasising the patient perspective, the practicalities of dealing with a chronic disease and the need to empower the patient suggests a qualitative and pragmatic methodology aimed at understanding and describing more than measuring and explaining. The aim of the investigations was to look at what diabetics really do in dealing with their condition, and not necessarily at what they are supposed to do from an academic perspective. An ethnographic approach was used to provide in-depth insights and detailed descriptions of chronic disease self-care practices. This was done by going 'native', i.e. shadowing selected subjects' activities, as well as interviewing them a number of times. The focus was on the strategies and perspectives of patients dealing with the disease in order to provide insights into the development of patient-centric solutions.

For this study, 14 type 1 diabetics were observed and interviewed. As mentioned, observations were performed in a support group, where patients support one another by giving emotional support and exchanging advice, tips and information (e.g. about snacks or recipes, events and initiatives, interesting books or articles and so on). Observations were also performed in a limited number of occasions in the form of shadowing (e.g. home visits) where I was invited to assist in daily routines (such as cooking, preparing for physical activities or buying food in the supermarket). The support group meetings were held once in a month (twice for special events) for about 3 h. I personally attended the meetings for 10 months. Members of the support group were also extensively interviewed along with other diabetes type 1 patients. A total of 14 semi-structured, in-depth interviews were performed between September 2008 and June 2009.[8] Interviews were informal, open and loosely structured, although some general topics were discussed. Chronic disease patients were interviewed extensively regarding their daily experience of dealing with the disease, their relationships with medical personnel, and the pros and cons of using self-care technology. Interviewees were regularly invited to provide practical examples and stories instead of talking in general terms. Some medical experts (a few pharmacists, two diabetes nurses, one GP and two endocrinologists) were also interviewed about their relationships and issues with patients as well as their opinions on the proposed design approach. Further qualitative data were gathered during a design workshop in the form of a focus group where four participants with diabetes were invited to develop and discuss design concepts and scenarios. The TiY prototype was later tested by some of the same individuals who were interviewed, and the feedback they provided generated further insights into their perspectives. The qualitative data analysis was informed by Grounded Theory [38], and it was aimed at categorising data into emerging categories and topics. For this reason, all interview and focus group transcriptions and field notes from observations were processed with NVivo, a powerful software tool for qualitative research. The names of the individuals in this paper are purely fictional.

4 Case study and data analysis: investigating diabetes self-care practices in order to inform design

Diabetes is a growing metabolic disorder characterised by chronic hyperglycaemia (high levels of sugar in the blood)

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[6] See, for instance, the success of the German diabetes management programme that gives great scope for patient involvement in primary care, Stock et al. [35], Szecsenyi et al. [36].

[7] A look at any self-monitoring device today is illustrative of this trend. Measuring and counting physiological values are systematically emphasised to the detriment of paying attention to what cannot be measured. Universal biomedical knowledge is privileged over the experiential in the decision process, thereby reproducing the traditional asymmetry between patients and medical professionals. Similarly, individualistic thinking and autonomy of choice is privileged over dialogue and negotiation (see Mol [37] for a discussion of this logic of choice and the proposition of a much-needed logic of care).

[8] Diabetes patients were interviewed for an average of 90 min each.

that results from the body's difficulty or inability to produce and/or use insulin, which is a hormone that helps the body use blood sugar for energy. Type 1 diabetes develops when the body can no longer produce insulin, requiring it to be injected. In type 2 diabetes, the body gradually loses its ability to use and produce insulin, which usually leads to affected individuals having to stimulate the production of insulin with tablets. These conditions produce both immediate complications (ranging from chronic fatigue and blurred vision to even becoming comatose) and a series of long-term complications generally due to the deterioration of blood vessels (cardiovascular and coronary heart disease, retinopathy, kidney failure and so on). Today, thanks to the development of artificial insulin, the mass diffusion of portable glucose monitoring devices (glucose meters), and clinical evidence (through extensive clinical trials) on the benefits of strict control, the importance of tight regulation of food intake, physical exercise and insulin has been established as the correct way to manage diabetes in Western countries.

In the next section, I focus particularly on the analysis of a series of factors that informed the design of the TiY prototype, which will be discussed later on. There are three important findings that emerged from the data analysis: diabetes is not just a disease but rather it is a lifestyle, diabetes manifests itself in different ways and people develop different attitudes towards their disease, and finally, the relationships and interactions between patients and medical experts can be problematic.

4.1 Diabetes as a lifestyle: the logic of compromising

One thing that is immediately striking in interacting with people affected by diabetes is that the disease is so pervasive in their lives that it takes the form of a lifestyle. Its effects are intrinsically linked to so many everyday activities that it is practically impossible to compartmentalise the disease. In this sense, the previously mentioned distinction between acute disease and chronic disease and its social implications become quite evident. While we find a clear distinction between 'normal life' and the status of being sick in acute disease, diabetes and practically all chronic diseases are, as one of our interviewees noted, 'everywhere' in your life. Geraldine, a diabetes type 1 patient, made this point clear while talking about her first diagnosis and how suddenly her life had to change.

> **Geraldine**: "Everything changed. Because you have to think about your blood sugars all the time no matter what you do, you go out for a walk you go into town, you play football with the kids, you go for a snack, you go for coffee with somebody… blood sugar is involved in everything you do, and then first you have to find out how—let's say—swimming is affecting you, or I go running everyday so how does it affect me?"

Paula, who often meets Geraldine at the support group, reaffirmed a very similar position.

> **Paula**: "Because it's constantly in your mind, for example, if you go shopping: I don't see the food […] I only saw carbohydrates 30 grams, 40 grams, 3 units of insulin, 4 units of insulin… you just start to think in a complete different way […] but in the back of my mind it's constantly: ok, if I was outside with students playing football, how intensive was it? How long did we stay? When did I last have food? When did I last have insulin? When am I going to next take it? So it's a constant thought about what's going on".

Sadly, no matter how good you are, or have been, in managing your glucose levels, glycaemia is currently impossible to master, as shown by the following extract from another patient.

> **Gabriela**: "Even if we did the very same things every day and ate the very same things at the very same time every day it still wouldn't be the same every day because you have things like stress, illness, exercise […] and then hormones just play into it and you can't measure those".

Even experienced patients can find it difficult to have constant control over their glucose levels. Mastery is always temporary, if ever possible. This is particularly true, as I noted repeatedly in my interviews, when there is a significant change in the diabetic's life: a new baby, a new job, moving into a new house or place, temporary illness or stress, or just simply ageing. Changes like these can considerably impact diabetes and require the patient to consult with their doctor in order to tweak and adjust their insulin regime. As concisely summarised by another interviewee, the idea of total control is not realistic: 'I feel like if I have optimum control then I'm losing out on life in some way'. This statement also shows that compromising is probably the usual strategy that people with diabetes employ in order to cope with the disease while dealing with other aspects of their life (on compromising, see early work by Kelleher [39]). Far from the episodic nature of care in the acute disease model, chronic conditions require continuous care practices that manage the disease in an open and flexible fashion. The daily experience of patients with diabetes is therefore characterised by a complex interplay of expectations, experiments, compromises, and attempts to make sense of glucose levels and bodily sensations. A patient-centric and empowering approach to the design of support tools suggests looking at how to support the ongoing and open-ended regulation of such elements and not how to adhere to a universal solution. As also shown in Kanstrup et al. [33], type 1 patients often make their own plans to deal with the disease, which represents a good illustration of empowerment in practice. During my research, many patients mentioned their need to plan and adjust their insulin regime to make it fit with the practicalities of everyday life (see Storni [40] for more details on the skills developed by individuals with type 1 diabetes). Marco, an experienced patient diagnosed 17 years ago, describes his plans in this way.

> **Marco**: "…so what happens is that you make some sort of mental plans, something like: I read 200 with the meter, if I do 2 units of insulin I will go to 120, with 3 units I will be around 80 and so on […] Every time, I make a plan depending on where I am, what I am supposed to do, and it changes according to the fact that I am at home, in the office or not, whether I can prepare my food or just get something from a menu. For instance, when I know we are going to be walking for a long time because we are sightseeing somewhere or we are in the countryside, I tend to keep my level of glucose a little higher, so instead of 10 units of insulin before lunch, I take only 9 or 8. If I know I will have a football match to play I will do even fewer units".

Another patient explained that she plans similar activities based on experiments that follow what she called the 'rule of three': 'if that [one insulin intake] brings my sugar within target two days in a row, and I have ate and done the same things in those days, I have a good idea that's the right amount for those things'.[9] These examples show that patients develop a set of skills and lay expertise that help them to make their condition better fit with their life. It is important to note that these skills and expertise are unique and personal because diabetes affects people in different ways, as discussed in the next section.

4.2 Different diabetes for different people

Another challenge that was highlighted during the investigation of the practical aspects of living with type 1 diabetes was that diabetes not only manifests itself differently in different patients, but also impacts on patients' lives very differently. It was surprising to find that the exact same activity can affect different patients in different ways, sometimes even in radically opposed ways. For instance, I came to know several patients whose glucose levels rise considerably when they drive. On the contrary for other patients, their glucose levels drop considerably when they drive. Both effects have a biomedical explanation, i.e. different levels of stress while driving. Patients also differ in their attitudes towards diabetes. For some, diabetes is not 'such a big deal', and it is not very difficult to deal with, whereas for others it's a nasty and ubiquitous enemy that is very hard to live with. These different attitudes are illustrated in the next series of extracts where patients talk about their initial diagnosis as well as their current daily practices. The first participant talks about his diagnosis and the way he currently copes with diabetes.

> **David**: "I suppose I didn't find getting used to it too difficult to be honest…[…]…and no, it did not stop me to try new things. I've heard of people before who have a strict diet and stick solely to it, but I don't believe you should let the condition or disease control you".

In contrast, another patient recalls her diagnosis as a nightmare and her present situation as a constant struggle.

> **Geraldine**: "No clue, that was the biggest thing. Injections for the rest of my life, you know, somebody who doesn't have experience of that, that is a huge thing. Terrible".

In a particularly extreme case, the next subject is even happy to have developed diabetes as this extract from his interview shows.

> **Thomas**: "Deep fat fryers or anything like that … all gone completely, I eat an awful amount of fruit a day now.
> **Interviewer**: Do you feel a lot healthier, though?
> **Thomas**: Oh brilliant, if you'd seen a photograph of me nine years ago you wouldn't believe I'm the same man. I was dying. I was actually dying. […] Funnily enough I found it a healthy way of living because I don't drink and I don't smoke, I don't do anything like that anymore…"

This last patient views diabetes as his escape hatch from a very destructive lifestyle. This again reaffirms the fact that different patients see and experience diabetes differently and develop different attitudes and practices towards the disease even though it is basically the same condition from a medical perspective. Indeed, all the interviewees agreed that it is impossible to separate the medical aspects of the condition from the practicalities of daily life.

4.3 Biomedical condition or 'just' complicated lifestyle?

When diabetes is experienced, it is not simply a medical condition reducible to a series of biomedical factors,

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[9] After all, reproducibility is not only a prerogative of experts and the producers of scientific knowledge.

physiological values, tests and the prescribed logic of tight regulation. Individuals with a chronic disease, and diabetics in particular, cannot afford to play the ‘sick role’ as prescribed by Talcott Parsons. As mentioned, diabetes is a lifestyle entangled with unique and personal elements for each person it affects. However, this subjective and personal perspective on the disease is often a source of frustration in the medical encounter where there is just the time, resources and capabilities to treat it as a biomedical condition (that is to look at the body as a machine, Leder [14]). Indeed, the interaction between patient and doctor can sometimes result in a conflict between two distinct perspectives and their implications in care practices. This seems especially true with very experienced patients. Some of the participants in this research talked about doctors being particularly defensive when patients express their doubts, explore other ideas or challenge some of the doctor’s decisions.

> **Paula**: “It is hard to find a specialist who acknowledges that the patient knows just as much, here it is always the opinion: ok I am the doctor you are the stupid patient, you do what I tell you… but that’s not right! A diabetic needs to be an endocrinologist, a sports adviser, a nutritionist. You need to be all that in one person in order to deal with your diabetes but doctors don’t understand […] They think you are stupid, they don’t realise that you think about what you are doing because they don’t live with it, they don’t see the numbers, they just read it on paper, they go home at night and eat their dinner and don’t think about carbohydrates and the whole lot”.

When talking about her attempt to build a constructive relationship with her endocrinologist, especially concerning her desire to self-adjust the insulin regime, Paula stated that:

> “she didn’t really see it as a problem as such, but on the other side, how could she? She’s not living with it; she only sees it on paper! She doesn’t live with diabetes! It’s completely different… so sometimes doctors can’t relate to your concern in a certain problem because they just don’t have it.”

As clearly explained by another patient (Gabriela): ‘In order to get proper care you have to start testing or training the doctors’. Consider the following extract:

> **Geraldine**: “I’ve been seeing a new doctor for the last couple of weeks so she’s been messing with my insulin.
> **Interviewer**: What do you mean?
> **Geraldine**: …she’s added an extra injection actually that changed… I’m on five injections a day; she’s added another one. She’s split my long-acting insulin into twice a day because she believes the long-acting one doesn’t last the twenty four hours. […] that is not true, my numbers are just fine…now I have to start again…”

Here, once again, the conflict between doctor and patient revolves around a different understanding of their respective roles and boundaries and the nature of their relationship. According to Geraldine, the insulin is *her insulin*. Therefore, adjustments such as the one prescribed by the doctor, if not negotiated and discussed, represent an invasion of a personal sphere and a reaffirmation of the superiority of the biomedical perspective over the concerns of the patient. Sadly, these situations tend to escalate and can lead to a strong distrust of medical support. The following extracts are from a design workshop that was run with four patients, and it portrays a discussion among participants about what they call the ‘it’s your fault’ attitude.

> **Paula**: “On paper it’s so hard but in everyday life so many influences come into it, but it’s you who control it and if you can’t manage it, you lose control.
> **Christine** (sarcastically reaffirmed): It’s your fault!!!
> **Paula**: Yea, and that’s why you don’t ask for it, you think that I’ll find a way around it to get your control back.
> **Christine**: And going back to the doctors when you go into their office, if your numbers are out, it’s your fault… what are you doing that is making these numbers high? So therefore you’re taking ownership of the blame…
> **Paula**: So you just keep it to yourself and that’s where the support group comes in because in the support group nobody says: oh that’s your fault, it’s like: oh try this one maybe it works better”.

In this context, it is pertinent to question the role of self-care technology and its potential to complicate rather than facilitate the relationship between the medical professional and the chronic disease patient. The rationale for using monitoring technology is in fact quite in line with a biomedical and disease-centric approach to chronic disease, but often monitoring technology fails to account for and support the often unique issues that the patient has to deal with. In this way, its design fails to meet the premise of patient empowerment and self-care, and becomes counterproductive because it limits self-management of the disease. This issue seems to confirm Radley’s [41] early scepticism about traditional consultations in chronic disease; he claims: ‘The implication here is that the person must take his or her illness and cope with it in his or her own life, removed from the attentions of medical personnel. Where acute illness can be discussed from the perspective of the doctor (that is, from the standpoint of biomedicine), the special problems of living with chronic illness evade these kinds of explanations'.

The sometimes-strained relationship between doctor and patient can result in situations where the patient prefers not to raise issues or ask personal questions of the doctor, knowing that they will not find the answers they want. The next extract demonstrates this clearly.

> **Geraldine**: "You don't want to seem stupid for suggesting something that the doctor is going to turn around and say: no that's not relevant. You might think you are learning all these new things and you think they're relevant but if she's not open to it then you're not going to be forthcoming…that's what's missing from that side…well we make up for it!"

In exploring these issues in detail, it is clear that medical interactions and self-monitoring practices are characterised by a reductionist way of thinking, especially when you consider glucose meters and their related journaling activities, which represent a fundamental practice in diabetes self-management. While it is true that affected people might find it useful to take notes of different things (e.g. what they have eaten, for how long they have run, how they feel), I noticed during my research that the 'non-numerical' information was often disregarded or overlooked by doctors who want their patients to just keep track of their numbers. When asked about their journaling practices and what sort of extra information patients tend to write down, I noted once again that some patients tend to hide this information from doctors.

> **Gabriela**: "I type those [extra information] out for my doctor because if I handed that to her she would be like, what is this? So she has a format where I just put in the numbers, I just put in the readings and the units. That's all! She doesn't want to know anything else. […] she's not really doing her job properly, she doesn't look at what I eat. […] Some doctors would make a judgement on one reading".

The current design of glucose meters does not seem to adequately take into account patients' concerns but rather they replicate the biomedical reductionism described so far. Gabriela continues her explanation by bringing in her glucose meter and by showing how it represents yet another extension of biomedical reductionist thinking.

> "I got this new meter about two years ago and this is supposed to do most of this for me but you see it has a log book, you cannot input, let me see… glucose by meals, you can enter your meals but you have to enter them as, you basically have to enter the amount of carbs, you can't say what it was, just say 35 grams of carbs and then fibre, fat and protein. It's just very restrictive, it gives you, it's like multiple choices so you can't actually free write, it does give you a section to make notes."

As you will see later from the evaluation of the TiY prototype, some of the participants keep two separate logs when journaling their values, one for the doctors where they put what the doctor wants and one for themselves with what matters from their perspective. One of the participants made the interesting distinction between those regular readings that a diabetic takes because the doctors ask them to (which are labelled as 'fetish' by the participant) and those readings that take into account daily activities and support adjusting the insulin intake. Most of the current glucose meters on the market have a specific design that enables, reaffirms and reproduces a biomedical perspective that leads to the mentioned fetishisation of biomedical data to the detriment of personalisation and patient empowerment. Specifically, they reaffirm the quantitative and positivist epidemiological model and the traditional separation between laypersons and experts that typically characterises the acute disease model.

5 Implications for the design of solutions to empower the patient in diabetes

Apart from a series of recent contributions discussed in the literature review, the market seems to be dominated by an endless variety of personal tools that enable patients to keep track of their glucose levels, insulin and food intake. The majority of these tools are designed from a clinical perspective to suit medical experts in the context of acute diseases, clinical validations and controlled settings. However, these tools fall short in addressing the irreducible heterogeneity, complexity and uncertainties of patients' chronic care practices outside of hospitals and clinics. Ignoring patients' concerns might amplify the 'it is your fault' attitude and the need for patients to 'make up for' the doctors', and the glucometers', lack of consideration of their view.

The key challenge is to find ways to make room for potentially conflicting practices and perspectives and to view them as an opportunity for: mutual learning, the formulation of better questions, the discussion of a variety of different concerns, as well as improved accountability for self-care practices through the constant generation of evidence on their effects. In the next section, I describe an attempt to address this challenge, which partially illustrates a much-needed re-evaluation of our design assumptions. This is done by means of a design concept for a mobile phone application supporting the personalisation of diabetes journaling and self-monitoring practices with an emphasis on the patient's perspective, his/her personal reflections, explorations and sense of empowerment.

5.1 Journaling and the Tag-it-Yourself prototype

The case study analysis showed that journaling glucose levels, insulin intakes and other information, such as weight, test results, etc., is probably one of the key management practices enabling diabetic people to keep track of their values in the attempt to maintain control over their sugar levels. Journaling is crucial for at least two reasons. First of all, journals are the tools that patients use to keep track of their values, and it is in revising these values (e.g. in the attempt to find patterns) that they can make sense of the disease, gain knowledge and possibly more control over the disease. However, the data also clearly show that while the activity of keeping track of glucose readings and insulin intake suits the doctor's perspective, it falls short in providing patients with a more comprehensive variety of information that is potentially useful from their perspective. The second reason why journaling is significant is that journals often act as boundary objects [42] in the medical encounter and are partly responsible for both facilitating and inhibiting the discussion of certain things and not others. It should be noted, though, that journals are not 'reductionist' per se. In attending the support group, I noticed how the very same object that contributes to making medical encounters particularly frustrating for some patients becomes a trigger for open conversation about what went wrong or right in other encounters. In the support group, patients exchange their journals willingly, point out things together, discuss alternatives, add notes and tell their personal stories to one another. In these interactions, numerical data are important but only if linked with their corresponding daily activities. Aware of how poorly supported note-taking is in current glucose meters and journal templates, and how limiting it is to reduce their disease to a series of physiological values, the purpose of the proposed tool was to allow patients to keep track of whatever matters to them, trying to avoid any theoretical distinction between helpful and unhelpful information in self-care.

The findings that emerged from the case study also informed the design of the TiY tool, notably, that diabetes is a lifestyle issue, that it is different for different people, that the idea of total control over one's glycaemia is unrealistic and that diabetes impacts people differently even during similar activities. Because diabetes is so ubiquitous and intermingled with the practicalities of daily life, it would be wrong to design a support tool that reduces it to mere physiological values using biomedical language (also considering that this logic often frustrates the medical encounter and reproduces a problematic asymmetry between what doctors know and what patients experience and learn). It would also be a mistake to expect to be able to prefigure what should be monitored and what should not in self-management (e.g. driving is an issue for many, although often for different reasons).

A decision was made to experiment with an open-ended editor that would allow bottom-up personalisation of self-monitoring practices through the creation of unique categories of data, referred to as 'tags', to fit the patient perspective and to allow them to generate evidence on their own terms about the effects of their self-care practices. The open-ended nature supports the idea that things change continuously and unforeseen needs could emerge at any time, even for patients who are very experienced.[10] The facility to generate lay categories of data underlines the fact that patients reflect on their own experience and develop lay expertise about how to deal with the mundane practicalities of their life and that this information is essential to good care and positive health outcomes. The TiY [43–45] is currently based on an iPhone app.[11] The idea is to enable the patient to 'tag' events in everyday life by tracking lay activities as well as by attaching all sorts of multimedia information to more traditional glucose readings and insulin intakes (e.g. individuals can take a picture of their meal, a product in a supermarket or a place where they have done some physical exercise). In this way, the possibility to explore meaningful correlations and patterns and to track and generate evidence of the effects of their actions is enhanced, thus improving sense-making and a feeling of control. The attached information can be in the form of pictures, audio/written notes or, indeed, patient generated tags, which represent the key contribution of the TiY prototype.

Tags can contain numerical values. For instance, physical exercise can be tracked in terms of minutes of training or, if equipped with other devices, in terms of burned calories. Similarly, beers can be tracked in terms of glasses or pints, and breakfast in terms of cups of cereal or of consumed carbs, and so on. As a new tag is created, the patient can select a button on the glucose tracking page to attach tag-related information to a specific glucose reading or to track something as a simple independent record. Ideally, tags could be linked with networked devices that automatically feed in data regarding specific activities (cooking, running and so on) without relying on manual entry. The log function allows the patient to review glucose readings along with patient-generated tags that are presented textually and graphically, thus enhancing the ability

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[10] For instance, one of our interviewees, who is considered an expert because she had perfect numbers for a long time, developed bulimia and all of a sudden had to start journaling an awful lot of new things that were irrelevant before.

[11] TiY source code (https://github.com/ansig/Future2).

to see patterns, tinker with aspects of daily life and possibly reveal how certain mundane actions affect glucose readings. The intention is to improve the possibility of gaining more control over the disease as well as the quality of dialogue with medical staff.

5.2 Evaluation of the TiY prototype

Informed by the qualitative investigations that are partly reported in this paper (see [27, 40] for more details), the TiY prototype was also evaluated with real users as part of an iterative and human-centred design process, whereby design and prototyping sessions were interspersed with user tests and feedback. The tests were principally aimed at assessing the general appreciation of the bottom-up tag generation idea and its actual use in everyday life as well as garnering information about issues in self-care practices. In this sense, evaluation did not follow the format of clinical trials (a complete evaluation of the tool or a clinical trial was beyond the scope of this project) but followed the logic of constructing a modest but highly detailed case study with a series of type 1 diabetics and, where possible, their formal and informal caregivers.[12]

Two rounds of tests were run for the TiY. The first round involved four type 1 diabetics and lasted for 2 months. These four participants were members of the support group where observations were made. The tests were complemented with a home visit and phone calls. Patients were equipped with an iPhone with a developer copy of the TiY prototype installed on it. The first test was made on an early version of the TiY that did not feature graphical representation of the data. The second round of tests involved two diabetics (different from the ones participating in the first series of tests) who were equipped with the current version of the TiY for 6 weeks. This second iteration of the prototype, which featured graphical representation of data, resulted from feedback provided in the first round of tests. During the first round, users were also asked to keep a diary. In this sense, the TiY prototype itself also acted as a technological probe (see [29] for a discussion on the use of technological probes in diabetes research) providing us with further information about its use and the concerns of the user.[13]

During the series of evaluations, a wide range of tags were created such as meal tags to highlight pre- and post-meal readings or the type of meal, e.g. ‘porridge breakfast’ or ‘muffin breakfast’; tags to track sports and other physical activities, e.g. ‘gym’, ‘walking’, ‘jogging’, ‘running’ and ‘swimming’; diet tags to track intake of ‘carb(ohydrate)s’, ‘fats’, ‘fibres’, ‘snacks’, specific food or drinks, such as specific types of cereal, cheese or beer, or new types of food ordered in restaurants, such as ‘sushi’ or ‘pizza’; tags for medical tests, such as ‘HbA1c’, ‘ketones’ and ‘CBC’; tags for medications, individual symptoms or ‘sick’ days; tags for different types of insulin, such as ‘Bolus’ and ‘rapid’; tags for daily activities, such as ‘driving’ or ‘travelling’; and so on.

On average, 40 different tags were created during the tests ranging from only two general tags for one patient (‘food’ and ‘exercise’ as non-numerical tags that were usually complemented with written notes) to 14 tags for another patient, ranging from specific activities, type of food or drinks, symptoms such as feeling low, and medications usually created numerically in lay units (such as bottles of beer) or units from the provided metric systems (such as minutes for cycling, or grams for carbohydrates) that were rarely accompanied by a note.[14] Some tags were used regularly by all participants, such as ‘breakfast’, ‘lunch’, ‘snack’, ‘running’ or ‘jogging’. It was also noticed that some tags were created but then never actually used. In a couple of cases, participants modified previously created tags to better fit their use, as in the case of a tag named ‘pizza’ that was changed to ‘eating out’ and that was often complemented with a picture of the dish in question. Another example was the case of one tag ‘lunch’ which then evolved into two different tags: ‘lunch light’ and simply ‘lunch’. Interestingly, one participant started to create a collection of pictures of food labels that displayed nutritional information. We were happy to notice that these pictures were also used to later support her shopping at a supermarket to check different nutritional values of a new brand of cereal.

One of the early suggestions about tag creation referred to the fact that meal tags, and possibly also exercise tags, are so basic in diabetes self-management (at least for type 1) that some users would expect them to be already pre-prepared in the journaling tool. Although this point was understandable, it was also true that people used different strategies in creating meal tags too. For instance, one participant found it useful to distinguish between different types of breakfast, one based on porridge and another based

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[12] In this sense, the selection of subjects did not follow a randomised assignment, although it was somehow guided by a series of principles such as the user must have a form of diabetes requiring journaling and monitoring (therefore the focus on type 1); the user must have a certain level of familiarity with the use of a mobile phone; the user falls within the most common age bracket for smartphone owners of 18–50.

[13] Signed consent forms were collected under the guidance of the local ethics committee in all three series of tests, and patient data were stored and managed according to the guidelines of the local data protection authority.

[14] This might allow us to say that there is an inverse relationship in the tag design style of different patients between tags carefully specified that do not require further notes and tags that are quite generic but complemented with a written note.

on muffins. This pattern was recurrent in main meal tags, which ranged from generic ‘lunch’ and ‘dinner’ to more specific ‘light lunch’, ‘pasta’ or ‘pizza’ and so on. Another interesting case concerns tags created to flag pre- and post-meal readings, thus facilitating sorting of all glucose readings associated with a particular meal.

Similar to what was noticed in the use of traditional paper-based journals, it was observed that users sometimes postponed recording or tagging a certain reading and came back to it in the evening to add extra information that they could not input at the time for whatever reason. The TiY tool enables editing of the data itself, as well as modifying the time and date, and the entry was made. After 4 weeks of the first round of tests, the use of the TiY tool started to degrade and, in some cases, was completely suspended during the last 2 weeks of the tests.[15]

Interesting data emerged in relation to the participants’ comments about using the TiY tool with their doctors. Three participants were ostensibly reluctant to use it in that capacity, although for different reasons. One simply reaffirmed what we learned already during our early investigations, as shown in the following extract.

> **Stephen**: “I don’t think it’s something my doctor would like to work with as he recommends journals for use with set formats and this would be something different that he wouldn’t know anything about”.

However, another two participants raised a quite unexpected issue related to the fact that the data stored on the TiY had been entered and structured in a personally understandable manner and in its current format wouldn’t be understandable to an outsider.

> **Eoin**: “I don’t know if anyone else would be able to understand what I put in, but I understood it”.
> **Andrea**: “How I used tags especially was using a management system in my own head. It all makes perfect sense to me, but if I was showing it to somebody else, I don’t think they’d have a clue of what I was recording. It would only work like that if I was to make a summary of recordings myself and explain it to them”.

This second participant, however, reaffirmed the purpose of the tag editor and, in particular, how it could support a positive discussion with the doctor. The patient-centric log provides contextualised and potentially key talking points to trigger narratives, explanations and discussions that seem to be currently limited by current journaling systems. The suggestion is to widen the scope of the medical encounter by better using the little time available to fine-tune the many heterogeneous factors at play. The aim is also to reduce the instance of mutual blaming and the ‘it is your fault’ attitude that was witnessed in the empirical investigations by allowing the generation of bottom-up evidence[16] to justify certain actions. Some of the participants believe that this could be very useful, as the next extract shows.

> **Paula**: “It might be nice…just to see if I show that graph to my doctor and she says try to make that adjustment and I do it and it’s still not working, then I can add a comment to the actual graph and use it to try a new thing”.

Also, doctors (2 specialists and 1 general practitioner) expressed appreciation for how easy it was to access glucose readings and related information. The main concern for them was data fabrication. One particular endocrinologist described a series of cases where patients fabricated data for various reasons (e.g. to appear more compliant with the suggested therapy). In addition, doctors reaffirmed their interest in using the tool for purely medical data; any other type of entry did not seem to be relevant.

> **Brian, endocrinologist**: “I expect the patient to follow my advice. If they have different issues (social, psychological or dietary) we have experts that deal with those specific areas”.

Although understandable, a statement like this reaffirms a disease-centric perspective where the ‘medical’ side of a disease is considered first and foremost and the ‘social’ and ‘psychological’ aspects are considered separate and of secondary importance, and under the jurisdiction of yet another expert!

6 Conclusions and future steps

Concerned with the growing impact of chronic diseases in our society, I began this research to see how ubiquitous technology, especially ICT, could be used to facilitate self-care and patient empowerment in chronic disease care and management. I reviewed a series of studies in the area of HCI, health informatics and participatory design, which

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[15] This could be motivated by the fact that the user knew that they had to return the iPhone after the trial, and also because exporting data from the iPhone was not possible so that all of the users involved continued to use a more traditional paper-based journal along with the TiYtool.

[16] The argument made against reducing complex phenomenon to a normative approach can be extended to the very notion of evidence that populates many discourses in contemporary health policy. The question can simply become that of asking who decides when it counts as evidence and what language is used to express this evidence. The risk is that evidence in chronic self-care ends up referring to evidence produced in experimental settings (e.g., clinical trials) that might have little to do with the evidence of actual self-care practices in chronic disease.

dealt with the patient perspective and personal self-care practices. I have demonstrated how the notion of empowerment is difficult to implement because it often clashes with some of the assumptions and connotations of the current clinical model and its principles.

Through qualitative investigations based on ethnographic observations and interviews, I have exposed some of the practicalities of dealing with diabetes *in the wild*, and I have started to map some of the issues and concerns of chronic self-care from the perspective of the patient. The first issue is the chronic nature of the disease and the constant need for compromising, which defies attempts to separate the medical aspects of a disease from the intricate complexities of daily life. The second concerns the wide variability of not only the severity of the disease, but also of the self-care practices and the patient's attitude towards their disease. For this reason, a *one size fits all* strategy is inadequate. Self-care solutions need to be tailored to individual patient needs and should allow appropriation of designed solutions [27]. Finally, the third issue is the often problematic relationship between the patient and the medical experts in chronic care, especially when it is characterised by a marked asymmetry. In particular, I showed that attempts to reproduce a clinical perspective and apply its metrics in new settings for chronic self-care can lead to conflicts and frustrations on both sides, such as mutual blaming or hiding information from the doctor, thus increasing the separation between patients and their doctors to the detriment of good dialogue and much-needed collaboration. I also discussed how the growing diffusion of patient-care devices risks further fetishisation of biomedical and epidemiological data. This brings us to the need for those disciplines concerned with ubiquitous ICT (from HCI to health informatics) to critically reflect on the impact and the limits of a disease-centric approach to chronic care and self-care, and to promote a more patient-centric and holistic approach where the needs and concerns of the patient, irrespective of the level of care required and the notion of empowerment are taken seriously.

The key fact is that chronic care is delivered by a variety of different people who bring different (and sometimes inherently conflicting) perspectives, expertise, concerns and information to the table. The challenge is not about applying universal knowledge to solve a problem for good but it is instead about managing a problem that will always be there. Technology has its role in this, and it can support some stakeholders better than others. Equipping patients with technologies that suit the doctor's needs and perspective assumes that health outcomes are simply the result of a delivered, and clinically measurable, medical solution that requires compliance. Such a strategy may verge on the paradox of 'empowering' patients to better silence their voices, but poorly supports them with the practicalities and complexities of dealing with the disease.

The knowledge, language and expertise, acquired through experience and not clinical trials, of individuals with a chronic disease and their various caregivers should be given due consideration when dealing with the heterogeneous aspects of chronic care, thus improving health outcomes. They need to be supported and heard as much as the clinical experts.[17] There is a need for new design approaches in the development of ubiquitous and personal technology for the patient where what falls outside the clinical domain in self-care practices is not seen as a complication to be explained and disciplined, but rather an occasion to fine-tune the many and different variables at play by enriching the expertise and perspectives of all stakeholders.

The TiY prototype illustrates a possible approach to design that rethinks the role of technology supporting self-care practices and the patient. The first principle is that the patient should be encouraged to actively intervene in the open-ended negotiation of the very terms under which their condition is described, understood and discussed. The second principle derives from the first and assumes that the patient should be allowed to take ownership of the technology by adapting it to their unique situation and concerns. Design and policy should support patients' concerns by providing a channel to express those concerns and a means by which individuals can safely explore, reflect on, and tinker with their treatment, body and technology (as suggested by Mol [37]). Initial approaches for this type of tool (more thoroughly discussed in Storni [40]) could be: to support the patient to adjust their medication to better fit their lives (as opposed to technologies that dumbly impose compliance with universal solutions), to help individuals to make sense of certain bodily sensations, to tinker with the therapy to gain knowledge and control and to gather new bottom-up evidence about the effects of certain self-care practices (or of what the doctor asks the patient to do). With such an approach,[18] modestly illustrated by the TiY tool, patients are empowered not only because they actually produce and take ownership of their own health data, but also because they can start keeping track of virtually everything they are concerned with from their own perspective, thereby acting as proactive investigators of their own unique circumstances. The tag generator of the TiY journaling tool offers a degree of flexibility enabling individuals to personalise their self-monitoring practices. If

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[17] Although the area of e-fitness and nutritional education is also growing, there is still the tendency to compartmentalise the different aspects of healthy living (also in the sense that devices tracking and monitoring sport activities might not be interoperable with others monitoring food intake or physiological value), or, more importantly, impose a standard, often quantitative, limiting user appropriation.

[18] Elsewhere I define such an approach as modest and cosmopolitical [43], or based on a design-for-future-uses approach [44].

the TiY tool is properly connected to networked devices, patients could contribute valuable information and insights about self-care practices and routine activities. In a scenario where millions of people will develop a chronic disease and will have to start taking care of themselves in a complexity of different settings, discussing and debating relevant information or evidence might become key to avoiding what risks becoming a new global paternalism [46].

The idea of patients as active producers of useful information, evidence and knowledge (from practical to medical) about care practices is not new [7]. It is currently being reaffirmed in different papers showing new forms of patienthood where new practices and ways of integrating, compensating, counterbalancing or disputing the current clinical model are possible.[19] Some already talk about popular epidemiology [47], unified approaches to social-medical discovery [48], patient-driven research [49], participatory medicine [50], crowdsourcing platforms for self-care expertise [51], medicine 2.0 [52, 53] or even biohacker's laboratories [54, 55]. Literature on patient associations (for instance [56, 57]), movements and lay expertise [40, 58], as well as patient online communities [17] further contribute to depicting a scenario where the agency of patients, especially individuals with chronic disease, is radically reworked.[20]

In this sense, the empowering principles behind the TiY concept and its ability to be adapted to the unique circumstances of a patient can be extended not only to different diseases (e.g. cardiovascular diseases, obesity, asthma and lesser known diseases), but also well beyond the journaling tool described in this paper to include a whole variety of self-care practices and technologies that might point to new social and holistic experiments, new forms of collectively generating and validating knowledge, new evidence about care practices and potentially new and better ways to inform medical research.[21]

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[19] This point resonates with Hartsock's [59] standpoint on feminist theory according to which: "…Accurate knowledge must derive from affected communities. […] Knowledge from affected groups is not merely another voice in a relativistic world. Instead knowledge is a counter-hegemonic force introduced by those who are usually excluded from science".

[20] To some extent, this is already a reality on websites like patientslikeme.com [60] and cure-together.com.

[21] In their paper promoting the need for participatory medicine, Utley-Smith et al. [61] also noted: 'Quasi-experimental trials and qualitative mixed-methods studies have been used with increasing sophistication in supplementing or supplanting designs that leave too many questions of the interactions between causality and context unanswered'.

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