

# Complexity in an Uncertain and Cosmopolitan World. Rethinking Personal Health Technology in Diabetes with the Tag-it-Yourself

Cristiano Storni

· Interaction Design Centre  
Computer Science and Information Systems  
University of Limerick  
(Ireland)

---

## ABSTRACT

This paper reports on a project aimed at improving our understanding of self-care practices and technology, and at designing solutions to support everyday self-management in chronic disease. Diabetes type 1 self-care practices are here discussed as an illustration of complex issues increasingly seen in our society. Drawing on some literature from Science and Technology Studies and from empirical evidence from an ethnographic study of self-care practice in diabetes, this paper suggests to rethink some of the assumptions of the traditional medical model and shows how these seem to be taken for granted in the design of patient-care systems. In particular, it argues for an approach that acknowledges the uncertainties of chronic self-care and so the need to avoid normative approaches that give voices to the clinical and scientific aspects of the disease but tend to silence the lay perspective of the patient. The idea of cosmopolitanism is introduced to suggest the need to support – by design – different perspectives and expertise in self-care practices. This idea invites us to connect the advantages of different ways of knowing a complex matter by seeking complementarity, integration, dialogues and negotiations among the involved stakeholders. In line with this proposed approach, the paper introduces the Tag-it-Yourself journaling system enabling the personalization of self-monitoring practices in diabetes, and an improved visibility of the patient's perspective, concerns and knowledge.

---

Keywords: *patient care, self-care, chronic-disease self-management, mobile health, complexity, uncertainty, cosmopolitanism.*

Paper Received 01/11/2011; received in revised form 14/11/2011; accepted 15/11/2011.

## 1. Introduction

This work refers to a research project aimed to expose to analysis the practicalities and intricacies of dealing with a chronic disease from the patient's perspective, and to

---

Cite as:

Storni. C (2011). Complexity in an uncertain and cosmopolitan world. Rethinking personal health technology in diabetes with the Tag-it-Yourself. <i>PsychNology Journal</i> , 9(2), 165 – 185. Retrieved [month] [day], [year], from <a href="http://www.psychology.org">www.psychology.org</a> .
---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

· Corresponding Author:

Cristiano Storni

Interaction Design Centre, Computer Science and Information Systems department, University of Limerick, Ireland

E-mail: [Cristiano.storni@ul.ie](mailto:Cristiano.storni@ul.ie)

discuss the role of design and technology in the growing and rather complex area of chronic self-care (Barlow, Wright, Sheasby, Turner and Hainsworth, 2002; Bodenheimer, Lorig, Holman and Grumbach, 2002; Wagner and Groves, 2002). This paper focuses on a design solution that was developed to improve the personalization of self-monitoring practices in diabetes type 1. This particular focus is motivated by the fact that the organization and delivery of health services for patient care are currently undergoing deep changes in order to deal with the problematic trends that will bear heavily on health care systems in the next decades. Indeed, constantly increasing health care costs (due to an increasing demand for new treatments as well as a shortage of specialized medical personnel) are converging with the concerns of a rapidly aging population, and an explosion in chronic diseases (especially diabetes and heart disease)<sup>1</sup>. In this progressively complex scenario, new areas of scientific research (such as genomics), the notion of patient empowerment, and the idea of personal care generate understandable enthusiasm and have become phenomena of increasing importance alongside the spread of home and mobile-care systems, networked medical devices, eHealth infrastructures, and health-based social networks (Bauer and Ringel, 1999; Wootton, 2000).

Such enthusiasm reflects the idea of progress and modernity in society which – through the development of advanced technology and organizational forms – unavoidably brings more complexity to our lives. In such a context, it becomes clear then that a serious reflection on the role of design and interactive technology in helping people to deal with the complexity of their chronic conditions outside clinics and hospitals is becoming key (see Unruth and Pratt, 2008).

Despite their importance and magnitude, self-care practices and the patient perspective are still much understudied in the field of design, HCI and Health Informatics with the few exceptions criticizing the mainstream (over)emphasis on the clinical perspective (as also discussed by Koch in his review of tele-medicine and home-care literature (Koch, 2006). Ballegaard, Hansen and Kyng (2008) for example, stress the importance of designing self-care technology with an attention to the aspects of everyday life, and the involvement of patients in the identification of problems, the development of concepts, and the evaluation of the proposed solutions

---

<sup>1</sup> For instance, the World Health Organization counts more than 220 millions people with diabetes with expectation to double this number by 2030. At the same time, it expects that more than 23.6 million people will die from cardiovascular disease. The WHO also predicts that by 2030, three-quarters of all deaths in the world will be due to chronic diseases (such as cardiovascular disease, diabetes, etc.). If current trends persist it is estimated that as many as one in three adults will have a chronic disease by the year 2050.

(on this see also Aarhus and Ballegaard, 2010). Similarly, Axelrod, Fitzpatrick and Burrige (2009) underline the need to understand new domestic environments as they represent a new set of challenges for the design of assistive technology. Storni (2010) discusses the notion of appropriation as key to understanding the multiple ways in which patients make medical knowledge and technology their own in everyday life. Drawing on theories of social shaping of technology, he argues that evaluation studies of complex interventions involving self-care practices need to give a more explicit reflection on role of technology; too often enrolled in a traditional, disease-centric model of care and neglecting the proactive role of the patient. Before that, Orel (1995) first discussed the role of what he called self-vital technology, and anticipated a series of design issues for self-care devices such as the need to think of patients as (pro)active experimenters.

In line with this literature, this paper aims to expose to analysis part of the complexity involved in chronic disease care, and to reflect on the design implications for the design of interactive systems which tackle this complexity. In particular, this work draws on a recent work by sociologist of technology Michael Callon and his affiliated (2009), and argues for a new approach to the design of tools and services to deal with complexity in general, and chronic disease care in particular. Specifically, Callon's notion of uncertainty and the related idea of cosmopolitanism are discussed as they suggest an interesting shift from a traditional positivist attitude toward complexity to a more modest<sup>2</sup> approach that acknowledges the limits of normative methods (based on the assumption that lay people should comply with what the expert says) and the need of plural viewpoints. This approach may represent a way to rethink the role of design and technology dealing with highly complex matters (such as chronic-care). Within this conceptual framework, a case study concerning self-care practices in diabetes type 1 is discussed. It shows how the notion of uncertainties and cosmopolitanism help to rethink some of the assumptions and connotations of the traditional medical model, and how these assumptions are more or less uncritically produced and reproduced (inscribed, embedded, scripted) in the current design of technology to be used by the patient. It is argued that a more modest approach to design - that acknowledge the need to support plural viewpoints and not only the normative viewpoint of the expert - is more adequate to deal with the complexity of new emerging field of self-care

---

<sup>2</sup> The notion of modest technology here refers to Jasanoff's *technology of humility* (2003), which is described as a much-needed approach to complement the hubris of positivist approaches traditionally inspired by the myth of progress, control and predictability, and which fail to acknowledge the limits of control and the lack of perfect foresight.

practices especially in the rapidly growing area of chronic disease. As an illustration of this more modest approach, a design concept, called 'Tag-it-yourself', supporting the open-ended personalization of self-monitoring practices in diabetes is described.

## **2. Theoretical framework: complexity in an uncertain world**

In 1986, the German sociologist Ulrich Beck published 'Risk Society'; a work that soon became a touchstone in contemporary sociology (Beck, 1986). One of the key assumptions of Beck's risk theory is that our society is becoming more complex through the development and use of more complex technologies and organizational forms that are supposed to be essential for the modernization and the globalization process. As an effect of these processes, our society has become more complex and potentially unpredictable. In this sense, the idea of risk has become a more dominant and characteristic feature of our modern and global society. In a recent work, sociologist of technology Micheal Callon and his associates (Callon, Lascoumes and Barther, 2009) built a critique of some of the notions characterizing this modern(ist) perspective. Drawing on this critique, it is argued that the notion of risks and the underlying idea of complexity that is implicit in Beck's view could be misleading and inadequate to inform the design of technologies intended to deal with complexity and complex issues in our society.

Although questioning the traditional myth of unavoidable progress, Callon shows how Beck's theory of risks still relies on a positivist and rationalist perspective based on a traditional separation between scientific knowledge and popular beliefs. In this traditional conceptual framework, it is assumed that: "in order to make the right decision in complex situations the only thing we should do is to rely on indisputable knowledge and field experts" (Callon, Lascoumes and Barther, 2009, p.1). This perspective, the authors continue, "bears the stamp of an asymmetry between experts (specialists who knows best and who are supposed to assess and manage risk) and lay people (non-specialists who instead are often at risk). The former, assuming that they are faced with an ignorant or even obtuse public, take the mission of enlightening and instructing the latter" (p. 33)(e.g. to address potential risks in complex situations, to inform decisions based on available scientific evidence, and so on).

The authors suggests that many of the complex situations in our contemporary society are better understood in light of the notion of uncertainty rather than the notion of risks and its assumptions. One of the arguments is that risks and uncertainties are

indeed false friends. The notion of risks resonates and links to the idea of rational and informed decision, and assumes that all options have been explored and the possibility of harmful effects has been foreseen. Even though we are not able to know whether a harmful event is going to occur or not, the assumption is that we do know the statistical probability of its occurrence (thus the notion of risk). On the contrary, the notion of uncertainties underscores the fact that scientific knowledge often proves to be incapable of anticipating the effect of certain decisions, understanding all the possible options, and informing a rational decision. The idea of risks and that of uncertainties imply radically different decision-making processes in complex situations, and so suggest different design assumptions in the design of supporting and assistive technology.

According to this argument the real challenge in uncertain situations is that “it is no longer a matter of identifying and negotiating risks, as in a contract between insurer and insured, but of establishing constraining procedures for managing the apparent contradiction between minority points of view (e.g. lay perspectives) and what some consider to be the general interest” (Callon, Lascoumes and Barther, 2009, p. 16). This translates to the need of finding ways and procedures to deal with the different and often clashing perspectives characterizing complex issues that are too often reduced to a dominant viewpoint to the detriment of its others (in our case the taken-for-granted clinical perspective which often silence the perspective of the patient).

This distinction brings us to the second notion that is useful to re-think some of the assumptions of our understanding of complexity and the issue of approaching it with design and technology. Once we have acknowledged the limit of the notion of risks and the rationalistic and normative underpinning of traditional decision-making in conditions of complexity, we start to appreciate a new landscape, where the great modern divisions become outmoded: “to start with we should accept the fact that the knowledge of specialists is not the only knowledge possible [...] we should recognize the richness and relevance of knowledge developed by laypersons” (Callon, Lascoumes and Barther, 2009, p.11); they are not simply passive elements. Rather, both traditional experts and laypeople possess specific forms of knowledge (a capacity of diagnosis, an interpretation of the facts, a range of solutions) that have the potential to mutually enrich each other. We define this character cosmopolitanism. This position acknowledges that when we have indisputable knowledge and all options are known and have been assessed, we can adequately deal with complexity by assuming the knowledge and decisions of specialists as superior (therefore also treating all the rest

as a superstition to be silenced (by design)). However, when uncertainties predominate, it is suggested that complexity should be dealt with differently (and so with different designs). In these situations complexity is cosmopolitan and is characterized by a variety of voices and different perspectives. Rather than assuming expert knowledge as the standard, it becomes important to make voices heard and issues (or risks, or controversies) debatable and negotiable. Any attempt to reduce this complexity to a specific expert perspective (or language, or domain of knowledge) will simply fail to appreciate the important contribution of the different expertise and perspectives in play, perhaps even limiting them, and will probably complicate rather than ease the approach to complexity.

In the next pages this argument (based on what Callon define as the principle of precautionary action) is applied in the context of self-care practices in chronic disease which is the subject of this paper. It is shown how self-care practices, especially in chronic disease such as diabetes, are a highly complex matter, and they could be better understood in terms of uncertainties and through the lens of cosmopolitanism, and that this is a more adequate way to rethink the role of design and technology in such complex situations.

Through an overview of the results of our analysis (discussed in details in Storni, 2011), it is showed how the traditional medical model is still dominant and taken for granted, and how self-care technology is embedded in some of its modern(ist) assumptions (such as the intrinsic biomedical reductionism, or the asymmetry in the doctor/patient relationship) thus making it difficult to appreciate and support the role of different perspectives (of the patient and of their informal care givers) in everyday self-care practices or on the medical encounter.

This work is in line with some recent works on mobile, and home care technology in diabetes (Kanstrup, Bertelsen, Glasermann and Boye, 2008; Mamykina, Mynatt and Kaufman, 2006; Mamykina, Mynatt, Davidson and Greenblatt, 2008; Mamykina, Miller, Mynatt and Grennblatt. 2010; Preuveneers and Berbers, 2008; Smith, Frost, Albayak and Sudhakar, 2007), which represent an exception to the mainstream idea of predictive, persuasive and normative technology<sup>3</sup>. Going beyond the traditional focus on usability characterizing HCI research in the clinical domain, these works have recently developed a series of particular research perspectives to inform the design of

---

<sup>3</sup> Predictive approaches and persuasive technology (Fogg, 2003) are indeed based on the modernist assumptions based on the idea of scientific methods, rational decision-making process, quantitative risk assessment, and again, a marked separation between the knowledge of (medical) experts and that of other stakeholders (e.g. the patient). In this sense, they tend to be reductionist, normative and authoritarian.

technology supporting self-management. Mamykina and colleagues (Mamykina, Mynatt and Kaufman, 2006; Mamykina, Mynatt, Davidson and Greenblatt, 2008) focus on reflection and sense-making by putting the patient understanding as key to self-management, Kanstrup, Bertelsen, Glasermann and Boye (2008) aim to an holistic approach to design-for-more in diabetes. Smith, Frost, Albayrak and Sudhakar (2007) emphasise the utility of multi-media to support understanding and communication while Preuveneers and Berbers (2008) follow the idea of using mobile technology in diabetes self-management.

### **3. Case study: diabetes self-care practices**

This work is based on a case study on self-care practices and technology that focuses on diabetes as an illustration of a demanding chronic disease where self-care and -management is key. In order to expose to analysis the practicalities and intricacies of everyday diabetes self-care practices, the author has joined a diabetes support group for about ten months and extensively interviewed fourteen diabetics type 1. Observations were also performed in a limited number of occasions in the form of shadowing (e.g. home visits) whereby the author was invited to assist in daily routines (such as cooking, preparing for physical activities, or buying food at the market). 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 early design scenarios. In the context of this research, also two General practitioners, two specialist endocrinologists, two diabetes nurses and seven community pharmacists were also interviewed. 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 constantly invited to provide practical examples and stories instead of talking in general terms. Experts were also interviewed about their relationships and issues with patients, as well as their opinion about the design approach suggested by this research. Informed consent was obtained from participants in compliance with the suggestions of the local ethics committee; obtained data were stored and protected according to the guidelines of the National Data Protection Authority (DPA).

An extensive literature review in medical sociology and medical science was also conducted. Only part of the material and of the reviewed literature informs this paper. Reported names are purely fictional.

### 3.1 Findings

A more detailed discussion of the empirical investigation that informed this project is available in Storni (2011). The focus of this paper is more on how its theoretical framework has informed the operational design of the Tag-it-Yourself (TiY), and how it has the potential to improve the relationship between self-care technologies and chronic-care in general, and diabetes-care in particular. The role of the empirical investigation was to orientate a reflection about the possibility to re-think self-care technology and interactive systems in view of the exponentially growing area of chronic disease. It was in fact due to issues that emerged during the investigation that we started to perceive how some of the assumptions and connotations of the medical model, which can be easily taken for granted in design, need some serious discussion.

First of all, it is quite evident how diabetes does not fit with the traditional idea of the sick role and the disease-centric model of health where there is a clear-cut separation between being sick and being healthy. Diabetes is indeed ubiquitous and inseparable from any aspect of everyday life. The following extract, one of the many, clearly illustrates this aspect:

Mary, diabetic type 1: 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...

Another interviewee depicted diabetes as a constant in their life as reaffirmed by the next extract:

Orla, Diabetic type 1: 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 [...]

This constant nature is complicated by the fact that no matter how good you become in managing your glucose levels, total control or mastery is always impossible or temporary at best. One of the interviewees reaffirmed this point clearly:

Hellen, Diabetics type 1: even if we did the very same things every day and ate the very same things and 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.

This brief series of extracts already shows the open-ended nature of self-management in diabetes (you never stop, you are never 100% sure it is going to work) and therefore its uncertain nature where it becomes impossible to know and to measure all the things that could have an influence in an individual's sugar level. More importantly from a design perspective, it was quite remarkable to witness a huge variety and difference among patients: for some, living with diabetes is not a big deal and it is relatively easy to fairly manage glucose readings, while for other subjects (sometimes because of their attitude toward the disease, sometimes because of the personal/social circumstances which made it difficult to self-manage properly), diabetes is a constant struggles. In any case, self-care practices are, from a patient's perspective, a matter of unique and personal compromises, and this makes it very difficult to develop design requirements.

Other interesting and problematic elements refer to the variety witnessed in the voices and perspectives of those involved in diabetes (self-)care: doctors, specialists, nurses, pharmacists on the one hand, and family members, friends, support-group members or online mentors on the other. They bring a whole multiplicity of views which instantiate in a selection of advices and suggestions (or prescriptions) that are not necessarily aligned to one another, and within which patients often find themselves rather conflicted.

In some cases, this difference in viewpoints and advices polarizes and ends up generating conflicts and separations between patient and doctors that are difficult to manage and that risk compromising their collaboration. These conflicts often seem to originate from the inadequacy of some of the mentioned modernist assumptions of the traditional medical model (historically evolved within a model of acute disease and episodic care) especially in relation to the way they privilege the clinical perspective,

and fail to fully acknowledging the patient's viewpoint and agency. The following extract, from an experienced diabetic, clarifies this point:

Paulina, Diabetic type 1: '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 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'.

This aspect was often reaffirmed in the interviews, especially relative to the patient's opinion that a healthy specialist cannot understand the issues of self-managing and constantly dealing with the disease outside the clinics and the hospital because she/he has no experience of it. This perceived distance and asymmetry can have the detrimental effect: some patients start to lose confidence on how helpful the doctor can really be for them. As an effect of this, in the most extreme cases, patients start to keep things to themselves as they assume they are not going to find the understanding they might expect from the medical staff.

Geraldine, Diabetic type 1: 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 are not going to be forthcoming...that's what's missing from that side...well we make up for it!

This making up for the lack of expected dialogues with the doctors seem to be a rather concerning aspect especially in relation with the growth of chronic disease, and this reaffirms the need of more patient-centric approaches to chronic care. Indeed, when the role of the doctors is kept within the traditional paternalism (for instance due to lack of resource of specialized personnel to engage more directly with patients), the witnessed separation between the patient and the doctor grows worryingly wider and reflects on self-care practices themselves. Journaling practices, which are key to self-

monitor and self-management (in chronic disease in general), are an example of this further separation:

Geraldine, Diabetic type 1: 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 judgment on one reading.

During an interview with an expert diabetic (Marc), an interesting distinction emerged between self-monitoring and journaling. He argued how he sees two aspects of self-measurement. The first is to check the levels of glucose with respect to a value that is known and that diabetics should try to keep stable. Interestingly he defines this value as: a fetish! this is what your doctor asks you to do. The second aspect of self-monitoring has instead to do with assessing one's own physical sensations, or with checking the glucose to adjust insulin intake prior to (or after) a planned (or not) mundane activity (such as playing sport, eating outside, traveling, etc...). In this sense, glucose meters are re-appropriated by users to make them fit with the intricacies of their personal life. Design-wise though, glucose-meters seem to be rather restrictive: while they fit well with the clinical understanding of the disease and the doctor's need to have her/his patient to collect numbers (the fetishist aspect of self-monitoring that Marc mentioned), they seem to fall rather short in supporting patients themselves to see how these numbers related to the mundane aspects of everyday life in order to better deal with them (the other aspect of self-monitoring mentioned by Marc). The following extract from another participant shows this aspect and underline how current technology often assumes rational (and positivistic) uses:

Paulina, Diabetic type 1: 'I got this new meter about two years ago and this is suppose to do most of this for me but you see it has a log book, you cannot input other stuff, let me see... glucose by meals, you can enter you meals but you have to enter them as, you basically have to enter the amount of carbs [...] It does not allow input meal outside meal time [...] It's just very restrictive, it gives you, it's like multiple choices [...] can't actually free write...'

This brief overview of the research's results shows the complexity of self-care practices in chronic disease and how difficult it is to design pre-defined solutions that suit the huge variety of patients and their stories. Given the open-ended and personal nature of diabetes self-management, we learn that there is any number of pre-figured sets of design requirements that can actually fit and support the huge variety of users, their circumstances, their attitude toward the disease and their literacy, not to mention the fact that sometimes the very same activity (such as driving for instance) affects different people (or the same person in different times) in radically different ways. From a design perspective, this suggests that instead of designing a universal (clinical and rational) solution to be imposed on users, we rather need to enable them to design and personalize their own self-care practices to better fit with their life and possibly to support the generation of patient expertise in dealing with the disease. It therefore became important for our research to enable the participants to reflect on the lay aspects of their lives and then relate them to the clinical ones that are the only ones discussed in the medical encounter or supported by current self-care technology (as if it was designed with a medical expert in mind, therefore also preventing by design to look at the disease in different ways or terms!). It was decided that it was important to support the visibility of non-medical aspects that impact on health outcome and that – due to the above-mentioned reductionist and restrictive nature of current designs – seem to be difficult to bring to the surface, to debate and to discuss with a variety of formal and informal care givers in the negotiation of everyday care practices.

#### **4. Discussion and Design: the Tag-it-Yourself (TiY) approach**

The investigation showed that journaling glucose levels and insulin intakes is key in diabetes self-care practices as it enables diabetics to keep track of their values in the attempt to retain control over their sugar levels. Journaling turned out to be so crucial for at least two reasons. First of all, it is in reviewing the values tracked in the journal (e.g. in the attempt to find patterns) that diabetics can build sense, gain knowledge and possibly more control over the disease. However, as already discussed the activity of keeping track of glucose reading and insulin intake suits the doctors perspective but is limited in providing patients with a more comprehensive variety of information that is potentially useful for their own perspective. The second aspect is that journals often act as an exchange currency in the medical encounter, and are partly responsible for affording as well as constraining the possibility to discuss about certain things and not

others. In particular, it has been shown how a strictly quantitative approach makes it more difficult to talk about things that cannot be measured, even when these represent relevant concerns from the point of view of the user/patient<sup>4</sup>. As we become aware of how note-taking and the monitoring of non-clinical aspects are poorly supported in current glucose meters and journals templates (and how limiting it is to reduce the issues faced everyday by diabetics to a series of physiological values), the focus of our design shifted to allow patients to keep track of whatever matters from their point of view, thus complementing the clinical perspective with their own. Given these factors, and by acknowledging the limits of a prescriptive and normative approach in highly complex settings, we decided to experiment with open-ended editor that would allow bottom-up personalization of self-monitoring practices through the creation of unique categories of data (called 'tags') to fit the patient perspectives and to allow them to generate evidence about the effects of their own self-care practices (in their own terms and according to their own concerns and agenda). The open-ended nature of the editor supports the idea that things change continuously and unforeseen needs can emerge at any time, even for the most experienced patients. The possibility to generate lay categories of data emphasizes the idea that patients (should be supported to) reflect on their own experience and develop lay expertise about how to deal with the practicalities of their life - aspects that often cannot be reduced to biomedical categories, even if they equally contribute to good care and positive health outcomes.

The open-ended editor is called Tag-it-Yourself (TiY) and it is currently based on an iPhone App which we have tested with five of our participants for two months. The idea of the application is to enable the patient to tag things and events in everyday life by tracking lay aspects as well as attaching all sort of multimedia information to traditional glucose readings and insulin intakes. This improves the possibility to explore meaningful correlations and patterns, track and generate evidence of the effects of their actions, possibly improving reflections, sense-making and feelings of control. The attached information can be pictures (as suggested in Smith et al. 2007) notes (audio and written) (as suggested in Preuveneers and Berbers, 2008) or, indeed, patient-generated tags.

---

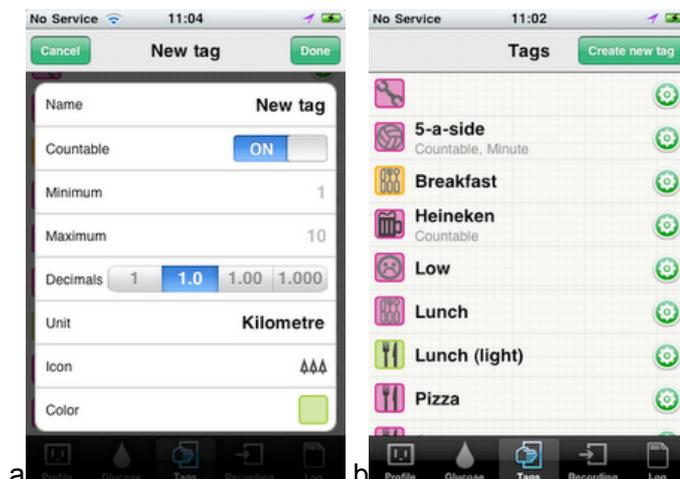
<sup>4</sup> However, we should notice that journals are not 'reductionist' per se. In attending the self-help group, it was noticed how the very same thing that contributes to making some medical encounters particularly frustrating for some patients, becomes a trigger for open conversations about what went wrong or right in certain situations. Patients in the group exchange their journals willingly, point to things together, discuss alternatives, add notes, and tell stories to one another. In their interaction numbers are important but not at all times and in all places.

The TiY present itself as an advanced journaling system with five pages accessible by five buttons in the bottom menu bar. The first page 'profile' allows inputting personal information (e.g. contact information, emergency contacts, type of insulin, and so on). It also gives access to a setting page where general settings can be managed (default metrics, default opening page, enabling password, and so on). The second button 'glucose' offers an easy-to-use wheel widget to input glucose readings (Fig. 1a). As a new reading is recorded, the application presents the patient with the possibility to attach extra and contextualized information such as pictures, notes, insulin intakes, or patient-generated tags (Fig. 1b). In case a user wants to keep track of aspects that are not necessarily related to a specific glucose reading, a record page (accessible with the fourth button in the menu bar) can be accessed enabling the record of notes, pictures or tags.



**Figure 1.** The interface to input glucose readings (a); as a new reading is recorded, the system offers the possibility to attach extra information to the reading in question (b). In the above case, a patient tested his/her glucose level after having run for 3.1 km. Extra information attached to this reading are: a tag about run (green icon), a picture (yellow icon), injected units of rapid insulin (violet icon), and information about a post-run snack (pink icon).

The tag editor (Fig. 2) can be accessed by the third button and offers the possibility to create lay categories of data concerning virtually anything matters from the patient perspective.



**Figure 2.** What the Tag editor (a) and how the tag page (b) look like after being personalized by a user. In this case a user has created a series of tags (some countable, some not) such as a five-a-side game, breakfast, a Heineken, feeling low, a pizza, and so on.

As showed in Fig. 2a, Tags can be countable or not and can relate to a large list of available international metrics (for instance going to the gym can be tracked in terms of minutes of training or, if further equipped with other monitoring devices, in terms of burned calories; beers can be tracked in terms of glasses or pints; breakfast in terms of consumed carbs, slices of bread or cups of cereals, and so on). As each new tag is created, the patient finds a new button in the glucose-tracking page that allows attaching tag-related information to a specific glucose reading (or to track something as a simple independent record). The log function allows the user to review glucose readings textually and graphically along with lay-generated tags that support further possibilities to integrate the multiple views in order to find patterns, tinker with aspects of daily life, and possibly see how these lay aspects affect glucose readings to improve control on the disease. A series of volunteering diabetics tested the TiY and expressed great appreciation for the journaling system and the idea of tags<sup>5</sup>. Patients found useful to create tags for a variety of things: meal tags to highlight pre- and post-meal readings; tags to track sports and other physical activities (gym, walking, running, swimming, etc); diet tags to track intake of, for instance, carbohydrates, fat, fibers, snacks, and new food ordered in restaurants; tags for medical tests such as HbA1c, Ketones, and CBC; medications; individual symptoms or sick days; daily activities (such as driving) or travelling, and more.

Patients found it very useful to be able to recall specifically tagged readings related to specific aspects of their life to look for pattern. This can be accessed by the fifth button

<sup>5</sup> A detailed report of the evaluation trials of the TiY is available in Storni, 2011.

that gives access to a log page (available in both textual and graphical form). The ability to customize graphical visualizations of the log further improved the possibility to make comparisons between different activities, values, periods of time or intakes (Fig. 3).

Patients also seemed to appreciate the idea of augmenting glucose reading with pictures also attachable to tags (and visible in the graph). Some mentioned how useful it would be to recall what they ate or to create a collection of food nutritional labels to enhance recall and awareness of this information. If further enabled with printing and reporting capabilities (currently not available in this version), the TiY could even widen the scope and quality of the medical encounter, with better use of the little time available, improved dialogues and support for a fine-tuning of the many and heterogeneous aspects in play. The idea is also to reduce the opportunity for conflict and improve collaboration, social learning and dialogue as, ideally, the creation of tags can be discussed and negotiated with doctors or other care givers.



**Figure 3.** The log as text that can be sorted according to time, tags, and attachments; the graphs selection menus where the user can decide what category of data to visualize (3b); shows an instance of the graph with two categories of data (and a feature that allow separate scrolling of same data along a timeline to further support comparison among different times, 3c).

Finally, as also confirmed by the next extract, one result can be to allow the generation of bottom-up evidence to support the effect of certain actions:

Paulina, Diabetics type 1: 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 show to my doctor and try a new thing.

## **5. Conclusion and further research**

This paper started by addressing the issues of complexity and by discussing two different approaches that have implications in the way we design interactive systems to deal with complex issues. This issue has been discussed in the context of self-care in chronic disease as an illustration of complexity which will be increasingly widespread in society, and where the role of technologies and interactive systems is central. Drawing on Science and Technology studies, and in particular the work by Callon, Lascoumes and Barther (2009), it has been discussed how complex situations, such as care in chronic-disease, are better understood in the light of the notion of uncertainties and through the lens of the idea of cosmopolitanism. The notion of uncertainty suggests a shift from a traditional positivist attitude toward complexity to a more modest approach that acknowledges the limits of positivist, normative and predictive approaches, the possibility of unforeseen consequences and lack of control, and the need for plural viewpoints and collective learning. The notion of cosmopolitanism acknowledges the co-existence of different domains of expertise and invites us to connect the advantages of different ways of knowing a complex matter by seeking complementary, integration, dialogues, negotiation and, mutual enrichment.

It is argued that this perspective better reflects the daily aspects of dealing with a chronic disease and has the potential to better inform the design of interactive systems dealing with complex situations, especially in relation to the open-ended and uncertain nature of chronic-care, and the problematic interactions between different perspectives in everyday care practices.

As an illustration of this approach, the Tag-it-Yourself platform is introduced. The TiY is a tool designed to enable the patient to personalize self-monitoring practices, and possibly to support the generation of patient knowledge and expertise in integration

and dialogue with its clinical counterpart. With the TiY, patients are in fact supported in their perspective not only because they actually produce and own the health data that their doctors want them to collect, but also, and more importantly, because they can start to keep track of and correlate virtually everything that concerns them, thus increasing their chance to explore and tinker (as argued in Mol, 2008, or Orel, 1995), to research and make sense of the many aspects of living with a chronic disease (as argued in Mamykina, Mynatt, Davidson & Greenblatt, 2008), to learn and improve their sense of control, their collaborations with other care givers, and, ultimately, their health outcomes.

One of the key intentions here is to avoid the risk of confusing patient discipline (as in the traditional model) with patient education and collective learning (where the experts also have much to learn from lay and affected people) and to explore the potential of design for the patient perspective to improve healthcare. As Suchman once observed: 'Technological change can [...] be an occasion for either the expansion of existing forms of authoritative knowledge, or for their transformation. At the core of this project is the question not only of how information flows, but of who defines what constitutes 'information' in the first place' (Suchman, 2002). With the TiY, the patient's agency and viewpoint are highlighted, to the extent to which she or he can actively intervene in the negotiation of the very terms under which her/his conditions could/should be described, understood and discussed.

As mentioned, the TiY platform confirms that patients do indeed appreciate being able to create their personalized journaling system, to create unique tags, and to use them to investigate and better understand their everyday issues and practicalities. Even doctors seem to be in favor (at least in theory) of supporting more holistic journaling practices, although they are understandably concerned with data fabrication. Unfortunately, the creation of a systematic trial involving medical experts was beyond the reach of our project, and this clearly represents an important step for future research along with the extension of the TiY approach to different chronic and lesser known diseases. A proper evaluation of this approach is however very difficult because only long-term trials have the potential to assess the impact of the idea of patients being technologically enabled to generate new data and information in relation to their health conditions and self-care practice (thus fueling their knowledge and expertise beyond the clinical perspective), not to mention the real impact of such an approach on the interaction with the medical staff (where the paternalistic tradition is still dominant).

For now, this work invites us to reflect on the nature of complexity and on whether some of the key voices in complex matters are being silenced by certain (design) assumptions. It suggests an approach that could be valuable in informing the design of interactive systems that deal with complexity in general, and with chronic disease (self) care in particular, and where to make things visible and debatable from different perspectives is more important than implementing a solution based on available expert knowledge.

## 6. References

- Aarhus, R. & Ballegaard S. (2010). Negotiating Boundaries: managing disease at home. *Proceedings of CHI'10* (pp. 1223-1232). New York: ACM Press.
- Axelrod, L., Fitzpatrick, G. & Burrige, P. (2009). The reality of homes fit for heroes: design challenges for rehabilitation technology at home. *Journal of Assistive Technologies*, 3(2), 9-23.
- Ballegaard, S. A., Hansen, T.R. & Kyng, M. (2008). Health care in everyday life: designing healthcare services for daily life. *Proceedings of CHI'08* (pp. 1807-1816). New York: ACM Press.
- Barlow, J., Wright, C., Sheasby, J., Turner, A. & Hainsworth, J., (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counselling*, 48, 177-187.
- Bauer, J. & Ringel, M. (1999). *Telemedicine and the Reinvention of Healthcare*. New York: McGraw-Hill.
- Beck, U. (1986). *Risk Society: toward a new modernity*. London: Sage.
- Bodenheimer, T., Lorig, K., Holman, H. & Grumbach, K. (2002). Patient self-management of chronic disease in primary care. *JAMA*, 288(19), 2469-75.
- Callon, M., Lascoumes, P. & Barther, Y. (2009). *Acting in an uncertain world, an essay on technical democracy*. Cambridge: MIT press.
- Fogg, B.J. (2003). *Persuasive Technology: Using Computers to Change What We Think and Do*. San Francisco, CA, USA: Morgan Kaufmann Publishers.
- Hartsock, N. (1998). *The feminist standpoint revisited and other essays*. Boulder, Colorado: Westview Press.
- Jasanoff, S. (2003). Technology of Humility. *Minerva*, 41, 223-244.

- Kanstrup, A., Bertelsen, P., Glasermann, M. & Boye, N. (2008). Design for more: an ambient perspective on diabetes. *Proceedings of Participatory Design '08* (pp. 118-127). New York: ACM Press.
- Koch, S. (2006). Home Telehealth- Current state and Future Trends. *International Journal of Medical Informatics*. 75, 565-576.
- Mamykina, L., Mynatt, E. & Kaufman, D. (2006). Investigating health management practices of individual with diabetes. *Proceedings of CHI'06*. 927-936.
- Mamykina, L., Mynatt, E., Davidson, P. & Greenblatt, D. (2008). MAHI: investigation of social scaffolding for reflective thinking in diabetes management. *Proceeding CHI'08* (477-486). New York: ACM Press.
- Mamykina, L., Miller, A., Mynatt, E. & Grennblatt, D. (2010). Constructing identities through storytelling in diabetes management. *Proceedings of CHI10* (pp. 1203-1212). New York: ACM Press.
- Mol, A. (2008). *The logic of care and the problem of patient choice*. London: Routledge.
- Orel, T. (1995). Designing self-diagnostic devices. In R. Buchanan & V. Margolin, (Eds.) *Discovering Design* (pp. 77-102). Chicago: The University of Chicago Press.
- Preuveneers, D. & Berbers, Y. (2008). Mobile Phones assisting health self-care: a diabetes case study. *Proceedings of Mobile HCI'08* (pp. 177-186). New York: ACM Press.
- Smith, B., Frost, J., Albayrak, M. & Sudhakar, R. (2007). Integrating glucometers and digital photography as experience capture tools to enhance patient understanding and communication of diabetes. *Personal and Ubiquitous Computing*, 11(4), 273-286.
- Storni, C. (2010). Multiple forms of appropriation in self-monitoring technology, Reflections on the role of evaluation in future self-care. *International Journal of Human Computer Interaction*, 26(5), 53-561.
- Storni, C. (2011). *Designing for Patient empowerment in chronic disease: the Tag-it-Yourself concept in diabetes Self-monitoring*. Manuscript submitted for publication.
- Suchman, L. (2002). Practice based design of information systems: notes from the hyperdeveloped world. *The Information Society*, 18, 139-44.
- Unruth, K. T. & Pratt, W. (2008). The Invisible Work of Being a Patient and Implications for Health Care: “[the doctor is] my business partner in the most important business in my life, staying alive”. *Ethnographic Praxis in Industry Conference proceedings, 2008*: 40-50.

- Wagner, E. & Groves, T. (2002). Care for chronic diseases. *British Medical Journal* 325, 913-914.
- Wootton, R. (2000). The development of telemedicine. In M. Rigby, R. Roberts, & M. Thick (Eds.), *Taking health telematics into the 21st century*. Abington: Radcliffe Medical Press.

