DESIGN FOR FUTURE USES: PLURALISM, FETISHISM AND IGNORANCE

(OR THE EPISTEMOLOGICAL AND CHRONOLOGICAL POLITICS OF DESIGNING FOR TYPE 1 DIABETES)

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ABSTRACT

In this paper, I question the epistemological and chronological politics of design. Concerned with the role of technology and design in a democratic society, I problematize the divisions between expert and lay knowledge, and between design (before) and use (after). I argue that designs that assumes those divisions risk of colonizing the future, and limiting the possibility of appreciating different forms of knowledge that are not available/voiced at design time. Drawing on a series of Science and Technology Studies about the interplay between knowledge and ignorance in our society, I argue for an approach to design for future uses that acknowledges our present ignorance and lack of control, and that aims at procrastinating and delegating design decisions until the actual future time of use, To illustrate this approach, I report on a design project concerned with chronic disease self-management and aimed at developing and evaluating a platform for the personalisation of self-monitoring practices in type 1 diabetes.

INTRODUCTION

The idea of the professional designer is a modern one. Inheritors of the Victorian spirit of progress, specialized designers use scientific knowledge, their skills and expertise; tools, specialized languages, and machines, to devise efficient solutions for those, the users, who are experiencing (or will experience) a 'problem'.
Concerned with the hegemonic potential of this modern approach to design and with the establishment of a more democratic design process, participatory and collaborative design emerged to challenge the assumed asymmetry between professional designers and lay end-users with the motto: *we should design together!* (Ehn, 1989, Schuler and Namioka, 1993).
Two issues were raised that are particularly important for this work. The first is that design is *political* because its product has the potential to redistribute power and authority in society. The second, which is a corollary of the first, is that design is epistemic because it has the potential to privilege certain forms of knowledge, and to reaffirm the assumptions that are attached to them (for instance, what count as relevant information). '*Designing together*' was therefore concerned with re-establishing the asymmetry between designers and end users as well as between their knowledge, values and expertise. Over the years, these two topics have received a great deal of attention in the fields of Human Computer Interaction and Participatory Design. More recently, a series of recent scholarships have started to ask deeper questions about the meaning of democracy and participation in design (DiSalvo, 2010, *et al* 2010; Ehn, 2008; Björgvinsson *et al* 2012, 2010). Reflecting these concerns, others further challenged the asymmetries of knowledge and expertise between professionals and lay people by opening up the design through post-industrial technologies (like open-source or personal fabrication) or social movements (such as design activism, DiY and DiWO, participatory innovation). In relation to these developments, some have explicitly challenged the separation between design and use, by proposing a series of intriguing concepts such as: meta-design, design-after-design, design-in-use[1] (Fisher *et al*, 2004; Redstrom, 2008; Ehn,

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[1] With a less prominent focus on power, this strand of work also reflect early studies in the social shaping of technology (MacKenzie and Wajcman;1985) and appropriation studies (Eglash *et al* 2004).

2008). In this work, I focus on the political and epistemic dimensions of design, and I try to bring two contributions to those concerned with the role of design and technology in the making of a democratic society. The first concerns my focus on the chronological asymmetry between design as future-making, and actual future uses. In particular, I discuss the separation between what is known, and assumed to be relevant at design time (which is therefore incorporated in the design itself), and what can be learned, and become relevant, at the actual time of use.

Indeed, design, from traditionally professional to more participatory, is often seen as *future-making.* Like prophets those involved in design predict, prescribe, and script how certain situations will/should/might be handled by future end-users. In this perspective, the design-time represents the 'present' that designers are concerned with (as in '*we design the future NOW*'); and 'use' represents the 'future' to be aiming at. In these terms, one might define design as a set of practices aimed at realising a certain desirable future, by the use of the resources and the knowledge available in the present. This sounds rather natural: we take the best knowledge available today, and the most representative experts (being those professionals or potential end-users, specialists or laypeople), and we try to design the best possible future, perhaps together.

I argue that, as the settings for which design is required grow in complexity (meaning that available knowledge and control are limited), the epistemic separation between the time of design and the time of use increases. Therefore, design as future-making becomes an increasingly problematic, and perhaps even dangerous, idea. Indeed, when use will occur in the future, what was fixed in a design (especially the epistemological assumptions about what knowledge is relevant or what counts as information) cannot but ignore what has become available as we moved from the past (when design occurred) to the present (for example new knowledge, new stakeholders, new information or issues). The problem is however not so much that what is available to inform the design today has the potential to fall short addressing tomorrow's contexts of use. This is an old argument that has been discussed extensively in different ambits[2]. The problem, I argue, has to do with the political and epistemological dimension of this separation. I want to discuss that knowledge and categories fixed in a design and circulated through scripts[3] can act as colonising forces[4] that, by affording certain behaviour, actually limit the possibility to appreciate what was not known at the time of design but became relevant at the time of use. As colonies, those conquered by a design will be likely to loose their language and perspective, and to be imposed a certain worldview. And this brings us to the second contribution of this work.

This concerns the specific application areas in which the chronological and epistemic asymmetry is challenged by opening up the design to future users. This work reports on a design project aimed at developing supports for self-care in chronic diseases, and raises issues about the epistemic and colonizing asymmetry between medical professionals and affected individuals. In particular, this paper reports on the development and evaluation of an open-ended platform supporting the personalisation of self-monitoring practices in diabetes.

The next pages are structured as follows. First, I re-frame the traditional separation between experts (designers) and laypeople (users). I do this in light of recent literature in STS that has addressed this division by re-working the notion of democracy and participation in science and technology. I argue that this literature can bring important contributions to those concerned with the political and epistemic dimension of design. I then move to a discussion of the separation between design and use, and I warn against the potentially colonising role of the present (design) over the future (use). Here I draw on a series of STS concerned with the production of knowledge in our society with a peculiar focus on 'ignorance'. Based on this discussion, I develop a pragmatist view of ignorance in design, and I discuss the paradox and potential danger of design as future-making which seems to overvalue what is known at design time to the detriment of what is ignored. What follows is then the illustrative description of the mentioned case study and its discussion. Mindful of the peculiarity of the case study, specificities and limit of the analysis will be highlighted in the conclusions.

PLURALISM: RE-THINKING THE MODERNIST SEPARATION BETWEEN EXPERTS AND LAYPEOPLE

There is an interesting parallel between recent developments in the agenda of the participatory and collaborative design research, and works in the STS, especially those of Actor-network theorists Bruno Latour and Michel Callon. The notion of democracy and participation is key in both discourses. Latour is concerned with describing our society by *dis-assembling it*, but he seems to be equally concerned with *reassembling the social* (Latour, 2005a; 2008), which sounds quite clearly a design endeavour. Even if not explicitly framed as such[5], Latour provides an articulated view that evokes the need to establish a *Parliament of Things* (Latour, 2004) and a *dinkpolitik* (Latour, 2005b) based on *making things public* and the *possibility to disagree*, and concerned with the *co-existence of differences* (humans and/or non-humans,

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[2] Early concerns were raise in CSCW (Robinson, 1993), in PD (Henderson and Kyng, 1991) and HCI (McLean et al. 1990), just to mention some foundational works in this area.

[3] See Akrich, 1992 for the popular notion of scripts in the description of technical objects; see also Storni, 2009 for its use in design studies.

[4] Link with post-colonial and feminist studies is clear here. While these approaches are concerned with issues of power and domination of one social group over the other (in different geographical areas, or different social ambits), I here focus on the chronilogical dominance of todays presumed knowledge over what is not known (yet).

[5] An exception in this sense is represented by the initiative Mapping Controversies and its explicit focus on the use of design (graphic dand information design) to render social controversies (Venturini, 2010).

their perspectives, ways of being and knowing, politics, associations with others) in a commonly built world. Owing much to these works reworking pluralism, Callon *et al* (2009) similarly argue for rethinking some of the assumptions of the modernist tradition of representative democracy, based on a form of consensual delegation that establishes a separation between the delegated expert and the delegating layperson. According to Callon *et al* this separation is not longer adequate to deal with today's complexity as:

> "*it bears the stamp of an asymmetry... The former, assuming that they are faced with an ignorant or even obtuse public, take the mission of enlightening and instructing the latter*" (Callon et al. 2009, pg. 33).

Rather, Callon *et al* argue that today:

> "*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*" (ibid. pg.11).

Similarly to Latour's parliament of Things[6], Callon puts forward the idea of *hybrid forums.* These are loci for debates that are aimed at generating social learning where the knowledge of the expert (based on formal *experimentum*) and that of the concerned laypeople (based on *experentia*) do not mutually exclude one another. Instead of former being used as a default while the latter is silenced, rather, they confront and enrich each other. They add:

> '*the procedure to be devised to organize this collective learning, all of which are directed toward the constitution of a common world, must allow for the simultaneous management of both the process of the fabrication of identities and the process of the fabrication and incorporation of knowledge'.*

Here the proposed model of democracy does not assume any consensual delegation and says very little about whether consensus is the actual goal. Quite the opposite, the reach of a consensus is seen sceptically because, as Jasanoff noted:

> *'Agreement is often reached to the detriment of opponents or the recalcitrant who have been unable to express themselves or who have been silenced or ignored. And then agreement reached at a given moment may very well no longer be valid a bit later when the circumstances have changed. Agreement is only rarely desirable!'* (cited in Callon et al. 2009).

The notion of democracy that emerges from these studies (Latour's call for the possibility to disagree, Callon's forums confronting different forms of knowledge, and Jasanoff's de-emphasis on agreement), resonates with the concept of *antagonist pluralism* proposed by DiSalvo in relation to the work of political scientist Mouffle. In her words, antagonist pluralism:

> *'creates a space in which this confrontation is kept open, power relations are always being put into question and no victory can be final. ... such an 'agonistic' democracy requires accepting that conflict and division are inherent to politics and that there is no place where reconciliation could be definitively achieved...* (in DiSalvo, 2010)

These models, but more explicitly Callon's, do not acknowledge any *apriori* asymmetry between the knowledge and expertise of the expert and that of the layperson, and challenge the very idea of representation in our democracy. Rather, it describes a dialogical democracy that offers the possibility to contest because it is open to new emerging identities and to the incorporation of new forms of knowledge. To some extent, this dialog and openness reflect what participatory and collaborative design practices have explored and developed over the years. In these terms, the two Actor Network theorists would suggest that the introduction of participatory and collaborative design methods (from future workshops to design games, from iterative prototyping to participatory assessment) and collaborative technological platforms (supporting global collaboration, crowd-sourcing, and so on) can be seen as ways to *fabricate proactive identities* of the participants[7]. In addition they can be seen to be an attempt to *incorporate their knowledge, skills and perspectives* in the design process thus achieving a certain level of social learning and democracy in the design process. This brings us to the second separation that we need to challenge, and that asks us to move our focus from the constituents of the design process (designer and users) to a larger setting examining the interplay between design and use itself.

FETISHISM IN DESIGN: RE-THINKING THE MODERNIST SEPARATION BETWEEN DESIGN (BEFORE) AND USE (AFTER).

As said, this idea is a modern one: designers collaboratively and materially envision and build the future at the present time, which in turn works to bring about a future. Unfortunately, no matter how 'prophetic' a design has been, the future that is brought about will inevitably be different from the one envisioned to inform 'its' design. To re-phrase a popular expression in the PD community: today's transcendence can never really be tomorrow's tradition. For instance, the prototype developed to explore a certain future, changes the very present within which requirements were identified to envision and develop a specific design. As the prototype is introduced for testing, the conditions upon which it was built (a certain user, her expectations and intentions, the context of use) slip away. The same thing can be said about end-users participating in a design process who - most of the time - are different from the actual future users, or - at least - from what they will become. Uses at design-time can obviously be only imagined, simulated, discussed, and represented,

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[6] Latour's discourse is more complex and it articulate a model of pluralism that explicitly consider and problematizes non-human agency which is not a central focus in this paper. A work discussing Latour model of democracy in design is under preparation.

[7] See also Callon on the role of hybrid collectives in PD, 2004

but say very little about actual future uses. What I am suggesting here is that design as future-making is surely an evocative metaphor but it should not be taken too seriously: end-users are not the condition of a collaborative design process, they are its results. In these terms, talking about end-users participating in the design process involves a certain level of fetishism. Future-users (as well as prototypes) are made-up entities that are mobilized in the design process: users before the actual use, prototyped uses before the real thing to be used. The issue here is that these participants (being those humans or non-humans) are not neutral, as they bring their attached perspectives, values and expertise. Therefore, in separating design (before) and use (after), we unavoidably tend to privilege present actors whose values, perspectives and expertise get incorporated in a design to the detriment of the ignored and future ones. Through such fetishism and combined with an uncritical emphasis on expert knowledge, these designs have an increased potential to act as colonizing forces for the real users to come. Let me be clear here. This problematic paradox of design (be it collaborative or not) is partly inevitable. We all need a bit of fetishism; just, we do not need to take it too seriously. Indeed, I suggest that acknowledging the fetishist nature of the future enacted at design-time, might be beneficial in order both to recognise the value of our present ignorance, and to re-think the epistemic and chronological separation between design and use. How to address the dangers of a design that acts as a form of colonization of the future then? I want to suggest that a more democratic approach to (collaborative) future-making, that appreciates pluralism and debate, should be based not only on the move of abandoning our separation between professional designers and lay users (as discussed in 2.1), but also by abandoning the division between design (before) and use (after), acknowledging that our ignorance and openness to future surprises is often more important than what we know and want to fix irreversibly through design. Recent STS studies about ignorance offer interesting reflections on this matter.

A PRAGMATIST VIEW OF IGNORANCE

Studies of ignorance (Gross, 2010, 2007; Gross and Krohn, 2005; McGoey, 2007, 2009) are becoming more prominent in Science Studies after realizing that our knowledge society is becoming a risk society (Beck, 1996). Recent STS studies expose this notion to analysis and show how this idea of a risk society assumes and consolidates expertise and knowledge (and so power) in the hands of few (Callon et al. 2009; Gross, 2010). In these works, modernist and hegemonic visions of risk assessment and predictive models (that use the expert knowledge available today to make decisions about tomorrow), are opposed to a more modest *precautionary principle* arguing for a *better safe than sorry* attitude toward decision making in the face of uncertainties (Callon et al. 2009, Jasanoff, 2007, Myers and Raffensperger 2005; Whiteside 2006). To frame this position within our concern with design, let me re-phrase the same statement that Callon used to discuss the asymmetry between experts and laypeople. Adapted to our concerns with the epistemological and chronological separation between design and use, his statement would sound something like this:

> *'to start with we should accept the fact that the knowledge available at design time is not the only knowledge possible (relevant)… we should recognize the limit of our current knowledge and the richness and relevance of knowledge developed (e.g. by actual future users) after design'.*

Rather than assuming the knowledge available at design time as the standard (being the knowledge of the professional designers or the one sparking from their collaboration with various lay stakeholders), it becomes equally important to make room for the future appreciation/incorporation of unpredicted and unpredictable novelties. This consists of the acknowledgement of previously ignored (and potentially surprising) issues, actors, perspectives, information, knowledge, limits, and so on. In some cases, reducing a design issue to resources/perspectives available at design-time, comes with the risk of irreversibly limiting and hindering the very existence of other actors, or the possibility of different perspectives and forms of knowing (potentially disagreeing with the imposed past). The mentioned studies of ignorance suggest that indeed, fixing today's categories for tomorrow come with the risk of transforming our present ignorance (as the opportunity to know – *questions* are unanswered and need to be formed) into non-knowledge (as the impossibility to access – *questions* are simply unasked and cannot be formed any more)[8]. In analogous terms, acknowledging ignorance at the time of design makes room to uses that still need to be formed, while non-knowledge restricts the possibility of unforeseen uses.

I argue that in design as future-making we run the risk that certain uses and the needs behind them are ignored/unaddressed and get irreversibly lost in the rush of fixing today's best categories. Studies exist which try to explore the possibilities for acting in the face of our ignorance, and the impossibility of predicting the future. In this ambit, the idea of experiment is of key importance as a way of linking ignorance and the incorporation of new knowledge, and to learn from and cope with the unexpected (Gross, 2010). Future-making is an activity in the face of uncertainties and, I argue, using a precautionary principle to acknowledge our ignorance can help to minimize the current fetishizing attitude of modern design practices. I suggest that such a principle can help to re-think design as future-making, become more open to different views, and procrastinate design-fixes to the 'time' they should belong to: the future present of use.

In the next section, I discuss a design process that is illustrative of the issues I have raised so far. The project

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[8] See Krohn (2007) for this key distinction.

was aimed at empowering individuals with type 1 diabetes by enabling them to constantly adjust and adapt their self-monitoring practices in the face of the unexpected, the unclear, the unknown (Storni, 2013a, 2013b). I discuss part of the project and what was developed. In particular, I focus on the evaluation of our design, which shows promising results in re-working the separation between design and future uses and that draws on the proposed pragmatic view of ignorance, and the precautionary principle that derives from it.

DESIGN FOR FUTURE USES: ENABLING THE PERSONALIZATION OF SELF-MONITORING PRACTICES IN TYPE 1 DIABETES

When looking at type 1 diabetes self-care practices, a series of key challenges for the design of tools supporting everyday self-management become immediately evident (Storni, 2013a). Diabetes is extremely complex, and becomes part of almost every aspect of one's life in a way that makes it inseparable from it. Type 1 diabetes self-care practices require a series of everyday compromises and delicate balances between different aspects of one's life. This ubiquitous nature of diabetes is clear when individuals were asked about their first diagnosis (names are fictional):

> ***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…*
>
> ***Julie****: 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 […]…so it's a constant thought about what's going on.*

As one can see, chronic self-management is extremely demanding and characterized by a series of difficulties, practicalities and intricacies; these are difficult to account for and to foresee and, consequently, to design for. The knowledge that is available to the experts (biomedical and clinical knowledge) has brought huge benefits, but unfortunately falls short in addressing the infinite numbers of mundane difficulties of living with a chronic disease on a daily basis. In spite of the enormous advancements of modern medicine, in diabetes things that worked yesterday might not work today; things that work in the hospital might not work in a domestic environment; and things that work for the patient might not work for the doctor, and vice-versa.

> **Louise:** *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.*

These extracts are interesting in many ways. First, they depict the heterogeneity of elements that are associated with diabetes self-care, and so show its complexity and entanglement with everyday life. Secondly, they offer an insight into how the everyday experience of the disease is populated by uncertainties, ignorance and surprises. These, according to some of the reviewed literature on ignorance, are not necessarily problems but could represent occasions for the development of new knowledge that might be useful to deal with such complexity. The reported extracts also give a hint of the regimental attitude that diabetics are often expected to adopt, according to the medical perspective that is traditionally concerned with the universalities of a disease and not with the idiosyncrasies of those affected by it. Indeed, the clinical perspective and knowledge - that plays a key role in informing the behaviour of affected individuals as well as the design of their equipment - is normative in nature. It derives this status from a set of assumptions (such as the objective and quantitative nature of knowledge, the notion of compliance, the separation between the medical and the non-medical issues, and so on[9]) that tends to treat deviations (such as non-compliant behaviors, the use of different types of information/set of values in self-management, and so on) as violations to be limited (by design). Design and technology can play a key role in this (for instance through the design of persuasive technology, prescriptive protocols, monitoring systems, and so on). This idea of an expert control over a rather passive subject clearly resonates with the discussed attitude of the professional designer over the end-user, and with the epistemic asymmetries that Callon finds inadequate to deal with complexity and uncertainties. As mentioned, biomedical and clinical knowledge is not concerned with the everyday experience of living with the disease and - in a sense – it makes it difficult to give room to the perspectives of the patient, her practical concerns, and mundane problems. Formatted as they are within a reductionist discourse of medical language, practices and technologies that assume a certain perspective, many individuals find it difficult to integrate and ground the medical knowledge in the context of their ups and downs, their subjective experience of the disease, and the situated nature of their problems. Chronic care in clinically uncontrolled settings is indeed uncertain. Much is unknown, unpredictable and out of control, not to mention the fact that each diabetic lives with a uniquely individual set of difficulties. With the exception of a series of established medical categories (such as glucose levels, insulin units), they all learn to pay attention to and deal with a large series of different, practical, and mundane things. In chronic self-care the medical, the para-medical and the mundane cannot be separated, and to reduce this complexity to a series of medical universalities is not enough. It not only belittles the key idiosyncrasies of affected individuals, but also hinders the appreciation of their different perspectives and the lay expertise that they (might) develop as they learn to take care of

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[9] See Storni and Bannon 2011 for a critical discussion of these notions toward patient centric infrastructures.

themselves (Storni, 2013a). Indeed, many of the participants complained about their doctors' reductionist obsession with numbers: *…some doctors would make judgement on one reading only,* or, *…she only wants to see the numbers*. The following extract about an individual with diabetes keeping two separate journals - one for her doctor and one for herself - shed some light on the potential conflicts that can emerge between the normative nature of the clinical perspective, and the assumed asymmetry with the lay perspective of patients:

> ***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. […]*

During investigations preceding the development of our platform, this friction between the two perspectives and related forms of knowledge was particularly recurrent:

> - ***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! […] They think you are stupid, they don't realize 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...'*

Being open to the concerns of the individuals extending (if not contesting) the clinical perspective became a key design concern for us. At the same time, being able to prefigure what diabetics should be concerned with (the 'extra information' our participant is concerned with) is an impossible design task. How to support everyday diabetes self-care with an appreciation of the limit of available biomedical and clinical knowledge but also be mindful of the impossibility of predicting what each of the potential 'users' will be concerned with? Our proposal became one of extending a traditional and exclusive focus on what we know today (and on the solutions that can be drawn from that) to incorporate the view that what we do not yet know should be equally important. The idea was to introduce – back to the discussed dialogic democracy and the idea of a precautionary principle – the possibility of disagreeing with or extending a design. New evidence which emerges during use could be incorporated into the design, thus potentially turning today's ignorance (on the effect of certain self-management practices) into future new useful knowledge.

Diabetes self-care represents a good case here, as we cannot really know in advance what a 'user' would need. Yes, of course, you incorporate the best knowledge available today in the design of any support for diabetes self-management. At the same time though, you might need to be cautious enough to acknowledge that diabetics struggle, cope with uncertainties, surprises and the unknown, but they also learn, reflect, experiment, tinker and try new things. Often they learn new facts that need to be incorporated in the design – after the actual design. With this in mind, we envisioned an open-ended journaling system that would enable users to personalize their self-monitoring practices.

The bottom-up personalization of self-monitoring practices was achieved through the creation of unique categories of lay data (called 'tags'). Tags fit the patient perspective and enable the exploration and the reflection on one's own self-care practices, thus potentially generating evidence about certain events or knowledge about the effects of certain actions. The idea is to enable the individuals with diabetes to create 'tags' and to start tracking any particular event that concerns them as well as to attach all sort of multimedia information to more traditional data about glucose levels and insulin intakes. The attached information can be pictures, notes (audio and written) or, indeed, patient-generated tags.

Tags can be countable or not and so, for instance, an activity in the gym can be tracked in terms of minutes of training or - if further equipped with other devices - in terms of burned calories; beers can be tracked in terms of glasses or pints, breakfast in terms of cups of cereals or consumed carbs, and so on). As a new tag is defined, a new button is added in the glucose-tracking page of the journal. This can be used independently or in relation glucose readings[10]. The log function allows reviewing (in both textual and graphical way) glucose readings along with lay-generated tags thus supporting further possibilities to compares things, look for patterns, reflect and perhaps start tinkering and experimenting with certain aspects of everyday life.

EVALUATION OF THE TIY PLATFORM'S USE

Tests principally aimed at assessing the general appreciation of the bottom up generation of Tags, and their actual use in everyday life. Tests were also used as conversation points to further investigate issues in self-management. In this sense, evaluation did not follow the logic of clinical trials in complex interventions but followed the logic of constructing a modest but highly detailed case study with a series of participants with type 1 diabetes and, when possible, their formal and informal care-givers[11]. Two rounds of tests were run for the TiY. The first evaluation trial involved 4 diabetics type 1 and lasted for 2 months (these 4 participants were member of a support group where initial contact and observation were made, see Storni, 2013a and b), and was complemented with home visits and phone calls. Patients were equipped with an Iphone with a developer

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[10] Ideally tags could be linked with a series of networked devices that automatically feed in data regarding specific activities (cooking, running, and so on) without relying on manual entry.

[11] In this sense, the selection of subjects did not follow a randomized assignment although 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 a certain level of familiarity with the use of mobile phone; the user fall within the most common bracket for smart-phone owners of 18-50.

copy of our prototype installed. The first test was made on an early version of the TiY which did not feature graphical visualization of the data. The second test lasted for 6 weeks and involved three diabetics (different from the ones participating the first series of tests) who were equipped with a new version including data visualization of the data log. During the first evaluation tests, users were also asked to keep a diary that was included with the iPhone[12]. During the series of evaluations all participants created a wide range of different tags reflecting their concerns (also emerging ones): meal tags to highlight pre- and post-meal glucose readings or the different type of meal (e.g. '*porridge breakfast*' or '*muffin breakfast*'); tags to track sports and other physical activities ('*gym*', '*walking*', '*jogging*', '*running*', '*swimming*', etc); diet tags to track intake of, for instance, '*carb(ohydrate)s*', '*fats*', '*fibers*', '*snacks*', specific food or drinks (such as specific type of cereals, cheese or beer) or new types of food ordered in restaurant (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 ('*Bolus*', '*rapid*', etc.) tags for daily activities (such as '*driving*' or '*travelling*'), and more. On average, almost 40 different tags were created during the tests ranging from only two general tags for one patient ('*food*' and '*exercise*' as non-countable tags 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 as countable in lay units (such as bottles of beer) or units from the provided metric systems (such as minutes for cycling, or grams for carbohydrates)) and rarely accompanied by a note. Some tags were particularly recurrent and used more often among our participants (such as Breakfast, Lunch, Snack, running or jogging). We also noted that some tags were created but then never actually used while journaling. In a couple of case we also noticed participants tunes previously created tags to better fit emerging concerns at use time (as in the case of a tag earlier named '*pizza*' and then modified as '*eating out*' often complemented with a picture of the dish in question, or the case of one tag '*lunch*' then evolved into two tags '*light lunch*' and simply '*lunch*'). Interestingly one participant started to create a collection of pictures of nutritional information in food labels to mind and better remember that type of information. We were happy to learn that these labels' pictures were also used to later support her shopping at a supermarket (e.g. to check different nutritional value of a new brand of cereals). One of the early user's suggestions about tag's creation referred to the fact that meal's tags (and possibly also exercise ones) are so basic in diabetes self-management (at least type 1 which was at focus) that some users would expect them to be already pre-designed in the journaling system. Even if this point was understandable, it was also true that people used different strategies in creating meal tags. For instance, one participant found it useful to distinguish between different 'types' of breakfast, one based on *porridge* and another based on *muffin*. This pattern was recurrent in main meals tags which ranged from generic '*Lunch*' and '*dinner*' to more specific '*light lunch*', '*pasta*' or '*pizza*' or '*sushi*'. Another interesting case concerns tags created to flag pre and post meal glucose readings whose function was not to solely track what was eaten, but to flag all pre- and post-meal readings attached to a particular food.

COMMENT

Our evaluation of the TiY platform is promising in many senses. It first shows that users are happy to engage in the development and definition of Tags that acquire the form of new design features. Some of the generated tags shared common concerns, while some others displayed unique ones. What is also key to notice is that participants engaged not only in tag creating but also and more interestingly in their ongoing evolution (adaptation, specification, simple deletion). In relation to the specific application field of self-care, especially in chronic disease, our evaluation further suggested how individuals with diabetics find it useful to extend medical records with lay categories and develop different types of knowledge and expertise to better ground medical knowledge in their everyday life (Storni, 2013a). We found that these activities are aimed at generating meaning, understanding and more specific questions about what is relevant in a certain situation (at least generating new hypothesis about the effect of certain actions in self-management). We only have a hint on this key aspect that is represented by a user creating a tag 'temperature' with reference to weather conditions. The participant in question is a runner and in monitoring her runs more closely she realized that when is cold and dry then she seems to need more insulin. It is difficult to say if she discovers a relationship between temperature and insulin absorption. We are happy enough to say that from an pragmatic point of view this might offer the possibility to improved one's control over sugar levels during sport activities, even if the doctor would not show the same interest on this issue. On the one hand though, our idea was also to improve the collaborations with the medical staff by providing a tool for the creation of bottom up evidence to fine tune care practices. For us, tag creation could have been a collaborative endeavour where the different perspectives can enrich rather than exclude one another. Indeed, this was also suggested by one participant who mentioned how the TiY could support an improved and rebalanced discussion with the doctor. The motivation was that the TiY might provides contextualized and potentially key talking points that one would not be possible to discuss otherwise.

> ***Paula:*** *It might be nice…just to see if I show that graph to my doctor and she says try to make that*

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[12] Inform consents were collected under the guidance of the local ethic committee in all the three series of tests, and patient data were stored and managed according to the guidelines of the local data protection authority.

> *adjustment and I do it and it's still not working, then I can track more closely, add a comment to the actual graph and use it to discuss it with her and maybe try a new thing.*

Doctors (3 specialists and 1 general practitioner) expressed a certain appreciation for the idea (especially in relation with the easy way to recall readouts and related information); they however were concerned with data fabrication, a concerning aspect that they all seem to be familiar with.

DISCUSSION

I have started this paper by questioning a series of modern separations in design, and I have raised issues over the political and epistemic characters of design. In particular, I exposed to analysis the chronological and epistemic separation between design and use, and I discussed the tension between what is known and assumed to be relevant at design time, and what can be learned and become relevant at the time of use. With this focus, I have first re-discussed the traditional asymmetry between experts and laypeople in light of recent discourses around democracy in techno-science (Latour, 2005, 2008; Callon et al. 2009) and in design (DiSalvo, 2010, 2012). Then, I have discussed the separation between design-before and use-after. I argued that the idea of design as future making might come with the risk of colonizing the actual future. To fill the gap between their present and the future they design for, future makers incorporate and fix today's best knowledge and other fetishized entities into their design scripts. However, as fixed scripts reach the actual future context of use, they might prevent, limit, and hinder the possibility of appreciating and producing new perspectives, and incorporating them into the design. In recent STS concerned with knowledge production in our increasingly complex society (also concerned with democracy), we can find an interesting distinction between ignorance and not-knowledge. I argue that this distinction is relevant to rethink design for future uses. In pragmatic terms, we discussed ignorance as an opportunity to develop new lines of enquiry and experiments with the potential of generating new knowledge and expertise. This is possible because in acknowledging that present knowledge and control are limited (precautionary principle), new questions, languages, and perspectives can be explored at any time. Non-knowledge is instead defined as the actual impossibility of developing new forms of knowledge. As an effect of the undisputed authority of dominant perspectives and forms of knowledge, the generation of new questions becomes increasingly difficult also because future explorations of new angles (based on new questions or different languages) can be seen as a violation. In line with those who argue for new models of dialogical democracy, who rework pluralism, and who are critical of the emphasis on consensus and agreement, I suggest a design for future uses that rebalances its colonizing potential through two key precautions. The first concerns the asymmetry between expert and lay forms of knowledge, and it challenges the assumed authority of the former by avoiding any strong assumption about the respective relevance in future uses. The second concerns the epistemological and chronological asymmetry between design (before) and use (after), and it challenges the colonizing power of the former (uncritically packing available best knowledge into design scripts) by rather appreciating our ignorance (at the time of design) and the lack of control of over future uses. Without these two precautions, design becomes a dominating force imposing a language and a worldview to those who are 'conquered' by it. To support this argument and resonating traditional critiques of the healthcare system[13], I introduced and discussed an illustrative case study in diabetes care. This setting is indeed rather complex and characterized by different forms of knowledge and a degree of uncertainty. The case study concerns the design of a journaling platform to support the personalization of self-monitoring practices in T1 diabetes. In our approach, we first of all realized that relying on the medical expert view only (the biomedical and clinical one) would reduce a complex issue like everyday diabetes self-management to its universal medical aspects, thus frustrating and failing to fully support the experience of living with the disease on a daily basis. As mentioned, we acknowledged that a normative approach - naturally attached to the authoritative nature of the medical perspective - would limit and constrain the possibility of tinkering with one's own treatment in the attempt to gain knowledge and control of everyday practicalities and difficulties.

In investigating everyday practicalities linked with diabetes self-management, we further acknowledged that it would be impossible to try to foresee all potential requirements and incorporate them in our design. Thus, we realized the need of enabling the possibility to extend (on an ongoing and open-ended basis) the capability of the journal system to better fit the unpredictable and often-idiosyncratic aspects of chronic self-management. The introduction of the tag editor enabling the creation of personal and unique categories of data, extending the clinical ones, represented for us a way to give value to the language, knowledge and perspective of the patient[14]. Tags become means to

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[13] This argument clearly resonates with an established tradition of critical studies of healthcare that build on the notion of power and dominance (for instance Foucault Biopower, or Illich's Medical nemesis; see Storni, 2013a for a discussion of some of these works as key for the development of the self-care movement in the 70s).

[14] After the fact, the author came to know a similar project in a rather different context but with an even more prominent anti-colonizing design. This project concern the TAMI (Verran, Christie, Anbins-King, van Weeren, & Yunupingu, 2007), a custom-made database, for use by the Yolŋu Aboriginal Australians, who does not recognize the (Western) ontological division between nature and culture. TAMI's design aims to support the worldview of the Yolŋu and not assume the normative Western division. Its designers did not use any pre-set categories for - or relationships between – entities; instead, they enabled users to construct a classification system according to their perspective and understanding of relations at use time. TAMI utilizes a flexible tagging mechanism, which facilitates the creation of personalized data and metadata for each item in the database. The

express one's own concerns in one's own terms at any time (potentially destabilizing the power wielded by design time) . For us, tags also represented a way to appreciate that our ignorance and the lack of control with regards to future needs might be even more important than what we know (e.g. from doctors). Our idea of a bottom-up creation of 'tags' can be seen as a way to procrastinate and delegate to future users some key design decisions about what is becoming relevant in use and needs to be incorporated in the design. For instance, one of our interviewees (considered an expert who had perfect numbers for long time) developed bulimia and suddenly had to start journaling many new elements that were irrelevant before. Thanks to our approach to open up the design, she was able to shape the TiY to better fit this new unfortunate health status. In this sense, our design reflects many of the mentioned studies concerned with democracy and the role of design and technology. Resonating with the idea of dialogical democracy and feeding into the one of antagonist pluralism, our design allows the fabrication and incorporation of new knowledge as well as the simultaneous fabrication of new identities. In our case, new forms of patienthood where patients are not simply seen as more or less compliant (with a medical prescription or a fixed design) but rather as proactive and inquisitive explorers tinkering with their body, knowledge and technology (see Mol, 2008 for further support of this argument). Likewise, our design also offered, as noted by one of our interviewees, the possibility to disagree (e.g. with a design or medical advice that turned out to be incorrect or too narrow) so that new concerns/questions can be voiced.

CONCLUSION

Mindful of the political and epistemological dimensions of design, this paper builds a critique of the idea of design as future-making, with its potential of acting as a form of colonization of the future. I argued that this approach is potentially dangerous, and fails to achieve a truly democratic design process where the categories and the limitations of the present are not imposed on the future uncritically. Enabling the possibility of disagreeing, exploring new views, expressing new concerns and incorporating knowledge that was not available at design time, became ways for us to achieve what we might call a diachronic democracy (and a related diachronic pluralism and participatory design). This assumes pluralism and it is based on a precautionary principle where the separation between design and use is blurred because what we ignored at design time is not irreversibly lost into non-knowledge. Recent STS literature on ignorance highlights the importance of experiments *in-the-wild* in asking new questions and challenging authoritarian forms of knowledge. These studies that re-work pluralism and align with those concerned with democracy and participation, insinuate the idea of everyday experience as modest experiments with the potential to develop new ways of knowing[15]. Our lesson-learned - based on the experience of the TiY – is that instead of developing future scenarios with potential users at design-time (design as future-making), we might need to develop exploring/tinkering devices that enable the making of design scenarios at use-time enabling the open-ended and experimental exploration of unforeseen uses[16]. Two issues need to be clarified before to end though. First, I should be stressed that the TiY displays several limits in the way it is actually open to design in use. Many of the aspects of the design are indeed rather closed and irreversibly fixed (the navigation structure of the app, its look'n'feel, the fact that the app only run in a iPhone, and so on). In this sense, these design elements act as colonizing forces imposed on the future user (for instance it imposes the use of an iPhone). Secondly, further research and attention is needed to understand how the proposed approach could be extended to areas different from chronic self-care. Certainly, the proposed approach to design for future uses might open up to a more democratic design when facing highly complex settings characterized by different stakeholders and their potentially conflicting agenda and forms of knowing. The suggestion is to shift from a modern idea of design as future making to a more modest design for future uses, that appreciates not only plural viewpoints but also our ignorance at the time of design. I showed how this could be achieved by not relaying excessively on what is known and available at the time of design (especially authoritative forms of knowledge), and to procrastinate and delegate some design decision to actual future users. This shift in focus represents what I believe should be called the epistemological and chronological politics of design as it gives the ability to rebalance the asymmetries in power among different forms of knowledge, but also to overcome the problematic distance between present design and future uses.

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difference here is that the TiY display a more prominent emphasis on experimenting, tinkering and possibly creating new knowledge and not reaffirming an already existing (and exotic) lay world-view.

[15] To conceptualize the difference between experimentation in the laboratory and real-world experimentation, Wolfgang Krohn (2007) suggests that both types should be compared to the nomothetic and idiographic approaches to reality that were introduced by the philosopher Wilhelm Windelband (1980). Windelband saw nomothetic approaches to science as having the tendency to generalize from many cases to derive law like statements (as for instance we can see in the production of biomedical knowledge). Idiographic approaches, in contrast, highlight unique elements of single cases (as for instance we can see by acknowledging the unique idiosyncrasies of individual patients). Krohn therefore argued that nomothetic and ideographic approaches are both equally relevant for experimentation outside the laboratory (Gross, 2010). This suggests an interesting distinction between monothetic design (where the focus is on participation at design time via fetishes to realize a design for all in design studios) and idiographic design (where the focus is on enabling a myriad of collaborative future-making at use time *in-the-wild*).

[16] Candidate labels for this might be: Design for *thinging* as a larger category of *design for ignorance*, *controversial design, design for exploring, design for debate* (as in design noir (Ruby and Dunne, 2001)), design for ambiguity (a la Gaver (2003)), *design for users' reflexivity*, or *use as situated prototyping/future-making*, or – why not - *participatory use.*

REFERENCE

Akrich, M. The description of technical Objects, Bijker, W. E., Law, J. (eds) *Shaping technology/building society*, MIT Press, Cambridge, 1992

Beck , U. [1986] 1992 . *The Risk Society: Towards a New Modernity* . London :Sage .

Björgvinsson, E., Ehn, P., & Hillgren, P. A. (2012). Agonistic participatory design: working with marginalised social movements. *CoDesign*, *8*(2-3), 127-144.

Björgvinsson, E, Ehn, P and Hillgren, P-A (2010) 'Participatory Design and Democratizing Innovation. in *Proceedings of* PDC '10, Sydney, Australia: ACM Press, 41–50

Callon, M. (2004) The role of hybrid communities and socio-technical arrangements in the participatory design, Journal for the Center of Information Studies, 5, 3

Callon, M. Lascoumes, P. and Barther, Y. 2009. Acting in an uncertain world, an essay on technical democracy, MIT press, Cambridge

Eglash, R., Croissant, J., Di Chirio, G., & Fouché, R. (Eds.). *Appropriating technology. Vernacular science and social power*. University of Minnesota Press, Minneapolis, 2004

DiSalvo, C. (2012). *Adversarial design*. The MIT Press.

DiSalvo, C. (2010) Deign, democracy and agonistic pluralism, Proceedings of the Research Design Society Conference, Montreal, 6

DiSalvo, C., Light, A., Hirsch, T. Christopher A. Le Dantec, E., Goodman, K. (2010) HCI, communities and politics. Proc. in CHI, ACM Press, 3151-3154.

Ehn, P. (1989) Work-Oriented design of computer artifacts, L. Erlbaum Associates Inc. Hillsdale, NJ

Ehn, P. (2008) Participation in design things, Proc. of PDC 2008, Indiana, pg. 92-101

Fisher, T, Giaccardi, E., Ye, Y., Sutcliffe, A.G (2004) Meta-design: a manifesto for end-user development, in *Communication of the ACM*, 47, 9

Gross, M. (2007) The Unknown in Process: Dynamic Connections of Ignorance, Non-Knowledge and Related Concepts . *Current Sociology* 55(5):742–59

Gross, M. (2010) Ignorance and Surprise – Science, Society and Ecological Design, MIT Press, Cambridge

Gross, M., and Krohn, W. (2005) Society as Experiment: Sociological Foundations for a Self-Experimental Society . *History of the Human Sciences* 18 (2): 63 – 86 .

Henderson, A., & Kyng, M. There's no place like home: Continuing design in use. In J. Greenbaum & M. Kyng (Eds.), *Design at work: Cooperative design of computer systems,* Hillsdale, NJ: Erlbaum, 1991

Krohn, W. (2007). Nature, Technology, and the Acknowledgment of Waste, *Nature and Culture* 2 (2): 139 – 160

Latour, B. (2010). An attempt at a "compositionist manifesto". *New Literary History*, *41*(3), 471-490.

Latour, B (2004) The politics of Nature, Harverd, Harvard University Press

Latour, B. (2005a) Reassembling the Social, Oxford, Oxford University press

Latour, B. (2005b) Dinkpolitik, in Wieber and Latour, 2005, Making Things Public, Cambridge, MIT Press

Mackenzie, D. and Wajcman, J. *The social Shaping of technology*, Open University Press, Buckingham and Philadelphia, 1985

Mc Goey, L. (2007) On the will to ignorance in bureaucracy,36:2, 212-235

Mc Goey, L. (2009) Pharmaceuticals controversies and the performative value of uncertnainty, Science and Culture, 18:2, 151-164

MacLean, A., Carter, K., Lestrand, L., & Moran, T. User-tailorable systems: Pressing the issues with buttons. *Proc. of CHI 1990*, ACM Press (1990), 175–182

Myers, N. and Raffensperger, C. (2005) Green Systems. In Myers and Raffensperger (eds), *Precautionary Tools for Reshaping Environmental Policy* , 81 – 90. Cambridge, MA : MIT Press

Mol, A. (2008). *The logic of care: Health and the problem of patient choice*. Routledge.

Jasanoff, S. (2007). Technologies of humility. *Nature*, *450*(7166), 33-33.

Redström, J. (2008). Re: definitions of use. Design Studies, 29(4), 410-423

Ruby, F. and Dunne, A. (2001) Design Noir, the secret life of electronic objects, Birkhausen, Berlin

Schuler, D. & Namioka, A. (1993). Participatory design: Principles and practices. Hillsdale, NJ: Erlbaum

Storni, C. (2009) The ambivalence of engaging technology: artifacts as products and processes, *NORDIC Design Research Conference*

Storni, C. (2013a) 'Patients' lay expertise in chronic self-care: a case study in diabetes, accepted for publication in Journal of Health Expectations, Wiley and Blackwell

Storni, C. (2013b) Design challegens for ubiquitous and personal computing in chronic care and patient empowerment: accepted ofr publication in Journal of Ubiquitous and Personal Computing, Springer

Storni, C. and Bannon, L. (2012) Towards the Design of truly patient-centered infrastructure, in Chilamkurti, N. et al. Health informatics: An adaptive communication technology for Future HealthCare, Nova Science Publishers, New York

Storni, c. et al (2012) Exploring Actor Network Theory in Participatory design - Proceedings of the 11th Biennial Participatory Design Conference, Roskilde, 2012

Verran, H., Christie, M., Anbins-King, B., van Weeren, T., & Yunupingu, W. (2007). Designing digital tools with Aboriginal Australians. Digital Creativity, 18(3),129-142.

Venturini, T. (2010). Diving in magma: How to explore controversies with actor-network theory. Public understanding of science, 19(3), 258-273.

Whiteside , K. H. (2006) . *Precautionary Politics: Principle and Practice in Confronting Environmental Risk* . Cambridge, MA: MIT Press