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Patient innovation

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Patient innovation: an analysis of patients' designs of digital technology support for everyday living with diabetes

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Abstract

The aim of this paper is to identify characteristics of patients' contributions to innovation in health information technology (HIT). The paper outlines a theoretical definition of patient innovation and presents an analysis of four digital prototypes and 22 low-fidelity mock-ups designed by people affected by the chronic illness diabetes mellitus. Seventeen families (a total of 60 people) with one or more diabetic family members participated in design activities in a four-year research project focused on the design of digital support for everyday living with diabetes. Our analysis documented the originality of the analysed patient designs and identified three characteristics of patients' designs: socio-technical networks, objects with associated personal meanings and technology supporting the expression of identity. The paper concludes that patient innovation is defined by what is perceived as new by patients and/or others within the social system of adaptation. The analysed patient designs are original (as distinct from replications of or improvements on known products), and their characteristics are innovative contributions to the social system of everyday living with diabetes (i.e. they are perceived as new to the patients in the research study). The results of the analysis contribute to the credentials of patients as key actors in HIT innovation and call for participatory approaches in health informatics.

Introduction

Patients tend to be human factors rather than human actors in the design of digital technology for healthcare (termed 'health informatics', 'e-Health', 'health information technology' (HIT), 'health information systems' etc.) (Bannon 1991). A recent literature review called attention to the lack of literature documenting the role of patients in the design of health information systems and argued that most HIT has been designed for the use of providers rather than patients (Bélanger et al. 2012). Bélanger et al. (2012) called for the involvement of patients as designers, not just testers, of new technology: '[M]ore than being only involved in checking the accuracy of information in the PHRs, patients should participate in designing systems that they will be willing and able to use' (Bélanger et al. 2012: p. 658). Consequently, these authors called for 'participatory research' and identified patient participation as 'one of the missing links' to improve patients' use of HIT and, with this, health outcomes from HIT (Bélanger et al. 2012: p. 658).

The lack of attention to patient participation in the design of health information and communication technology (ICT) can be interpreted as an underestimation of patients' ability to contribute to the design

and innovation of health ICTs. In this paper, we outline a theoretical definition of patient innovation to bring clarity to its meaning and expectations, and we present an empirical analysis of patients' designs through a design research study investigating the originality and characteristics of patient innovations. First, we introduce definitions of innovation, user innovation and patient innovation. Second, we introduce methods and materials from the research project in which the patient designs were produced. Third, we outline the results of the analysis of the patient designs, which we subsequently discuss, and then conclude the paper with the characteristics of patient innovation.

Definitions: innovation, user innovation, patient innovation

Innovation

In *Diffusion of Innovation* Rogers (1995) investigated how and why technology is diffused into culture. The book was originally published in 1962 and has been updated several times, including as recently as 2003. It has been influential in most innovation research (judging by the number of times it has been cited). It presented an analysis of the processes, coined 'diffu-

sions', by which innovations (primarily in technology) are communicated through certain channels over time among members of a social system. The book contributed to the broadening of the narrow perspective on innovation as being the efforts of a single genius or as single products. Rogers defined innovations as 'an idea, practice, or object that is perceived as new by an individual or other unit of adaptation' (Rogers 1995: p. 12). We work from this definition of innovation in the presented study.

User innovation

Eric von Hippel's books *The Sources of Innovation*, published in 1988, and *Democratizing Innovation*, published in 2005, investigated the value of user innovation. Similar to Rogers, von Hippel emphasised that innovations are rooted in peoples' needs. He identified the 'need [for] specific innovations' carried out by 'lead users' as the solution to product innovation. Lead users (LUs) are end users that 'face the needs that will be general in a marketplace, but they face them month or years before the bulk of that market place encounters them…' (von Hippel 1988: p. 107). Von Hippel and colleagues have investigated various types of LU innovation, for example surgeons as LUs of medical equipment (Lettl, Herstatt & Gemuenden 2006), elite mountain bikers as LUs of sport equipment, and advanced software programmers as LUs of computer games (von Hippel 2005). Von Hippel's analysis also documented the market and sales value of LU innovations: for example, in 1988 he presented an analysis of LU innovations compared to non-LU innovations (i.e. innovations achieved by professionals, in this case the company 3M). The findings of that study were as follows: 'The lead-user-developed product concepts had projected annual sales in year 5 that were greater than those of ideas generated by non-LU methods by a factor of 8 – an average of $146 million versus an average of $18 million in forecast annual sales' (von Hippel 1988: p. 139).

Von Hippel's studies have been influential because they were the first to document LU contributions to product development with a hard-cost analysis. However, the studies have been criticised for their market-oriented perspective, which excluded non-product innovations (e.g. innovations of new work practices and social innovations in general), and neglected the quality of innovations (e.g. the design of a good fit between the product, its users and use practices) (Björgvinsson, Ehn & Hillgren 2012; Buur & Matthews 2008) in favour of attention to sales. Another central critique of von Hippel's studies is the narrow attention on LUs, which excluded a wide range of people and innovative potential. Rogers is a good

source to return to in order to explain the consequences of focusing primarily on LUs. He outlined a typology of users with the following adaptation categories: first are 'innovators', who are the front-runners of technology. Roger's 'innovators' are comparable to von Hippel's LUs: they have a high risk tolerance based on resources, skills and interest in experimenting with the development and use of new technology to advance their everyday activities. Second, those who are fast at adopting technology are, according to Rogers, 'early adopters', who are not as willing to take risks as the innovators. Other categories are the 'early majority', who are often in contact with early adopters but are slower at adopting technology; the 'late majority', which is sceptical towards new technology; and 'laggers', who are characterised as being occupied with traditions and having low interest and/or resources (Rogers 1995: p. 282 ff.). Von Hippel's definition of LUs corresponds to Rogers' category of innovators of technology. According to Rogers (1995), only 2.5% of people are innovators. From this perspective, LU innovation excludes 97.5% of users.

In contrast to von Hippel's focus on LUs, the research field of participatory design (PD) has called attention to including people from the margins in technology innovation (Björgvinsson, Ehn & Hillgren 2012) and, in general, including all types of people, acknowledging that they are experts in their own everyday activities (Greenbaum & Kyng 1991). Von Hippel's user innovation is rooted in business research. In contrast, PD is rooted in Scandinavian union projects from the 1970s (Bansler 1989) and works from an inherently democratic perspective on technology production, wherein those affected by technology should be part of the decision-making for democratic reasons; that is, people's right to influence their everyday practices (Arnstein 1969). This also includes learning perspectives and an attention to mutual learning; that is, development of methods and tools for shared knowledge production among various stakeholders in technology design (Greenbaum & Kyng 1991). While von Hippel has worked on, and succeeded in, documenting the contributions of LU innovation, PD researchers seldom question users' contributions. Rather, they work from a fundamental belief that users are skilled people (Greenbaum & Kyng 1991) and, consequently, important actors (rather than factors) who can contribute to quality in technology design (Bannon 1991). In cases of minor contributions from user participation, the methods or facilitating skills of the designer are typically questioned, not the users' ability to innovate (Bødker & Iversen 2002). However, studies of end users' contributions to design are rare (Bratteteig & Wagner 2012; Kanstrup 2012).

The following analysis attempts to increase the documentation of user contributions to technology design in general, and specifically to the documentation of patient contributions to the design of HIT.

The research presented in this paper is inspired by the analysis of the documented value of user innovation found primarily in von Hippel's studies, but it emphasises the importance of working from a multilateral PD perspective. This includes a broad perspective on users (in this case, people affected by the chronic illness diabetes), rather than a categorisation of users in relation to technology enthusiasm skills. This perspective on user innovation entails analytic attention to the quality of patient innovation in relation to their everyday life with chronic illness, in contrast to measures of sales and market share.

Patient innovation

As elaborated by Bélanger et al. (2012), literature is scarce on patients acting out the role of innovators of HIT. However, though it is easier to find studies where patients participate as testers rather than as innovators of technologies, examples do exist. Within PD research, Andersen (2010) introduced the term 'participatory patients' to 'promote attention to patients as particular users or workers and force organizers of PD projects in health care to think of how and what kind of participation the involved patients collaborate in inscribing' (Andersen 2010: p. 124). Examples of participatory patients (although not an exhaustive list) include participation of cancer patients in the design of social support systems (Skeels et al. 2010; Wärnestål & Nygren 2013), participation of children and adolescents in the design of mobile learning technology for self-management (Glasemann, Kanstrup & Ryberg 2010), participation of elderly people in the design of technology for independent living (Essén & Östlund 2012; Lindsay et al. 2012) and participation of patients with cognitive disabilities (Prior 2010; Wu, Richards & Baecker 2004). All these studies – carried out with a broad variety of patients of different ages and capacities – demonstrated that patients could be included as participants in HIT design. However, none of the studies documented patients' contributions to the design.

Our analysis is based on data from patient participation in design activities, as suggested by Bélanger et al. (2012) and Andersen (2010). The analysis investigated the originality and characteristics of patients' designs (von Hippel 1988, 2005) and contributed to the understanding of patients as key actors in HIT innovation (cf. Andersen 2010; Bélanger et al. 2012). We define patient innovation as patients' development of ideas, practice or objects that are perceived as new by themselves and/or by others within the social system of adaptation (Rogers 1995). Thus, patient innovation is not analysed in comparison with high-technology innovation or market shares (von Hippel 1988). it is defined and analysed in relation to the existing practice of patients and their social system of adaptation. We acknowledge patients as key actors in their own treatment (Andersen 2010). With this definition, we outline a participatory approach that includes patients as key actors in HIT innovation.

Method

Patient innovation was studied in the maXi project (Nøhr, Bertelsen & Kanstrup 2009) which researched the design of ICTs for mastering chronic illness via participatory user-driven innovation processes (Kanstrup & Bertelsen 2011). Patients were recruited for participation as innovators of HIT, in this case digital technology for everyday living with the chronic illness diabetes mellitus.

Participants

Seventeen Danish families (60 family members in total) were recruited to the project. The study included the entire family of each diabetic, since the chronic illness affected the everyday life of all family members (Kanstrup et al. 2008). The participants were selected to represent a broad variety of the target group and were between 4 and 68 years old. Approximately 50% had type 1 diabetes mellitus (T1DM; insulin dependent diabetes) and 50% had type 2 diabetes mellitus (T2DM; noninsulin-dependent diabetes). Some were newly diagnosed diabetics, while others had more than 20 years of experience with the disease. Thus, the term 'patients' in this case refers to a broad category of people affected by diabetes mellitus, including relatives living with a family member with diabetes mellitus.

Process

Two iterations were carried out in the project: eight families were recruited and participated in the first iteration in year one, and nine families were recruited and participated in the second iteration in year two of the project. All families took part in (a) two-hour home interviews, (b) a three-hour workshop and (c) one weekend of exploring prototypes for digital health services in a living laboratory (Kanstrup, Bjerge & Kristensen 2010).

Table 1: Activities in the design process

Step 1: Home visits	Visits in the homes of the families to establish the first cooperation and learn about everyday living with diabetes.
Step 2: Workshops	Workshops at Aalborg University in which patients, researchers and technicians cooperated on the ideation of possible futures for everyday-life activities identified during home visits.
Step 3: Living lab experiments	Living lab experiments exploring digital co-designed prototypes in a series of installations at bakeries, a butcher's shop, a supermarket and restaurants.
Step 4: Design workshop	A concluding design workshop in which patients, in groups, designed mock-ups of technological solutions to support everyday living with diabetes.
Step 5: Analysis of patient innovations	**Analysis of patients' innovations from the concluding design workshops.***

* The last row (step 5) is in boldface to highlight the focus of this paper.

Patient innovation

A series of co-designed digital prototypes were designed and explored (Table 1, steps 1–3). Additionally, the patients designed a series of low-fidelity (low-fi) mock-ups at the concluding design workshops (Table 1, step 4, and Table 2 for elaboration). These products – the co-designed digital prototypes and especially the patients' low-fi mock-ups – constituted the data for investigating patients' contributions to HIT innovation.

The design workshops, at which the low-fi mock-ups were made, concluded the design iterations. At the workshops, the patients formed groups of five to eight people. All groups worked to design one or more ICT service to support everyday living with diabetes. To express their ideas, all users had access to several design tools and materials, including paper, pencils, plasticine, Post-it Notes, cardboard imitations of computers and mobile phones, stickers and Polaroid cameras. The design workshops lasted approximately 60 minutes, followed by 30 minutes of joint sharing and reflection on the designs. Since the design workshops were carried out after home inquiries, workshops and living lab experiments, patients were already tuned in to the task and warmed up for the activity, through several months of active participation and learning in the project (Table 1). All groups presented their designs to each other and participated in a subsequent interview on their experiences as designers in the project. The data that formed the basis of the following analysis were photos and recordings of the patients' presentations of their designs, voice recordings of the group conversations during the 60-minute design activity, and the follow-up interviews.

Results

Documenting patient innovations

The patients in the maXi project produced:
- Four co-designs, that is, prototypes designed in cooperation between participating patients and design researchers (Table 1, steps 1–3). These designs are presented in the left-hand column of Table 2.
- Twenty-two patient designs, that is, mock-ups designed by participating patients in the concluding design workshops (cf. Table 1, step 4). These designs are presented in the right-hand column of Table 2.

Figure 1: Patients in the process of making innovative suggestions at design workshops

Table 2: Designs from the maXi project:
in the left-hand column, designs made in cooperation between patients and design researchers;
in the right-hand column, designs made by patients in the concluding design workshops

DESIGNS MADE IN COOPERATION BETWEEN PATIENTS AND RESEARCHERS	DESIGNS MADE BY PATIENTS AT DESIGN WORKSHOPS
1. MaXine: a blood glucose simulator and learning system.	5. A PC solution with point of departure in MaXine but redesigned towards daily use for monitoring.
2. DiaPedia: a user-driven iPhone app. for food and restaurant information.	6. A mobile application for grocery shopping combined with personal blood glucose management and social community.
3. The interactive menu: a menu card providing mobile access to nutrition information.	
4. The interactive butcher's shop: interactive information system for the butcher's shop.	
	7. A necklace and earrings to monitor and measure blood glucose level.
	8. A watch to monitor and measure blood glucose level.
	9. A monster that helps to remember medicine.
	10. A variety (14 designs) of mobile applications that support communication between family members about blood glucose levels and everyday activities.
	11. An information infrastructure supporting data catch-up and use, from supermarket systems (via bar codes) to mobile phones, refrigerators, interactive cookbooks and personal blood glucose management systems.
	12. Two beepers that monitor and send alarms to family members if blood glucose level gets too low.

Table 2 shows the comparability of the designs in the two columns:
- highly comparable designs (design 1, 2, 5 and 6)
- non-comparable co-designs (designs 3 and 4)
- non-comparable patient designs (designs 7-12).

Two of the patient innovations (designs 5 and 6) were close redesigns of the digital co-designed prototypes. Two of the co-designs (designs 3 and 4) were not considered by the patients in the design workshops. Twenty of the patients' designs included a variety of design ideas without comparison to the co-designed digital prototypes (designs 7–12). Overall, 20 out of 22 designs made by the patients were original contributions, not merely replications or improvements of existing co-designs.

Characteristics of patient contributions
Original patient innovations included jewellery, alarms, mobile applications, watches and larger information infrastructures. The designs were especially characterised by combinations of medical technologies (blood glucose meters, calculators, etc.) and everyday-life objects (jewellery, watches, mobiles phones, etc.), and combinations of support to self-manage activities (e.g. to remember, calculate and intake insulin and diet, among others) using aspects of everyday life

(communication, fashion, grocery shopping, etc.). We categorised the patient designs as follows:
- designs focused on daily cooperation in the family (Figure 2)
- designs focused on decorations in the home (Figure 3)
- designs focused on fashion (Figure 4).

Designs for cooperation
Figure 2 presents a patient design of a beeper that monitors a patient's glucose level and sends an alarm to family members if it gets out of range (left), and a design of a mobile application to support communication between family members regarding glucose levels and everyday activities such as sports, shopping for groceries and being with friends, and one's general whereabouts (right). These designs represent the primary types of patients' designs: a total of 14 mobile applications (design 10) and two alarms (design 12). The designs are characterised by their focus on supporting cooperation (vs self-management) in daily tasks related to living with diabetes, including a wide range of activities from grocery shopping to blood glucose management and social relationships. The designs all touch upon the need of diabetics and their families to cooperate with trusted people. A diabetic child explained design 12 to his mother as follows:

'It is a mobile beeper where you can see how I am'. An adult diabetic presented design 12 as a wish to increase his mobility: *'As it is, I never go to remote places where there is no mobile connection'.* Designs 10 were presented as examples of daily cooperation on self-management. Examples included checking on family members: *'I need to know if she is okay'* (husband to diabetic), *'I need help to plan food for the day when I am very busy with meetings at work'* (adult diabetic, planning grocery shopping and food) and cooperation in sport activities.

Designs for the home

Figure 3 presents examples of patients' designs in which the home setting is addressed. Here patients emphasised the designs' ability to support a home-like atmosphere. Patient design 9 (photo on left), a monster to help remember treatment, was designed by a child who envisioned this as a 'cool' decoration for her room. Design 11 is a kind of collage of functionality, combining a mobile application for grocery shopping with personal glucose management and social community. When designing mock-up 11 in Figure 3, the patients (in this group, all women aged 30 to 65) placed candles in the middle of the design collage. A quote from their discussion during the design process emphasised their focus on decoration and the atmosphere of the home: *'Okay, so we want candles. Let's place them in the centre like this. It's cosy writing like that. It must not be too technical. Cosy'.*

Designs for fashion

Figure 4 presents examples of patients' designs in which lived life and identity are put at the forefront, with a focus on fashion. The photo on the left shows jewellery imagined with built-in glucose measurement technology. Likewise, the right-hand photo is a watch also imagined with built-in glucose
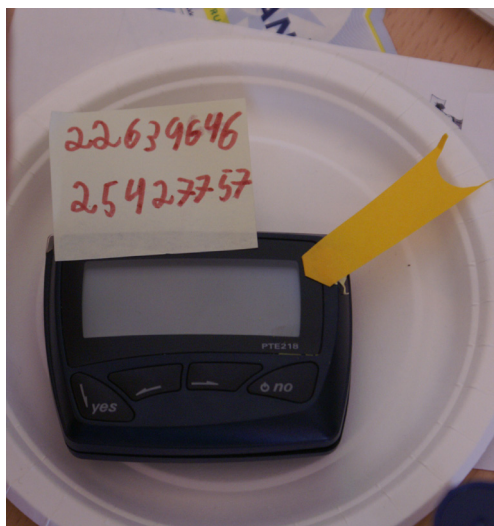

Figure 2. Left: patient design 12 – a beeper that can monitor blood glucose level and send an alarm. Right: patient design 10 – a design of a mobile application to support cooperation in a series of daily activities
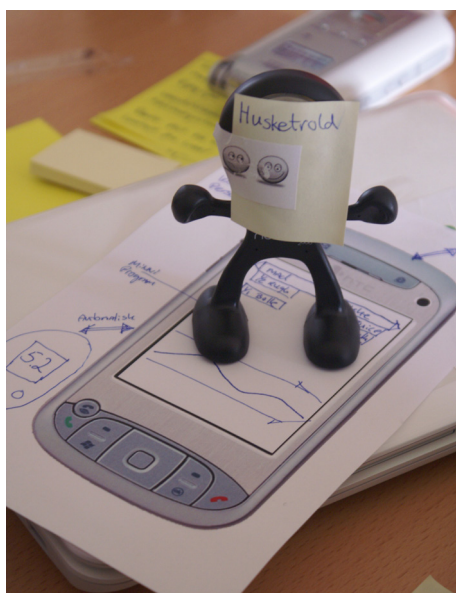

Figure 3. Left: patient design 9 – a monster that helps to remember medicine. Right: patient design 11 – patients working with design materials, including 'cosy candles' for a mobile application for grocery shopping

Figure 4. Top: patient design 7 – jewellery to monitor and adjust glucose levels. Bottom: patient design 8 – a watch to monitor blood glucose levels

measurement technology. The designs have fashion as a primary focus and monitoring of the blood glucose level in the background. The patients who designed these were teenagers who emphasised the need for technology that is not just designed for illness or medical activities. One of the patient designers stated: *'I say, "I am Anna". I don't say, "I am diabetic"'* (teen diabetic). The emphasis in these designs was on how to blend into everyday life, for example with friends at school, in the city, at sport activities, at a café. Anna explained: *'I would prefer not to say that I am diabetic'* (teen diabetic). The patient who designed the watch said: *'It has to be fashionable'* (teen diabetic).

Discussion

Originality of the patient innovations

Are the patients' designs in this project original, innovative contributions? Or are they merely replicas of the co-designs made during the design project? Table 2 shows that the patients' designs are more than just reflections of co-designs made during the project: *20 (out of 22) designs made by the patients were original contributions.* The patients' designs combined different existing products into new ones – for example combining a glucose meter with jewellery, combining watches and mobile phones, combining toys with alarms, and a variety of designs connecting people via mobile infrastructures for family members, service providers, friends and healthcare professionals. The patients' designs also combined in novel ways medical perspectives that are traditionally in the foreground of diabetes technology (glucose measurement and management) with everyday life objects such as jewellery, watches, toys and mobile phones. The designs also combined management of chronic

illness with everyday life issues such as identity and family cooperation.

This combination of everyday issues and objects with diabetes management and technology was new to the patients participating in the research project. In terms of the definitions of innovation presented above, the patients' designs presented ideas that are perceived as new to the patients in the study and their social system of diabetes self-management practice. Those ideas have not been addressed by existing technology in these people's everyday lives, nor are related technologies available for purchase. The lack of technologies in the patients' lives that match their ideas for how to make a fit between illness and everyday diabetes practice indicates that there is a gap between patients' needs and existing technology for everyday living with diabetes. Including patients as innovators in HIT can provide attention to and ideas for how to bridge this gap.

Characteristics of the patient innovations

As indicated above, a central characteristic of the patients' designs is how they combine the domestic and personal sphere with the design of medical technology.

Designs 10 and 12 in Figure 2 bring family cooperation into the design of technologies for self-management of chronic illness. They represent the primary types of patient designs from the project and are characterised by an attention to cooperation among actors in order to assist patients in everyday living with a chronic illness. Research on tele-medicine has shown that patients become competent actors in their illness when they are participating in a 'socio-technical network' that supports them in their health activities (Oudshoorn 2008: 285). *These designs are all concerned with supporting the socio-technical networks of the patients.*

Designs 9 and 11 in Figure 3 are examples of the domestication of medical technology. The emphasis is on decoration and atmosphere (a 'cool' teenage room and a 'cosy' atmosphere in the house). Research on people's attachments to objects in their home has shown that people's sense-making is primarily related to non-causal relationships, such as family belonging, associations and harmony (Krippendorf 1995). Objects that are merely objects are only in the background (or environment) of people's lives, while objects with associated meaning (i.e. objects related to memories, identity, feelings, etc.) are in the foreground of their lives. *These designs are examples of patients' designs of HIT that have associated personal meanings.* Finding the right combination of medical ideals and personal everyday-life issues is indeed a balance (Glasemann, Kanstrup & Ryberg 2010), and the patient designs from the maXi project provided insight into potential coherent connections between medical objects and everyday living.

Patient designs 7 and 8 in Figure 4 are examples of how patients' bring their own identity to the foreground of technology, with a focus on fashion and being 'me' in contrast to being diabetic. Studies of how people experience living with a chronic condition have shown that people feel predominantly healthy and that a predominant concern with illness will mean that 'a large part of a person's whole is missing and therefore denied' (Lindsey 1996: p. 466). Research on teenage patients provides similar insights into this target group's need to push illness to the background – to 'enable young patients to be "regular" teenagers' (van der Velden & El Emam 2013: p. 16) and to use colours and personalised details in designs (van der Velden & Machniak 2014). Additionally, Pullin (2009) has emphasised the need to embrace fashion in general when designing medical devices and has provided several inspiring examples of, for example, ear-wear, communication technologies and wheelchairs (Pullin 2009). Designs 7 and 8 are *examples of patients' designs of technology that supports the expression of identity* (rather than their illness).

Conclusions

In this paper, we have outlined a theoretical definition of patient innovation, that is, *patients' development of ideas, practice or objects that are perceived as new by themselves and/or others within the social system of adaptation.* This definition contributes to the clarity of the meaning and expectations of patient innovations as defined and analysed in relation to the existing practices of patients and their social system of adaptation (in comparison with high-technology innovations or market share). The definition acknowl-edges patients' participation as key actors in their own treatment and emphasises a consequent participatory approach to patients as key innovators of HIT.

From this perspective, we analysed patients' designs in a design research project focused on the design of digital support for everyday living with diabetes. The analysis documented the originality of patient innovations: 20 out of 22 designs made by patients in the design research project were original contributions. Moreover, our analysis identified three characteristics of the patients' designs: patients' designs of socio-technical networks, patients' designs of objects with associated personal meanings and patients' designs of technology that supports the expression of identity.

The results of the analysis contribute to the definition of patients as key actors in HIT innovation and call for participatory approaches in health informatics.

Acknowledgements

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