



The non-participatory patient

Juan Sanin
juan.sanin@rmit.edu.au
RMIT University, 16 Cardigan St. Carlton, Victoria 3053. Australia

Abstract

This paper discusses tensions and paradoxes of codesign paradigms and calls for more plural approaches to participation in order to establish collaborations with non-participatory users. It builds on research experiences in the field of design for wellbeing to challenge assumptions about user participation and introduce the concept of ‘the non-participatory patient’. This conceptual figure is used to represent those users who do not engage with codesign activities, or those who engage, but contribute in ways that contradict expectations of designers and industry partners. It is argued that most service design projects are not able to account for the needs and preferences of non-participatory users, who are most of the time excluded from design processes and outcomes for being considered as disengaged or disobedient. These experiences make evident the need for collaborative tools, techniques and formats beyond those traditionally used in codesign, and able to bring more plurality into service design.

Keywords: codesign, non-participatory patients, design for wellbeing

Introduction

We live in the ‘era of participation’ (Smith et al., 2017). The confluence of participatory design philosophies and co-creation paradigms have institutionalised the idea that not just designers, but also users, play a crucial role in design processes (Sanders & Stappers, 2008). This new era

has generated multiple transitions and assigned new roles to designers and users. Designers have become facilitators of design processes and users are considered to be creative experts of their own experiences, engaged in participatory processes and empowered. In this new era, it is almost inconceivable to create products, services or policies without active participation of people.

In healthcare, the era of participation is lived intensely. Authors talk of a 'participatory zeitgeist' to describe a new spirit of "citizen engagement, public participation and involvement of people with lived experience in health system redesign and service improvement" (Palmer et al., 2019). Designers looking into this field talk of participatory patients and patients 3.0 empowered by digital platforms (e.g. Andersen, 2010; Clemensen et al., 2016). Governments influenced by this paradigm implement new health standards requiring hospitals to engage patients in the design of new services (e.g. Australian Commission on Safety and Quality in Health Care, 2012). And hospitals and universities create codesign centres to facilitate collaborations between designers and health stakeholders (e.g. Reay et al., 2017).

This new era is far from perfect. The participatory zeitgeist has paradoxes and tensions that demand more plural approaches to collaborative design processes. As I argue elsewhere (Sanin, 2019), it is paradoxical how ideas of participation, power and democracy have been appropriated to introduce neoliberal agendas in healthcare and how corporate involvement is creating tensions between expected outcomes of industry partners and research findings. The unequal relationships across participants in healthcare projects can produce problematic group dynamics, where care providers hold power over patients by prioritising scientific points of view and clinical procedures over participants' opinions and experiences (Geuens et al., 2018). Pierri (2018) discusses the paradoxes of participation in the context of mental healthcare, and building on social studies, explains how optimistic accounts have constructed a script of a 'compliant participant' where certain types of participation are encouraged and requested from individuals, and those who disobey this script are seen as disengaged or irresponsible. Andersen (2010) has shown that when these scripts are put into practice, project outcomes meet expectations of the 'participatory patient' but disempower less-active ones and overlook their needs.

Although an extensive review of critical approaches to participation is beyond the scope of this short paper, it is important to note that participatory design practitioners have critically analysed tensions,

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paradoxes and power relationships at play in the participatory process. Collaborative research can be characterised by tensions between designers and stakeholders, including industry and community partners (Grönvall et al., 2016; Newell et al., 2006). Some of these issues are the result of assumptions that non-academic stakeholders have in relation to skills and expectations of final users. However, we designers also exercise academic power when we introduce co-design methods and activities assuming they will help people to express their ideas in creative ways, and when our reports place emphasis on aspects and outcomes that advance our own research agendas.

This paper builds on personal research experiences to show that not all patients 'comply' with participatory paradigms and to point out the existence of non-participatory patients. The paper discusses a twofold paradox: the assumption that all patients want to participate in codesign projects under specific conditions, and that their participation will confirm industry and academic expectations. In doing this I provide two personal accounts of encounters with non-participatory patients that challenge these assumptions and remind us to be open to the plural character of participation (Pihkala & Karasti, 2016). In these accounts I engage with politics of self-representation, following calls for reporting not just success but also unresolved and uncomfortable aspects of design practice (Light, 2018).

Taking engagement and empowerment by granted

The participatory patient is a conceptual construct visible in academic, government and industry accounts focused on health services. Some of the most solid assumptions revolve around patient engagement with codesign activities and empowerment through Communication Technologies (ICT).

Most design accounts assume that users of health services are willing to participate in codesign projects and that those who engage represent the majority, including those who do not participate. Health organisations invite users to leave opinions in suggestion boxes or participate in committees of consumer representatives and collaborate with designers running codesign workshops where users are asked to contribute to design processes by using toolkits and making or testing prototypes. Most of the time, the outcomes of these

collaborations confirm expectations and provide positive responses to project ideas. Based on the new services, guidelines and policies are designed. The truth is that these formats are unable to capture the voice of non-participants and that disengagement, complaints or dissent are rarely captured and generally excluded from design processes.

Another assumption is a direct correlation between ICT and empowerment. Health studies argue that information is crucial for patient empowerment since it provides patients with possibilities to participate in decision making, manage treatment, play an active role in self-care and collaborate with other patients (Jørgensen et al., 2017). Designers have assumed that digitalisation makes information more available and accessible, and mobile devices, apps, and social networking sites are believed to empower patients by helping them to access information, monitor medical conditions or be part of online communities where they share experiences and get responses to their questions. It might be true that some patients feel empowered by information, but this is not a rule. And although digital platforms play an increasing role in everyday life, it does not mean that they are the best option for information delivery and access.

What most academic, government and industry documents do not account for are the forms of participation exercised by non-participatory patients: those who decide not to participate in codesign activities; or those who participate, but whose input is not taken into consideration as it is felt to be in tension with the design of digital services. The next section presents two encounters with non-participatory patients that challenge the assumptions explained above and provide insights for collaborating with them.

Collaborating with non-participatory patients

Empowered patients, disobedient participants

This account presents experiences from a codesign project run in partnership with a cancer centre, aimed at improving information delivery services. In these project patients participated in these projects, but their contribution took an unexpected path and contradicted the assumptions guiding the project's objective.

Empowering patients is a fundamental premise of the 'participatory zeitgeist'. Meeting patients' information needs is crucial for their empowerment. Academic literature and policies assume that well-informed

patients will have an active involvement in their own care, participate in decision making and engage in self-care practices. Patients are encouraged to read information delivered to them, keep a record of their treatment, find answers for their questions, participate in support groups, and gain health literacy (Jørgensen et al., 2017). In response, health organisations implement ICT (e.g. health information systems, social networking sites) to promote empowerment by meeting patients' information needs.

The project discussed here was based on the premise of digitalisation and aimed to better understand the information needs of cancer patients to inform the design of a digital health information system. My role was to run codesign workshops to bring the 'patient voice' into this process, for which I designed a series of tools that would facilitate patient participation and help them, and their relatives, to identify their information needs and propose topics they would like to find in the information portal.

As soon as the project started a series of complications related to the collaboration format and what participants had to say emerged. The physical and emotional condition of patients complicated the idea of having codesign workshops. Instead, collaborations took the form of one-on-one conversations in the oncology unit when they came to have chemotherapy and their information needs were discussed using a toolkit that was completed not by them, but by a clinician.

What patients said in these conversations contradicted initial assumptions. They did feel empowered, not by the information received, but by the treatment they were receiving and the support of relatives and healthcare professionals. Most patients were satisfied with the information delivered and thought it was enough. Many were overwhelmed by the amount and type of information given to them, reported issues trying to process it and felt threatened by some contents. Several patients preferred to leave treatment decisions to doctors, and thought that healthcare professionals, not themselves, were responsible for their care.

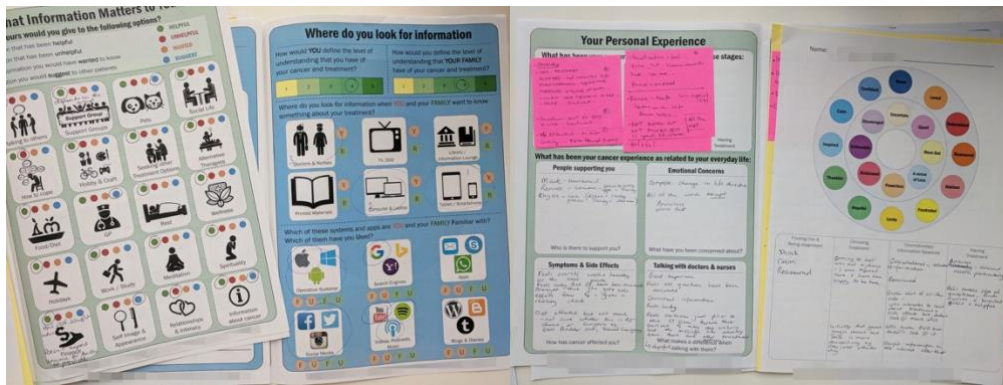


Figure 1. Toolkit used to facilitate conversations with patients and relatives

The idea that they would prefer digital platforms as information sources became problematic. All of them, old and young, owned mobile devices, knew how to use the search engines, and were active users of social media. However, most of them reported distress after using digital platforms and finding conflicting information about treatments, worst case scenarios, and sources claiming to have found miraculous cures. Overall, ‘the patient voice’ agreed that the most trusted information sources were their doctors, and that personal communication was by far the best option. Just a few agreed with the idea of using ICT for delivering information, but only to complement the role of healthcare professionals.

Creative people, disengaged participants

The second account presents experiences of a collaborative project to improve therapeutic services in a psychiatric unit. However, the people I was supposed to design with were not interested in becoming project participants. Since they did not take part in the activities I proposed, I had to participate in their own creative activities in order to collaborate with them.

The ‘participatory era’ is based on the conviction that users want to engage in design processes. The expression ‘designing with people’ - usually used to explain this ethos - prefigures a specific form of collaboration where designers leave the abstract space of experts, people leave the concrete space they inhabit, and both come together in the realm of collaboration (Lee, 2008). This realm, also known as third space (Muller, 2003), is created by designers using tools and techniques that facilitate creative contributions of people to the design process (Sanders & Stappers, 2014). If patients do not come to this realm or do it wrongly, they might be considered, as Pierri (2018) points out, as disengaged.

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In this project, I was in charge of collaborating with staff and patients of a psychiatric unit codesigning a series of tools for assisting with the delivery of sensory therapies. In preparation for this collaboration, I revised literature on codesign projects in mental health (Jakob & Manchester, 2017; Maldonado Branco et al., 2017) and collaborated with industry partners planning a series of workshops that would help me to engage with future users. These collaborations were going to happen in a room allocated for the project – beyond patient and staff areas – which seemed an ideal third space.

After a couple of meetings with staff and initial contact with patients, I realised that they were not interested in the collaboration as I proposed it. Staff did not see the point of creating tools for sensory therapy because when the project was being prepared, their roles had changed, and these therapies were removed from their routines. The idea of attending workshops to explore and share ideas using paper tools or prototypes was completely unattractive to staff and patients, who were busy in other activities in the unit wards. Although they were interested in the idea of having a designer working with them, they did not want to become my project participants. They did not want to leave the concrete world of people to come into the realm of collaboration.

After some weeks of unsuccessful attempts and frustration, by coincidence I found out that another way of collaborating would be to step outside of the ‘realm of collaboration’ and step into the world they inhabit: the psychiatric ward. Once there, I became a regular participant in improvised art sessions run by staff using reclaimed clinical furniture, painting and office supplies. Although the sessions were not ‘art therapy’ and were not based on ‘arts in health’ frameworks, they had a positive therapeutic effect for participants.

As a participant of their own creative activities – rather than as a facilitator of a codesign process in a third space – I was able to work with staff to reframe the project and design tools and guidelines to introduce ‘creativity and mental health’ frameworks (Gillam, 2018) into the art activities and increase their therapeutic benefits. I organised a series of non-disruptive interventions in the psychiatric ward, where I introduced a series of art tools and supplies and a series of examples and ideas to show how they could be used in their activities. I took part in these interventions as a participant, rather than as a facilitator, and did not propose a specific script, but left patients and staff to appropriate the materials as part of their creative process. Based on the outcomes of these interventions, and through more formal collaborations with staff, I developed a systematic

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toolkit to deliver art activities as part of a program of diversional therapies that we called 'creative wellbeing'.



Figure 2. Design interventions (left) and final 'creative wellbeing' toolkit (right)

How can we account for non-participatory patients?

Although my encounters with non-participatory patients were challenging, they provided learning experiences in relation to plurality, and in particular,

to the many forms of participations – in plural – that coexist in collaborative research (Pihkala & Karasti, 2016). The first experience showed that traditional formats can be inconvenient under specific circumstances. Having individual conversations facilitated an honest collaboration, where participants felt safe and expressed points of view that would have been difficult to share in a workshop or a committee of consumer representatives. Patients did engage in project activities but participated in ways that contradicted the idea that ICT would empower them. In the second experience, at the psychiatric unit, I had to move out of the comfort zone of a traditional codesign project to enter into the everyday of this place. There, designing as people, rather than with them, I became a participant in ongoing co-creative initiatives taking place at the psychiatric unit. As an insider, I was able to gain insights that would have remained elusive in a traditional participatory format and realised that what the project aimed to deliver was not exactly what the staff and patients wanted.

Despite the benefits of collaborative approaches to design there is still a need for more plurality in the participatory era. Pihkala & Karasti (2016) remind us that participation, more than a stable process, is a complex web of engagements and responsibilities that require constant negotiation to facilitate not singular, but plural forms of participation. The experiences shared above do not call for new methods, tools or techniques, but for forms of collaboration that go beyond traditional formats to establish dynamic engagements with non-participatory users. These are users who might not be interested in participating in traditional workshops, do not share visions and objectives of projects, or have something to say that is different to what project stakeholders expect to hear. These users, as the examples showed, have important contributions to make to design processes, and not including them will limit the scope and reduce the impact of future services.

Conclusion

This paper has challenged assumptions about user participation at the centre of codesign paradigms. Using personal research experiences in the context of design for wellbeing has made evident the existence of non-participatory patients. It is not my intention to suggest that participatory approaches to the design of health services are inappropriate. On the contrary, I feel that, most of the time, design participation projects and outcomes are beneficial for participants and future users. The contribution

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to this conference is to point out the need for plurality in participatory processes, in particular for adapting mindsets, methods and outcomes to engage with non-participatory patients.

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