# Cultures of Participation in the Healthcare Field: Could a VideoGame-Based Perspective Be Useful?

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**Abstract.** The games for health field links many actors with many complementary roles. In an ideal world, all the stakeholders participate to each Participatory Design loop and all continue to participate meaningfully as the design is specified, implemented, delivered, installed, and used. In this paper we argue that before a successful Participatory Design session can take place all the stakeholders need to construct a common Culture of Participation. In order to construct this shared Culture of Participation we propose to use games (in place of Participatory Design sessions) to reach a sufficient level of shared understanding that will allow to improve rehabilitation methods and treatments.

**Keywords:** Participatory design · Games for health · Serious games · Culture of participation

## 1 Introduction

In a 2007 paper, Carroll and Rosson [1] observed that Participatory Design integrated two radical propositions about design at its origins. The first is the moral proposition that the people who will be affected most directly by a design outcome should have a say in what that outcome is. This leads to the assumption that users *have a right* to be directly included in the design process. The second is the pragmatic proposition that the people who will need to adopt, and perhaps to adapt to an artefact, should be included in the design process, so that they can offer expert perspectives and preferences regarding the activity that the design will support, and most likely transform. The pragmatic proposition leads to the assumption that the direct inclusion of the users' input will *increase the chances of a successful design outcome.*

In an ideal world, all the relevant stakeholders participate to each design loop and all continue to participate meaningfully as the design is specified, implemented, delivered, installed, and used. The Participatory Design (PD) process becomes a social negotiation among partners, and the designer's responsibility in this process is to faithfully translate, collaborate, and respond to the concerns of the other stakeholders [1].

We would like to argue that, for this social negotiation to be fruitful, all the stakeholders need to construct a common Culture of Participation [2], which will create the shared background on the top of which Participatory Design can take place. A Culture of Participation (CP) describes how participants will act and react to


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Participatory Design. It reflects the values that underpin participatory practice and the reasons for involving and being involved, when and how participation is used, and the extent to which the different actors are listened to and appropriate action is taken [3]. Cultures of participation require contributors with diverse background knowledge who require different support and value different ways of participating. The difficulty to make all these different contributors work together is particularly evident in the games for health field.

The health field (excluding for the moment the gaming part) links many actors with many complementary roles. At the centre is the patient, the person whose health will be considered. Around her, people whose numbers and richness of roles vary gravitate. Doctors, specialists, auxiliary nurses and other therapists, spouse and family are all people who interact with the patient, and can influence in one way or another (i.e., more or less directly) her health. The scenario becomes increasingly complex when we add to the scene also the professionals who will develop the games for health. While this inclusion allows for taking into account not only the health aspects but also the playful mechanisms linked with video games, doctors and game developers rarely share a common Culture of Participation. If we consider Participatory Design in terms of who should sit around the table during the design phase, we are tempted to look only at the primary circle represented in Fig. 1: the patient, the healthcare staff, and the game designers. However what happens is more similar to the secondary circle. Sitting around the table are not only the primary stakeholders, but also the beliefs they have, their cultural background, their habits in participation, and we could go on adding the

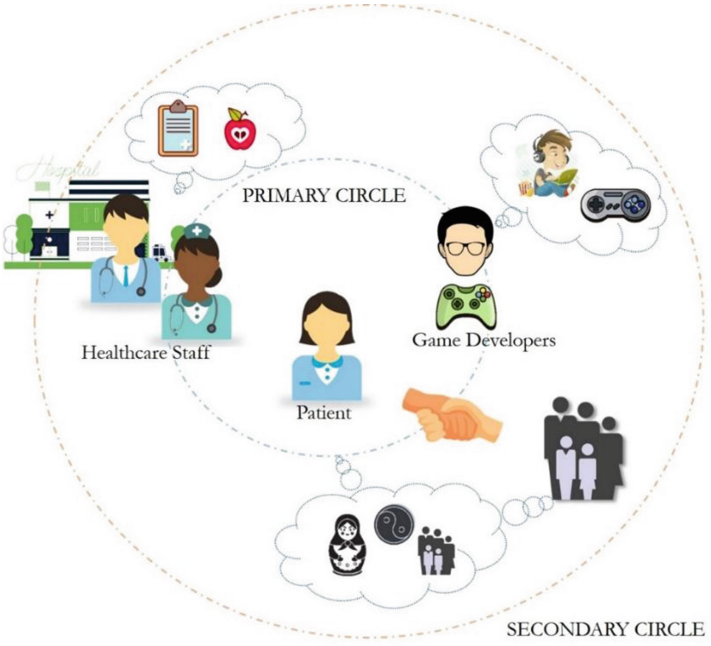


**Fig. 1.** The Game for health ecosystem

sociopolitical and technical structure (such as the hospital, the game studio where the game will be developed and so on) surrounding each of these actors.

In addition, health professional are adopting new collaborative practices to handle cost-containment policies and the need to take care of increasing numbers of patients and elderly people staying at home; collaborative practices that are more similar to Engestrom knotworking [32] – where people are loosely connected - than classical structured healthcare collaborative practices [33].

To better understand if and how the actors and elements in the secondary circle can participate in creating a common Culture of Participation for the games for health domain, we will first look at the cultures of participations for each different stakeholders and then try to understand where these cultures could meet. At the end of the paper, we will give a suggestion for a possible reversal of perspective. It is worth to note that this work does not pretend to be exhaustive. It will not take into account for example the socio-technical and political implication of a shared Culture of Participation, elements that will need to be taken into account for a real application of the proposed approach.

## 2 Culture of Participation in the Healthcare Field: The Health Personnel and the Patient

When we talk about Culture of Participation (CP) in the healthcare domain, we first think about humanitarian assistance, particularly during a crisis. During a period of humanitarian crisis, hundreds or thousands of people around the world organize themselves to provide logistical, food or medical support for local people in need. Many organizations like the *Red Cross* or *Médecins Sans Frontières* are able to quickly provide emergency medical assistance across the world. However, humanitarian aid is increasingly structured and professionalized, with humanitarian organizations now looking for professionals and specialists from diverse professions. Laypeople across the world support these humanitarian organizations mostly thorough financial participation. On a local level, medical institutions and services – through their health personnel – constitute complex systems. They include highly specialized knowledge and skills aimed to treat the higher number of people possible. They form what can be called an expert group, using their special skills on a second group, the laypeople (patients and relative), which is inherently in a subordinate position: this second group is requesting care and is usually devoid of health competencies. The relationship between the health personnel and patients and families is thus an asymmetrical one. On the opposite side there is peer communication between colleagues, where health professionals (we are using here health professional as a generic term, even if the relationship between e.g., doctors and nurses should be further expanded) turn to each other for information and decision support. It is through the multitude of conversations scattered during the clinical day, for example, that clinicians examine, present, and interpret clinical data and ultimately decide on clinical actions [4]. Social interaction between peers is composed of sharing and interpreting information as an interactive process that emerges out of communication. Discussing a medical problem with a clinical colleague or with a patient results thus in very different conversations. Unsurprisingly, human

agents communicate more easily with others of similar occupation and educational background, since they have similar experiences, beliefs, and knowledge [5]. Still, these kind of conversation are local and time limited, constructed around a particular patient or case, and thus very dependent on the context and on the people participating in the conversation.

Not only do patients and health personnel not share a common knowledge, but neither do they share a common Culture of Participation. For example, cultural issues play a major role in patient compliance, and in her willingness to participate to the Participatory Design culture [6]. Patients and their families bring culture specific ideas and values related to concepts of health and illness, reporting of symptoms, expectations for how health care will be delivered, and beliefs concerning medication and treatments. In addition, culture specific values influence patient roles and expectations, how much information about illness and treatment is desired, how death and dying will be managed, bereavement patterns, gender and family roles, and processes for decision making. Unfortunately, in the asymmetric relationship described above, the expectation of many health care professionals (that patients will conform to their health values) have frequently created barriers to care that have been compounded by differences in language and education between patients and providers from different backgrounds. In this scenario, the *faith* the patient has in her doctor, could influence the acceptance of the therapy. During a project on the usage of mixed reality and games for post stroke rehabilitation, the author of this paper heard more than once (from patients not used to playing video games) statements such as: "if my doctor says it is useful, then I will do it" [7]. The acceptance/resistance to the usage of the proposed tools was thus subordinated to the confidence relationship between the patient and the doctor. In this setup is kind of improbable that the designer, the patient, and the doctor, will be on the same level while doing PD sessions.

The scenario becomes more and more complicated if we analyze the implementation of a shared Culture of Participation between health institutions. While from an insider perspective the above mentioned culture of information sharing and discussion is the norm, between hospitals it involves mostly information sharing (when it is not clearly hampered by the *publish or perish* factor[1]). Finally, the healthcare sector is known to be relatively change resistant (e.g. [8]), and with a reason. Introducing new technologies and treatments usually involves going through long and complicated approval processes as the risks associated with healthcare are extremely high. A wrongfully applied treatment or a poorly designed technology might at best not help a patient's recovery, but potentially leads to worsening of a patient's condition, or even death.

Still, healthcare is one of the most promising domains for the application of end-user development [9] and cultures of participation [10]. In many cases, patients have such specific conditions that they are in a 'universe of one' [11]: a unique case. Therefore, standardized technologies and treatments might not deliver an optimal solution and it seems only logical to allow doctors, therapists, caregivers and even patients to adjust these technologies to better fit the needs of the individual patient [12].

[1] Publish or perish" is a phrase coined to describe the pressure in academia to rapidly and continually publish academic work to sustain or further one's career.

Different attempts to create formal practices for Participatory Design in the health domain have been proposed. Arstein [13] described the different possible interactions between the power holders and the powerless, and proposes a 8 levels ladder of participation from "citizen control" to "manipulation". Each rung corresponds to the extent of citizens' power in determining the end product. Tritter et al. [14] judge Arstein's ladder not adapted for health and too power oriented which limits effective responses and undermines the potential of the user involvement in the process. For this reason they propose a new model and argue that user involvement in improving health services must acknowledge the value of the process, and the different knowledge and experience of both, health professionals and laypeople.

In recent decades, a number of user-centered approaches have been introduced for the development of health information systems, like usability engineering [15] or contextual design [16]. In particular, PD methods have widely been applied in the field of health informatics [17–19]. Indeed, Clemensen [18] adapted PD adding a clinical trial phase to take the experiment into a real life situation, testing the idea with health care workers and patients who have not participated in the project. They conclude that PD provides an effective means for researchers from the seemingly disparate worlds of health science and computer science to work together.

Still, we should keep in mind that whatever designed artefact (and thus also computer based systems as games) conveys a cultural message and that technology and its adoption are not neutral phenomena that give equal chance to concordance and dissent: through the design of an artefact, the invisible work of 'others', alternative cultures and sciences (and thus alternative solutions) are receding [20].

## 3 Culture of Participation in Game and Serious Game Design

By observing the practices of the gaming industry we realize very quickly that every game studio (and we could say each team–artists, game designers, developers-in a studio) sets up its own strategy for game design and game development. As in the game market originality is the factor that can give a competitive advantage, information sharing between studios is not the norm (with a dynamic that is not different from the scientific publish or perish one). Inside each studio, information and conversation sharing vary depending on the size of the studio, the type of product, and the interaction that developers have with their gaming community (that, in the case of Serious Games for health, could be brought back to patients and family).

Still, sectors of the game development market share a common culture, a game culture based on the games they played as children plus the game culture of the studio they are currently working in. In game developers conferences- GDC[2] for example –it wasn't unusual some years ago to hear discussions on if or not casual gaming should be considered a real form of gaming. The logical structure of those discussions wasn't far from the one used in the artistic domain when evaluating if a particular form of art – graffiti for example- should be considered art; and concerned categories such as the

[2] http://www.gdceurope.com/.

artistic value of the final game, the time spent developing it, and so on. While at first glance it could seem that the Game Development field does not involve a Culture of Participation, things change when we look at the relationship developers/players. Opposite to what happens in the healthcare field, where the patient is not consulted about the diagnosis or the creation of a new therapy, in the last ten years the game development field has seen many initiatives promoting broad participation and reconciliation between game designers and players. Not only we assist to the practice of beta testing, in which early version of the games are released to get costumer advices on future developments, but also crowd-funding has been a key driver for video game creation (for more information see e.g., [21]). Many projects were possible only thanks to this participatory funding system. In this way consumactors (a term defining users that are consumers and actors at the same time) could define the major trends to be followed by the industry[3].

In the same way, game jams (i.e., gathering of game developers for the purpose of planning, designing, and creating one or more games within a short span of time) take now place on a planetary scale and help further democratize video games creation.

Hence, the video game industry has taken advantage of its Culture of Participation to bring closer game creators and players, increasing its own potential and diffusion.

In what concerns the Serious Game for health field, the Culture of Participation of this domain is more similar to the scientific one, in particular through the usage of Participatory Design. Different specific approaches have been created to integrate the serious and playful dimensions, in particular, giving the final user (in most cases doctors) power on the content of the Serious Game. In his analysis work, Djaouti [22] reviews a dozen of different design tools and methods for conceiving educational serious games, such as the one focused on the usage of technical tools [23], the content centered model [24], design patterns for serious games [25] or the DODDEL model [26]. All these methods aim to enable people new to game creation, but with competences on the serious domain, to make pedagogical games aimed to transmit knowledge or skills. This kind of approach allow the designer to understand the needs of patients and therapist without becoming an expert of the domain.

## 4 Discussion: Is It Possible to Create a Shared Culture of Participation in the Games for Health Domain?

The actors we described until now have thus very different Cultures of Participation that are not always compatible. In addition, even if we did not address the PD expert's Culture of Participation, it is worth to note that saying that it is the designer's responsibility in the PD process to faithfully translate, collaborate, and respond to the concerns of the other stakeholders is not neutral on consequences. In some way we are saying that the designer is an expert of expert, someone with a meta-knowledge who will know what is better to take and what to leave from the PD session with the concerned actors. This assumption - not necessarily false and surely useful to have a

[3] The pertinence and openness of this approach has still to be proved.

final artefact by the end of the process - could lead to adoption problems if the artefact wasn't created in a shared CP [34]. In our specific context, the risk is amplified by the kind of tools we are designing: serious games in the health field. These tools require a high level of acceptance by two stakeholders, the healthcare professionals and the patients, of a tool that is not devoid of stigmatization [27]. Still, considering the point of views of a maximum of different types of actors during design phases could potentially lead to better solutions and offer patients the best possible treatment for their situation.

Even if from our discussion, it seems difficult to reconcile the video games and the healthcare worlds, there is a notable example proving that it is not only possible but also profitable to make the video games and the medical worlds to cooperate through technology: *Foldit*. *Foldit*[4] is a puzzle video game invented to imagine protein folding possibilities in order to improve the knowledge about proteins and their modeling. Thanks to this experience that brought together more than 200 000 *non-expert* users, players and researchers have been able to find the 3D structure of a retroviral HIV protease, a necessary step in the development of a treatment drug.

Games for health are still recent and, as seen above, very few methods or tools exist in order to improve communication and collaboration between all the different concerned actors. Donnellon et al., [28, p.44] explain that when groups of participants do not have «shared meanings» or shared interpretations, they may engage in coordinated action by engaging in a set of communication practices that enable them to create "equifinal meanings." Equifinal meanings, they explain, are "interpretations that are dissimilar but that have similar behavioral implications." Achieving equifinal meanings does not require that participants achieve equal or overlapping understandings but rather that they develop a set of complementary understandings that lead to coordinated actions. If we look attentively, this is exactly what happened in the *Foldit* example, where people worked together in a loosely way, without necessarily sharing a common objective. The collective work in the *Foldit* project however, could potentially lead to a community who shares a common Culture of Participation that could be re-instantiated in other occasions. We believe that not starting from Participatory Design sessions but from videogames play is exactly the means we should exploit to create a common CP between health professionals, patients, and game designers. The act of playing together could thus be used as a pretext to create a shared language and a common understanding.

A first attempt by the authors to devise a coherent approach with various stakeholders through game play could be read in [29]. The game described in the paper had as aim to help with the rehabilitation of equilibrium disorders. It was however designed with the goal of adoption not only by patients and therapists, but also by the general public (for example, to be able to involve the family in the therapy). In order to achieve this goal, an incremental approach was put into practice, with game sessions (not necessarily involving the designed game) with all the different stakeholders. We tried thus to introduce the different actors to the game culture, and not only asked game designers to appropriate the healthcare one. This approach forced us to rethink Participatory Design sessions and the shift of perspective showed interesting results in a first experiment for the video game event MIG -Montpellier in Games.

[4] http://fold.it/portal/.

## 5 Conclusions

Participatory design is both a moral proposition where users *have a right* to be directly included in the process of design, and a pragmatic proposition *to create better artefacts*. Still, there is a lack of a common Culture of Participation that could prevent implementing both propositions when doing Participatory Design. We nevertheless believe that an increased Culture of Participation in this area would strengthen the creation, use, and potential of games for health [30]. Therefore, a fundamental challenge for supporting cultures of participation should be to conceptualize and create socio-technical environments able to take into account the different cultures of participation. We proposed to use games (in place of Participatory Design) to reach a sufficient level of shared understanding that will allow to create a shared Culture of Participation, thus allowing to improve rehabilitation methods and treatments.

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