Politics of participation in design research
Learning from participatory art
Knutz, Eva; Markussen, Thomas

Published in:
Design Issues

DOI:
10.1162/desi_a_00575

Publication date:
2020

Document version:
Final published version

Citation for published version (APA):

Go to publication entry in University of Southern Denmark's Research Portal

Terms of use
This work is brought to you by the University of Southern Denmark. Unless otherwise specified it has been shared according to the terms for self-archiving. If no other license is stated, these terms apply:

• You may download this work for personal use only.
• You may not further distribute the material or use it for any profit-making activity or commercial gain
• You may freely distribute the URL identifying this open access version

If you believe that this document breaches copyright please contact us providing details and we will investigate your claim. Please direct all enquiries to puresupport@bib.sdu.dk
Politics of Participation in Design Research: Learning from Participatory Art
Eva Knutz, Thomas Markussen

In design research, critique has recently been voiced against the way the notion of participation is understood and practiced. As the term has proliferated from its origin in participatory design into other approaches to design, “participation” has acquired a diversity of meanings and is used to indicate dissimilar practices. In participatory design, participation originally represented a social democratic belief that workers should be actively involved in managerial decisions about organizational change and the implementation of new technologies in their workplace. Now, participation is sometimes used to promote consumerist ideas of “democratic innovation” and a narrow, market-driven focus on how lead users might collaborate with designers in producing novelty products and economic growth.

Some critics have raised concern about these multiple meanings, pointing toward the need for a rethinking of participation in broader terms. Others lament that participation has lost its original alliance with socially engaged design practices and look toward critical theories from political philosophy and art activism to wrest the term out of the grips of neo-liberalism and the free market economy.

In this article, our aim is to restore the understanding that participation is a form of design activity that makes undemocratic forces and structures visible in a design process. In doing so, we do not make a plea for returning to a “good old” participatory design, although we sympathize with its care for excluded or vulnerable segments of society. Rather, we do so because we deem an increased awareness of the politics of participation necessary. “Politics of participation” refers to the ideologies underlying design approaches and implicitly valuing how control should be shared and for what purpose. In the design community, we see a widespread belief that the participation of people in design activities is to the benefit of all, while expert-led and design-driven approaches are less democratic. Co-design and user participation are good; design-led processes are too controlled, are exclusive, and indicate a reluctance to give up authorship. We would like to question this assumption. More specifically, we
argue that design-driven approaches to participation in some cases might be preferred over user-driven approaches and even can enhance forms of democracy for users whose views would otherwise be repressed. Not all people are able to participate. And designers need, in some incidences, to consider whether it is ethically responsible to let people participate. We always need to ask what participation is good for, who should participate, and when.

We draw on theories of participatory art to discuss and problematize dominant models of participation in design research. In doing so, we add to an ongoing discussion about the value of using studies on performativity and performance art to broaden the understanding of participation in design.4 However, we prefer the notion of participation to the terms performance and performativity for reasons we explain in the next section.

To initiate a more nuanced understanding of participation, we present three theories of participatory art, making initial conceptual distinctions and clarification. We present key concepts of each theory and use art projects to exemplify how the theories differ from one another in their explanatory scope. On the basis of this work, we are able to sketch three models of participation, all of which are founded on participatory art but that represent different politics of participation. The models prescribe different roles for the artist-designer, different forms of participation, and different degrees to which and purposes for which people are involved. To see the value for and influence on design, we then apply the three models in our case analysis of a design research project on patient democracy at the oncology department of a Danish hospital.

From Performance Art to Participatory Art

Studies of performativity and performance art have been valuable for increasing knowledge on a range of action-oriented and artistically inspired research methods in design research. However, we argue that the discourse on performance art does not provide full insight into the explanatory power of the term “participation” and that we still need to distinguish carefully between the two terms in at least three ways. First, in its current use, performance has come to represent ideals of “consensual collaboration” between the artist and audience, the designer and users, while neglecting the qualities of working with dissensus, provocation, and contestation as models of participation.

Second, performance art has inspired the working out of performative methods in design that can be valuable for generating and evaluating early ideas and design proposals. Vivid examples of such techniques include role play, body storming, and Wizard of Oz. However, performativity typically is exploited in this case as means for a commercial end—namely, the innovation of

---


new consumer products, media, or technologies. Meanwhile, the question of how products and technology perform politically motivated limits and organization back on people's everyday life is rarely raised from a performance art perspective.

Third, in HCI and interaction design, the notion of performance has been helpful in founding “experience design” as a new field that goes beyond the instrumentalist view of people as users. This expansion has significantly broadened the experience designer's method tool box, but left undiscussed are the questions about the instrumentalization of art practices for purposes for which they were not originally intended.

In this article, we introduce a model of participation that appreciates dissensus and the contest of democratic power (in all its variants) as much as consensual collaboration. Democracy does not necessarily follow from the sharing of control and from user participation; instead, democracy might also rely on being fundamentally questioned, disrupted, and renegotiated. Further, our model of participation does not have the democratizing of innovation as its ultimate goal; rather, we want to maximize design’s capacity to meet intractable social needs and create new social-material relations. In this sense, we argue, along with Björgvinsson et al. and DiSalvo, for replacing a product-centric view with an agonistic participatory approach in social design and social innovation. However, unlike these authors, we do not find our primary source of inspiration in political theories and philosophy. Rather, our aim is to demonstrate that a new model of participation can be grounded in theories of participatory art.

In this section, we present three influential theories of how participatory art might engage people willingly or unwillingly to construct counter-publics and a reconfiguring of the social order. More specifically, we discuss participatory art as potentially taking the form of “relational art,” of “participatory art,” and of “social works.” We deliberately choose the term “participatory art” to refer to the subject matter of all three theories, although the authors behind the theories would not agree on this overall unifying term. Generally, participatory art refers to art projects that involve “many people (as opposed to the one-to-one relationship of ‘interactivity’)” and that rely on the collaboration between the artists and the audience. However, it also leaves room for valuing “artistic mastery and individualism” over consensual collaboration without disqualifying this art practice as being non-participatory.

**Theory 1: Participatory Art as Relational Art**

The term “relational art” was coined by Nicolas Bourriaud to highlight art works that take inter-human relations as their point of departure. Art works can be relational in the sense that they...
construct what Bourriaud calls social interstices (a term he borrows from Karl Marx). Social interstices can be seen as “trading communities that elude the capitalist economic context by being removed from the law of profit: barter, merchandising, autarkic types of production, etc.” In art the social interstice denotes a micro-community that is tied together through meetings, encounters, and various types of collaboration rather than economic exchange. For Bourriaud, collaboration between the artist and the audience or the public takes center stage. Collaboration here might take the form of people’s involuntarily and momentarily participating in the artwork or of people’s voluntarily participating through more elaborate processes of collaboration. An example of the first would be the art project, Turkish Jokes (1994), by the Danish artist, Jens Haaning. When Haaning used loudspeakers installed in an immigrant area of Oslo to play recordings of jokes told by Turks in their native language, a new form of sociability was created through collective laughter.

An example of elaborate collaboration that relies on voluntary participation from the public is the artwork of Rirkrit Tiravanija, which usually takes place in gallery spaces where the audience is invited to meet, cook, read, or just spend time together. Here, socializing is the key element of the artwork. Characteristic for both Hanning’s and Tiravanija’s works is that they are open-ended, and very little control seems to be exercised over when the work ends. The control and authorship are shared, and basically everybody can participate.

Although Bourriaud sees participation as being symmetrical, consensual, and about the equal sharing of control, such characteristics are rarely, in fact, the case. The sharing of control often entails that one who has control is in a position to share and distribute it, which always raises questions of who has the power and authorship. Bourriaud assumes that relations that permit collaboration and dialogue are inherently democratic, so that what democracy means is never really questioned. Democracy has many faces and inevitably prescribes certain forms of participation while excluding others. As Rosalyn Deutsche argues, democracy can only be sustained if these exclusions are taken into account and opened up to contestation. Hence, moving toward a broader model of participation is necessary—to one that embraces dissensus and recognizes the artist as being the actor who configures the participation and the degree to which it is shared.

Theory 2: Participatory Art as Critical Practice
For Claire Bishop, participatory art is a practice that evokes an aesthetic rupturing or disturbance of the social order. Bishop is sceptical about the idea that the artist is conceived only as a collaborator and facilitator of situations and argues for the need to
appreciate artistic mastery and individualism. According to her, Bourriaud simply overvalues consensual collaboration without asking what it is for: “producing interpersonal relations for their own sake, and never addressing their political aspects.” For this reason, Bishop is not impressed by the work of Tiravanija and the form of open-ended participation that his work encourages. Such an art form institutionalizes participation and simply reduces participatory art to an instrument for bringing people together. It stages social relations as being neutral and de-politicized.

Bishop is interested in participatory art as an activity that disrupts or contest existing political or social structures. In her understanding of the “political” in relation to art, Bishop draws on Jacques Ranciére’s notion of aesthetic dissensus, which is the effect of non-violent critical aesthetic practices that disrupt the self-evident ways in which powerful systems control and limit certain groups in our society.

A paramount example for Bishop is the artwork, “250 cm Line Tatooed on 6 paid people” (1999) by Santiago Sierra, where a group of mine workers is lined up for a collective tattoo—a thin line across their back. In this artwork, as in many of Sierra’s other works, participation of the audience is problematized, and the control of the artist is taken to the extreme. In paying people for their participation, he turns raw capitalism and the exploitation of workers into his main artistic material. Sierra is in full control, and, contrary to Tiravanija, he cannot pretend that collaboration in art is free. It always has a price and manifests relations of power and authority.

Bishop’s model of participation favors art activism and the contestation of the political, economic, or social structures that inevitably limit our everyday lives. In this sense, participation is a way of making visible excluded or exploited groups of society, and it deals with questions of who has the right to speak, act, and feel. Bishop highlights the artist as the one who decides who can participate in the artwork and who cannot. The control therefore is not shared, and not everybody is allowed to participate. Although participatory art for Bishop is about critically challenging and destabilizing the status quo, she does not appreciate how art can be used to improve life conditions for people. This capacity is a central concern for the third model of participation we discuss.

**Theory 3: Participatory Art as Social Work**

Shannon Jackson introduces the notion of “social works” to emphasize the social engagement of participatory art practices. She distinguishes between two forms of engagement: Participation in art either exploits participants, not sharing any form of control with them, or the artwork is inclusive, using the means of dialogue and collaboration with the participants to achieve longer lasting...
social engagement. Unlike Bishop, Jackson privileges the latter because of its interest in building communities. Here participation is not institutionalized in an art context, as is often the case in relational art; instead, participation takes place in the public realm and for certain people. The control is shared, and the artist takes responsibility for its social engagement.

Jackson notes alternative purposes for social art practices: “While some social art practice seeks to innovate around the concept of collaboration, others seek to ironize it. While some social art practice seeks to forge social bonds, many others define their artistic radicality by the degree to which they disrupt the social.”\(^{17}\) She exemplifies these distinctions through the works of two artists representing opposing social art practices: that of Santiago Sierra, who Jackson describes as cynical and exploitive in his social engagement, and that of Shannon Flattery whose project, “Touchable Stories,” speaks to our sense of community and shared responsibility. Touchable Stories is a network of artists who create artworks based on themes from their local communities, with the purpose of bringing people and resources together through art and dialogue.

For Jackson, the raison d’être of participatory art is that its effects reach beyond the aesthetic and the political to embrace the social. She warns us not to overemphasize disruptive effects. Social disruption is too often celebrated “at the expense of social coordination.” We then lose sight, she says, of how art practices “contribute to inter-dependent social imagining”: Whether cast in aesthetic or social terms, freedom and expression are not opposed to obligation and care, but in fact depend upon each other.”\(^{18}\) In this sense, Jackson’s theory of socially engaged participatory art places itself somewhere between Bourriaud’s relational art and Bishop’s participatory art.

**Case Project: “Patient Democracy”**

To further show how these three models can increase knowledge of participatory approaches in social design, we apply them in an analysis of an ongoing design research project titled Patient Democracy. The project investigates the relationship between ideological representations of patient democracy and how health professionals practice shared decision-making with cancer patients at a large Danish hospital.\(^{19}\)

A change currently is under way in how healthcare provision is generally conceived and practiced for several reasons. Healthcare services previously has been based on so-called “consumerist models,” according to which patients could supposedly choose rationally among hospitals and treatment; now, a paradigm shift conceives of the patient as a “partner” of the healthcare provider.\(^{20}\) Consumerist models have failed to be socially inclusive

---

17 Ibid., 14.
18 Ibid.
Participatory Practices

<table>
<thead>
<tr>
<th>PHASE ONE: Disrupting</th>
<th>Aim</th>
<th>Means</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on critical engagement</td>
<td>To reveal and contest hidden power structures</td>
<td>Setting up participation through controlled disruptive activities</td>
</tr>
<tr>
<td>Grounded in “participatory art” (Bishop, 2012)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PHASE TWO: Probing</th>
<th>Aim</th>
<th>Means</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on collaboration</td>
<td>To form new social relations and collaborations</td>
<td>Setting up social meetings through dialogue, collaboration, and open-ended activities with the participants</td>
</tr>
<tr>
<td>Grounded in “relational art” (Bourriaud, 2002)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>PHASE THREE: Prototyping</th>
<th>Aim</th>
<th>Means</th>
</tr>
</thead>
<tbody>
<tr>
<td>Focus on empowerment and long-term social change</td>
<td>To empower people to take action in a process of long-term social change</td>
<td>Setting up new political structures that promotes long-term social change for the participants</td>
</tr>
<tr>
<td>Grounded in “social works” (Jackson, 2011)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Table 1 provides an overview of how the three theories of participatory art can help us understand various participatory practices in the project. Note that the order in which the three theories has been presented in this article is not identical with how they are applied to the case study.

The aim in the first phase, disrupting, was to reveal and contest hidden undemocratic forces and structures at work in the hospital, focusing on critical engagement. This phase can be appropriately understood as exemplifying theoretical and methodological principles underlying Bishop’s model of participation: participatory art as critical practice. In the second phase, probing, we focused on open-ended activities, the sharing of experiences, and collaboration with the patients; here, we applied Bourriaud’s model: participatory art as relational art. The third phase, prototyping, and have worked poorly in cases of life-threatening diseases.21 In addition, consumerist models benefit and empower management and budgets, not patients. “Patient choice,” “shared decision-making,” “patient involvement,” and “patient empowerment” all are concepts that reflect attempts within the public healthcare sector to increase patient democracy.

This research project investigates conditions under which cancer patients are informed, how shared decision-making is being practiced in a hospital, and what forms of democracy underlie this practice. Furthermore, the project explores whether design concepts for cancer patients can be developed that could increase a participatory form of patient democracy—that is, whether design concepts not only can help cancer patients in making “the right decision” but also can open up a range of possibilities for supporting and empowering the patients during their treatment. For this purpose, a team of design researchers has conducted a series of design experiments in collaboration with the Department of Oncology and the Health Service Research Unit at Vejle Hospital in Denmark.

Table 1 provides an overview of how the three theories of participatory art can help us understand various participatory practices in the project. Note that the order in which the three theories has been presented in this article is not identical with how they are applied to the case study.

The aim in the first phase, disrupting, was to reveal and contest hidden undemocratic forces and structures at work in the hospital, focusing on critical engagement. This phase can be appropriately understood as exemplifying theoretical and methodological principles underlying Bishop’s model of participation: participatory art as critical practice. In the second phase, probing, we focused on open-ended activities, the sharing of experiences, and collaboration with the patients; here, we applied Bourriaud’s model: participatory art as relational art. The third phase, prototyping,

PHASE ONE: Disrupting
Focus on critical engagement
Grounded in “participatory art” (Bishop, 2012)
To reveal and contest hidden power structures
Setting up participation through controlled disruptive activities
No shared control or shared responsibility with the participants. Designer takes full control and full responsibility for the outcome

PHASE TWO: Probing
Focus on collaboration
Grounded in “relational art” (Bourriaud, 2002)
To form new social relations and collaborations
Setting up social meetings through dialogue, collaboration, and open-ended activities with the participants
Shared control. Shared responsibility in that designer configures participation but participants as well as designer share responsibility for the outcome

PHASE THREE: Prototyping
Focus on empowerment and long-term social change
Grounded in “social works” (Jackson, 2011)
To empower people to take action in a process of long-term social change
Setting up new political structures that promotes long-term social change for the participants
Indirectly shared control. Designer takes full responsibility for the outcome

Table 2 | Politics of Participation

<table>
<thead>
<tr>
<th>Participatory Practices</th>
<th>Aim</th>
<th>Means</th>
<th>Politics in Relation to Control, Sharing, and Responsibility</th>
</tr>
</thead>
<tbody>
<tr>
<td>PHASE ONE: Disrupting</td>
<td>To reveal and contest hidden power structures</td>
<td>Setting up participation through controlled disruptive activities</td>
<td>No shared control or shared responsibility with the participants. Designer takes full control and full responsibility for the outcome</td>
</tr>
<tr>
<td>PHASE TWO: Probing</td>
<td>To form new social relations and collaborations</td>
<td>Setting up social meetings through dialogue, collaboration, and open-ended activities with the participants</td>
<td>Shared control. Shared responsibility in that designer configures participation but participants as well as designer share responsibility for the outcome</td>
</tr>
<tr>
<td>PHASE THREE: Prototyping</td>
<td>To empower people to take action in a process of long-term social change</td>
<td>Setting up new political structures that promotes long-term social change for the participants</td>
<td>Indirectly shared control. Designer takes full responsibility for the outcome</td>
</tr>
</tbody>
</table>

involved designing for long-term social change by reforming the law and empowering the patients to take control of the planning of their treatment. In this phase of the project, participation can be understood according to Jackson’s notion of “social works” and social engagement: participatory art as social work.

In the following sections, we examine how participation was used differently through the three phases of the project. We provide a brief description of each phase, discuss each theoretical model, and offer a definitive overview of the different politics of participation (see Table 2).

Phase One: Disrupting the System
The objective of the first phase was to explore how shared decision-making is practiced in the hospital. The design researchers visited six patient–doctor consultations and one morning conference between doctors and surgeons. The findings from the field observations subsequently informed several enacted scenarios in which the researchers used role play to explore different situations. The scenarios were constructed both from the doctors’ perspective and from the patients’ and family members’ perspectives.

One finding from the observations was that some patients did not want to make the decisions themselves but instead wanted the expert (i.e., the doctor) to make the decision for them. Another finding was that the doctor could or would only give advice in relation to medical treatment (e.g., chemo, surgery, and radiation), whereas many other issues (e.g., family relations, complementary and alternative treatment, hope, faith, and other existential issues) were brought up by the patients but were not discussed further by the doctor.
The researchers initially reenacted a number of doctor–patient consultations as observed during the field study (see Figure 1). Afterward, the researchers role played four alternative scenarios (Figures 2, 3, 4, and 5) in an attempt to make undemocratic structures visible and to explore new forms of collaboration between doctors and patients that might make the doctor–patient interaction and decision-making processes more democratic.

In Figure 1 the actual patient–doctor consultation is reenacted. Through this reenactment, what becomes clear is that the situation generally is lacking some democratic aspects. First, the doctor and nurse are the only ones who have access to the information on the screen. The patient and the family member are simply excluded by the spatial arrangement from having access to this information.

In the first series of disruptions (see Figure 2), the design researchers enact a scenario to contest the status quo: The patient and family member whisper to each other to make the lack of transparency visible; they share secrets and hide information in the same way that the doctor and the nurse share and hide information from the patient and her family member.
In the second series of disruptions (see Figure 3), the research team explores a scenario in which the patient and doctor share information either by putting the computer screen in the center of the space (left picture) or simply by removing it from the room (right picture).

With the computer in the center of the space, the technological reconfiguration allows the patient and family member to actually see the computer screen; however, the interaction is still confined by a scientific democracy in which the doctor controls the computer and the empirical facts and in which technology dominates the decision-making process.

The complete replacement of the computer with a series of x-ray photos put up on a board (right picture) enables the design researchers to explore a non-technological doctor–patient interaction in which the shared decision-making process takes place through dialogue and discussion.

In the third series of disruptions (see Figure 4), the process of shared decision making is enacted in a home-like consultation room, suggesting an informal doctor–patient interaction. This scenario explores what happens if the personal relationship between doctor and patient is increased and shaped around the idea of a friendship.
The scenario reveals a shift in the power balance between the two involved. By allowing the doctor and patient to act as friends, the scenario counteracts the doctor’s authority (as an expert in the field). Seen from the doctor’s perspective, the decision-making process becomes more complicated, as the distributed role of “friendly host” is not compatible with the professional relationship between patient and doctor.

In the last series of enactments (see Figure 5), the design researchers explore doctor–patient interactions that assume the form of a “walk and talk” meeting. These scenarios take place outside the hospital and thus outside the health professional’s domain. In these enactments, the significance of the walk to the conversation is explored (moving forward, defined by the distance from A to B), as is the presence of nature (light, smells, and sounds). In this scenario, a doctor–patient interaction arises that is dominated neither by technology nor by conflicting perceptions of the relationship. Instead, it takes form as a kind of shared journey, in which the existential dialogue, in addition to the medical dialogue, is given space.

_Phase One Discussion_

In the first phase, direct participation of the cancer patients was deemed to be unethical. The doctor–patient consultation at the hospital is the moment when a patient is told whether the cancer has spread, whether the chemo has worked, or whether the hospital intends to continue the medical treatment. At this time, the patient is in an extremely critical, vulnerable, and emotional situation. Instead of direct participation, the use of a dissensual model of participation was deemed necessary, in which the designer engages herself on behalf of the patients.

Participation during the doctor–patient consultation happened only through observation (using notation and drawing because recording was not allowed) and afterward through role playing. Here, the design researchers reenacted the observed
The reenactment happened in the same consultation room, shortly after the actual observation. Insofar as participation was used to disturb and question existing conditions of patient democracy at the hospital, we see many similarities with Bishop’s notion of participatory art.

The construction of alternative scenarios was used as a critical aesthetic practice to experiment with various notions and practices of shared decision making. Through these disruptions, we created transparency in relation to how shared decisions are practiced in the hospital and how the notion of patient democracy might be extended. This knowledge was shared with doctors, health professionals, and researchers from the hospital and was valuable in clarifying dilemmas and challenges in the organization. In addition, the field observations informed the next part of the design research process, which focuses on co-exploring patient needs.

**Phase Two: Co-Exploring Patient Needs**

The objective of the second phase was to investigate what the patient considered important during a period of cancer treatment. The investigation focused not only on the medical treatment, but also on patients’ values, which are deemed essential in constructing a meaningful course of treatment. To illustrate, these values might be related to patients’ everyday life, their social life, their subjective well-being, and their belief in survival.

For this purpose, a probe was constructed in the form of a suitcase brought to the patients’ home (see Figure 6). The suitcase was designed to suggest the idea of going on a journey with the patients, allowing the patients to express new possibilities and inspiring the research team in the subsequent design process. As a tool designed for inspiration, the probes were used according to the ways that Gaver, Dunne, and Pacenti originally introduced the approach. However, unlike these authors, we used the probes to collaborate with the patients and to co-explore the journey with them—much like Mattelmäki and her colleagues have further developed the probe approach.

More specifically, the patients were asked to “pack” this suitcase with five important values/objects/concepts they would need during a course of treatment. The probe contained 12 pre-defined values, identified through the field observations in the first phase of the project. These values included psychological and philosophical concepts, such as “dignity” and “peace of mind.” In addition to the pre-defined values, the probe also contained empty boxes for self-created values (again, see Figure 6).

---


The 12 objects included different material objects with sensory qualities that could be touched, smelled, or used. They were meant to trigger the patients’ own conceptions of a particular value. For instance, “comfort” was represented by woolly socks, “finding the right path” by a compass, and “peace of mind” by a candle that could be lit.

The probe session took place in the patients’ own home, on a day and time chosen by the patient (see Figure 7). The session started with something to eat and drink and involved a relaxed conversation about what the project was about. The researchers then “unpacked” the suitcase and took out each object one by one. Patients were then asked to “repack” their own suitcase with a maximum of five objects that they believed would be needed to bring them through the period of treatment. They were also asked to explain why a particular object was necessary to have in the suitcase. This process was co-exploratory and dialogical in nature. Both the patients and the research team could ask clarifying questions—for example, to understand the patients’ own descriptions of meaning in relation to the objects.

Three cancer patients participated in the project. Two of the patients already had completed their treatment, and the third still was going through treatment. We established no time limit for each probe session; the patients took as much time as they needed, and
each session lasted three to four hours. The sessions were recorded and transcribed. The probe sessions resulted in three different suitcases, each packed in different ways with different values. (Figure 8 shows one of these configurations.)

The patients evaluated all the objects carefully, including the ones they did not put in their suitcase. All three patients thought that “presence” (e.g., the presence of family, friends, or pets) was of great importance. Also, “direct communication” with the staff and the need for “structure” were seen as having great significance for their subjective wellbeing. All patients discussed how “dignity” is at stake when they experienced dramatic change in their physical appearance, for instance, due to hair loss or breast surgery. One patient placed this value in his suitcase and stated that for him “dignity is about keeping together one’s personality and integrity”—and for that reason dignity is important to protect through one’s treatment process. Finally, the concept of a “personal help-team” was discussed in detail. Here, the patients formulated clearly what kind of personal help they thought would benefit them. One patient (see Figure 8) used one of the empty boxes and labelled it “humor.” She saw humor and the ability to make jokes—even about serious matters—as an essential value that contributed to her experience of “presence.” The object relating to “Welfare technology” such as robotics, smart technologies, or telemedicine
(online consultation with patients at home) was evaluated as the least important of the values in terms of it being beneficial for their course of treatment.

**Phase Two Discussion**
In the second phase, both the patients and the research team participated in the probe sessions as active participants in a shared experience. Meeting the patients in their comfort zone, at a time that suited them best, gave space for intimacy and concentration.

The probe session was not intended to let the cancer patients determine whether shared decision making was beneficial to them, but to let them determine whether a certain value or concept would benefit their course of treatment. The design researchers’ roles were to “stage” this probe. Thus, like all probes, the designer controlled how it was made and (to some degree) how participation was configured. However, the control in the latter case was shared in the sense that the patients decided what should go into the suitcase and what should be left out. Here, probing served as an artistic tool for evoking uncertain situations or open-ended encounters to create new social roles and identities. As such, the second phase was closely related to the form of participation found in Bourriaud’s theory of relational art. The responsibility for this social formation of collaboration is shared between designer researcher and patient.

**Phase Three: Reordering the Relation of Power**
The objective of the third phase was to develop a design proposal that could empower the patients to take control of the planning of their treatment. Based on the probe sessions in Phase Two, three values and themes were taken up into the design process: “dignity” (specifically, regarding the loss of hair because of chemotherapy), “structure” (specifically, the need for structuring time), and “a personal help team” (specifically, personal forms of support, coaching, or therapy).

As a point of departure, the design researchers delved into the Danish Social Law. According to this law, cancer patients are allowed reimbursement for a wig, as well as funding for psychological counseling. (The Danish state pays for 60 percent of the first 12 visits to the psychologist.) However, for many cancer patients, using a wig is a poor alternative to real hair. Moreover, the probe sessions and interviews with cancer patients revealed that psychologists are surely not the only people who provide valuable help and advice for them. Thus, the question is whether these funds could be used to support patients in other ways—for example, by allowing the patients to decide for themselves what kind of support, help, and coaching they need during cancer treatment. By
bending the law, the design researchers developed a service design concept called “The Personal Help Team,” which enables cancer patients to organize the help and coaching they need.

The design proposal offers ten different services, ranging from an acupuncturist and psychologist (offering healing therapies), to a cleaning lady or nanny (offering more social and practical relief measures), to a philosopher (offering existential dialogues). The proposal includes 10 information cards (one for each service), a calendar that helps the patient organize the services using stickers, and a voucher with 40 clips to manage how the patient would like to spend the budget on help and coaching. The researchers also made a film in which they role played to accurately explain how the Personal Help Team works and to communicate the use of the voucher system (see Figure 9).

**Phase Three Discussion**

The third phase relies heavily on the direct participation of the patients in the second phase because the probing process was crucial in developing the actual design proposal. In this sense, control is shared, but the design researchers still configure the participation and take full responsibility for the social change implied by the suggested practice.

In this phase, role playing and video were used to envision how the Personal Help Team could change the decision-making process if a particular aspect of Danish social law was reformed or
reinterpreted or even suspended. As in the first phase, the doctor-patient consultation is reenacted based on the observed situation, and then an alternative consultation is role played that includes the Personal Help Team now as part of the consultation. The aim was to investigate whether and how the concept enabled the patients to reorganize the help and coaching they needed and thus (potentially) to allow them to participate in a process leading toward long-term social change.

The final design proposal was shared between researchers and healthcare professionals and has informed a new, large-scale, European Union-funded research project that aims to develop strategies, infrastructures, and tools to help patients live with cancer in their daily lives and to bridge the gap between two distinct communities: those who use conventional cancer treatments (offered by the hospital) and those who use complementary and alternative medical treatments (not offered by conventional healthcare providers). The design proposal is being developed as part of a more extensive prototype using a design process that involves both patients and doctors.

In this sense, our participation had the same social aims as the model described by Jackson. We wanted to foster change and enhance the wellbeing of vulnerable groups in society. Moreover, the patients’ participation in the ongoing development of the design proposal took place in the public realm—in this case as a collaboration between patients, health professionals, and design researchers. Again, see Table 2 for an overview of how participation was used differently through the three phases and how the phases relate to different politics of participation.

Conclusion
The outcomes generated from this research project are three-fold. First, a valuable method was developed for using disruptive participation to prototype patient democracies in healthcare. 24 Second, a probe was designed that increased the researchers’ knowledge of cancer patients’ needs before, during, and after their treatment. Third, a design proposal was constructed that took a specific physical and aesthetic form and both addressed (and questioned) the law and cancer patients’ rights. Additional results will come from the large-scale EU-funded project to help reveal how the outcomes of the three phases can be taken back to patient engagements.

In this article, we have argued that theories of participatory art can increase our understandings of participation in design research. Each theory represents a specific politics of participation, implicitly or explicitly valuing how control can be shared and for what purpose. Whether in the form of relational art, art activism,
or social works, participation can open up many roles for the artist-designer, and various effects may be evoked through participation. Future work is needed to help sort out the extent to which these politics are reflected in current participatory practices, methodologies, and theories in design. However, our results show that participatory art can productively lead to new knowledge of participation in design research.

Acknowledgements
We thank all patients and health professionals for participating in our study and for sharing their experiences with us. Thanks also go to Signe Mårbjerg for her valuable work done as part of the field studies.