Nurses' Journey Toward Genuine Participation: Becoming and Learning

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ABSTRACT
This paper contributes to the ongoing debate on participation in Participatory Design (PD) by drawing on the notion of *genuine participation* [8]. It clarifies nurses' empirical journey as one of *becoming* and *learning* [1, 6], where they move from being reluctant participants, attending only because management has instructed them to do so, to taking an interest and finding their voices in the design process. In this way, they are ultimately able to engage in genuine and willing participation. The main discussion points in the paper are the transitions in the nurses' journey toward embracing qualities of genuine participation, the nurse-researcher's reflections on her facilitation of the process, and collective learning as an integral part of the process.

CCS Concepts
• Human-centered computing → Collaborative and social computing → Empirical studies in collaborative and social computing;
• Applied computing → Life and medical sciences → Health informatics

Keywords
Genuine participation; mutual learning; participatory design

1. INTRODUCTION
In the "era of participation," we are witnessing new issues arising and old ones being readdressed in relation to the topic of participation in participatory design (PD). This paper takes an in-depth look at the *quality of participation* in a PD project. In addition, by paying specific attention to the unfolding, dynamic character of participation, it contributes to recent research that has called into question the customary roles and characteristics of participation seen as preordained, static categories.

The empirical basis of the paper is a project with an overall concern for how an electronic whiteboard can support healthcare staff when patients are transferred from the intensive care unit (ICU) to general wards, with a special focus on the initial 24-hour follow-up plan.

The ICU follow-up for hospital inpatients involves a 24-h plan and a nurse-to-nurse follow-up visit, that is, from ICU to general ward nurses. The plan is initiated and created by an ICU nurse; this plan is meant to assist general ward nurses, since they work under completely different work contexts than the ICU nurses do. Thus, it is intended as support for general ward nurses in here-and-now care, even though they may not have read the "heavy literature" (i.e., the journal, nurses' documentation, etc.) at the hectic time of receiving the patient. The plan contains elements pertaining to physical or psychological issues that need increased monitoring or consideration. The main concern with including nurses as participants was to ensure that they were truly engaged and interested. Having seen many projects more or less fail, or worse, be totally ignored, it seemed obvious that nurses should be engaged. However, the question that arises is as follows: How does one accomplish this in a busy clinical environment that encompasses different wards with different work conditions?

This paper aims to address the following research question: *How did the nurses' participation change from reluctant users to genuine participants through the process of becoming and learning?*

To reach out to as many nurses as possible, 24 workshops (1–1½ h each, with visits during the day, evening and night shifts) were held in four hospital wards (one ICU, *n*=8; three general wards, *n*=16), and approximately 85 nurses attended. The objectives of the workshops were to clarify the challenges and needs related to ICU follow-up and to anchor the project as widely as possible. Two nurses from each ward (*n*=8) and a clinical nurse specialist (anesthetic ward) participated in two design workshops (3 h each, designing the ICU follow-up procedure). The nurse–researcher (first author of this paper) organized and conducted all of the workshops.

As part of the initial inductive analysis carried out through reading and re-reading the transcriptions of all of the workshops, the nurse–researcher became aware of how the nurses participated and how their participation changed over the course of the workshops. This finding called for some conceptual assistance, and the notion of *genuine participation* was then used to identify a set of "transitions" (i.e., moments) during the design workshops when shifts in the quality of participation unfolded. In the next section, the nurses' journey toward genuine participation in the two design workshops is described as an intertwined process of "becoming" [1, 6] genuine participants through three major transitions [8-10], as well as mutual and collective learning [2, 7, 8].

2. GENUINE PARTICIPATION
Traditionally, participation in PD has been considered political and pragmatic [3]. The notion of genuine participation, in turn, focuses on "the fundamental transcendence of the users' role from being merely informants to being legitimate and acknowledged participants" [8, p. 5] to achieve its aim. As Simonsen and Robertson stated, "Any user needs to participate willingly as a way of working both as themselves (respecting their individual and their group's/community's genuine interest) and with themselves (concentrating on the present in order to sense how they feel

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about an issue, being open towards reflections on their own opinions), as well as for the task and the project (contributing to the achievement of the shared and agreed-upon goals of the design task and design project at hand)" [8, p. 5]. Being true to and participating as oneself entails the ability to sustain feeling that one is "good enough as one is" [9, 10]. Genuine participation involves what this paper describes as transitions: *as themselves, with themselves* and *for the task and the project* [8, p. 5]. Moreover, it depends on the willing engagement and learning of the individual participant, not only on the part of the designer but also that of peers. This willingness to learn can be linked to an examination of users' participating *as themselves*; one's actions may require reconsideration and revision, and this should not suggest that one is feeling inadequate [10]. It is a substantial component of participating *with themselves* that one knows and acknowledges one's fellow participants' work context; otherwise, it might be difficult to determine how one feels about an issue and equally difficult to reflect on it.

Traditionally, learning between the designers, users, and/or other stakeholders has been seen as mutual. It focuses on the relationship between the users and the designers and what they learn from each other regarding their respective areas of expertise [2, 7, 8]. However, the present paper stresses that learning from others' work routines and work conditions is equally important, especially considering genuine participation. The collective learning process facilitates the journey toward genuine participation in relation to individuals participating *as themselves*, *with themselves*, and *for the task and the project* [8].

The paper brings together genuine participation with the concept of "becoming," which reflects an on-going process and allows development in the direction of genuine participation to be explored. The use of "becoming" is inspired by Akama [1] and Reynold et al. [6]. Becoming a genuine participant reflects the process as a journey, and most importantly, it acknowledges what happens between the starting point and the final design: "This no longer sees the self or subject as the epicenter of knowledge and locates it in the between-ness that emerges among heterogeneity (…) all becoming together" [1, p. 5]. Becoming a participant is also described as "[a]lways in-negotiation recognizing that participation is a traveling concept and demands a blurring of the hierarchical binary of consent as give (active) and take (passive)" [6, p. 442].

3. NURSES' JOURNEY THROUGH THE DESIGN WORKSHOPS

3.1 The First Transition

From Frustration and Critique to Mutual Listening and Reflection "as Themselves": During the first design workshop, the nine nurses from the wards spent the first 90 minutes criticizing the electronic whiteboards and the fact that the hospital has different IT systems in the general wards and the ICU. The nurses interrupted each other and talked more and more loudly, leaning back in their chairs with arms crossed. These 90 minutes seemed important to the participants, as they had a lot of frustration to release. In this time, not a single positive word was said about the already-installed technology. A nurse from a general ward said: *"Why should we use it* [the electronic whiteboard]*? I mean, our secretary does it but she's only working daytime and only part-time. Hardly anybody ever touches the whiteboard whenever she's' not there"* (translated from Danish). Another nurse joined in: *"We didn't' ask for them* [the electronic whiteboards] *and nobody's' ever looking at them. Why use them if nobody's' looking anyway?"* An ICU nurse added*: "Yeah, we had to give the responsibility for updating the whiteboard on the nurse in charge in the evening and night shifts. Otherwise, nobody would do it."* However, by learning that they shared the same difficulties and frustrations and that it was not a lack of competence, it became clear to all participants that they were not rivals; instead, in the follow-up, they recognized that they were collaborators. Thus, not knowing it all became legitimate, regardless of the ward with which each nurse was affiliated, thereby forming the conditions for working *as themselves*. The pressure of having to know everything was two-way (the ICU nurses expected the general ward nurses to know as much as they did, and the general ward nurses expected the ICU nurses to know everything in regard to the patient); however, by sharing perspectives, it became legitimate and sufficient to participate as oneself, or more importantly, the nurses became comfortable with engaging as themselves without having to pretend to be better or to know everything. As time passed, the participants began to comment about one another and guide each other in the direction of the design project, reflecting on how to approach new technology. As one nurse pointed out to her fellow participants: *"Perhaps we could see this* [the project] *as a good thing—Something that actually could help us in our work so that we can concentrate on the core service* [the patient]*. I mean, instead of just complaining about the things that don't work…"* Another nurse made the following comment: *"Why not just try and make the best of what has been given to us? Let's see if we can make the system work for us."*

3.2 The Second Transition

From Defending Their Different Work Contexts to Associating with One Another to Become "with Themselves": The participants challenged the nurse–researcher by questioning why they had to design a "one-size-fits-all" follow-up plan. How could such a plan be drafted without including endless options? How would this potentially endless follow-up plan differ from the existing handover resume, which caused even the ICU nurses to become lost in the details? Although patients may suffer from the same diagnosis, they are all individuals. The concern within the group from the general wards was not that the ICU made a plan for others to follow but that the ICU generated this plan without having any kind of insight into other wards' work conditions; for example, a nurse from a general ward stated: *"You* [the ICU] *may not see it as an issue to hold the mask* [lung therapy] *for five minutes, but when I'm responsible for another 8–10 patients that also need care and attention… I mean…The things I could catch up on within those five minutes…just standing there, doing what feels like nothing. It's almost painful."* The discussions pertaining to the handover and follow-up procedures provided a great deal of insight into each groups work routines and workloads (e.g., six nurses for night shifts in the ICU, with a maximum of 9 patients, and one nurse and a nurse's assistant for night shifts on the general wards with a maximum of 22 patients, excluding those overcrowding the wards in the hallways). An ICU nurse expressed her respect for the general ward nurses' work as follows: *"…we sometimes feel stressed when we're in charge of more than one patient at a time."*

The demands of being present were indispensable in allowing the participants to understand one another and their different work conditions. Gaining insight into other wards' work conditions, the nurses started to understand the "whys" and "hows" they expressed before when questioning "the other's" approach. This enabled the group to sense how they perceived the ICU follow-up and to reflect on it among themselves. As four specialties were represented (ICU, medical, surgical, and orthopedic), the nurse–researcher asked the participants to concentrate on their type of patients and what would happen

with their archetypal patients in terms of follow-up issues. What would they need to know about the patient to take care of him/her? In other words, the nurse–researcher asked the participants to explore and investigate their concerns, thereby supporting them in expressing what was at stake from their perspectives (thus, they were working with themselves). Surprisingly for the participants, they agreed on almost everything. Every ward could identify with almost every issue concerning the former ICU patients in relation to the initial 24 h after the transfer; they even inspired each other and contributed their perspectives to the issues that others had to deal with (thus participating with themselves). Being present with representatives from other wards, as well as sharing and learning about different work conditions, created an open setting that everybody could enter equally and in which the ICU follow-up could develop. Nurses on different wards usually do not have the opportunity to meet and discuss work conditions with the other groups, which is what these workshops provided. Hence, the workshops created the possibility of learning from each other, gaining insights into different work conditions, and acknowledging each other as equals; thus, the nurses were able to work *with themselves*.

3.3 The Third Transition

From Participating Because They Were Told to Do So to Taking Ownership "for the Task and the Project": Through the processes of becoming genuine participants, this transition involved the evolution from the participants engaging as themselves (3.1) and with themselves (3.2) to being able to participate for the task and the project. It was evident to the nurse–researcher that the participants only attended the workshops because management had told them to do so. One nurse even explicitly expressed this as the group was welcomed: *"Well, thank you for welcoming us but we were told to be here…* [laughing] *Our colleagues did NOT appreciate us leaving the ward"*. However, after presenting the agenda for the workshops, the participants began paying attention, asking questions, engaging, and joining in the decision making. The nurse–researcher's first draft was rejected by the participants because the draft did not satisfy the different work contexts; moreover, the nurses from the general wards perceived that their professional integrity was being diminished: *"Oh, that's great! Now we don't even have to think!"*

As the participants designed the follow-up plan and made it their own, fitting it to their needs, they began to express their excitement over its realization and implementation: *"[T]his we can actually use… I mean… this could actually help us. Why haven't we been asked sooner…to participate in nurse-related issues?"* The nurses acknowledged the importance of the project, their stake in it, and how they could collectively contribute, which reflected genuine participation. They realized the importance of their participation; the project could not and would not succeed without them and their engagement. More importantly, they could see the benefits of the project and how it would be customized to fit their needs instead of something a designer or a technician—who might not have a clinical background—created; this was *their* product.

The last design workshop ended with the participants stating that they needed a third workshop where they could pilot the follow-up plan, giving them an edge over their colleagues in their respective wards. This would enhance their feeling of competence after the implementation while also passing their knowledge along to their colleagues. This transition went beyond what was delineated by "contributing to the achievement of the shared and agreed-upon goals" [1, p. 5] as the participants took ownership of the project. This kind of participation is considered the ideal way to genuinely participate [1].

4. THE NURSE–RESEARCHER´S REFLECTIONS

This section is written in the first person, as the nurse–researcher is also the first author of this paper.

Having worked as a nurse for 12 years, I thought that I knew what the ICU nurses—my old colleagues—wanted but also what the general ward nurses wanted, even though I had never worked in a general ward.

As an insider within the group of nurses, I knew the jargon at the hospital, which enabled the participants to speak freely and professionally without having to rephrase in layman's terms or to restrict themselves expressing the sometimes morbid humor used in hospitals. However, being an outsider as a researcher also made it easier for me to approach the general ward nurses. Since I had formerly been affiliated with the ICU, it was important that I did not make the project something that the nurses from the general wards had to do because the ICU told them to. Their view of me as a researcher (yet still a confidante) grew stronger as I became more confident in doing the research—one could say that I began participating as myself and became comfortable doing so.

As the participants went through the first transition, I intervened minimally for several reasons, as follows: 1) I did not know how to convince them that follow-up was the appropriate step, although 2) they could see the point of follow-up from a professional perspective after I presented the results from the previous workshops, and (probably most importantly) 3) I was extremely scared (what if they blamed me?) and thought about getting my old position back at the ICU. When I could see the participants making their first transition in the direction of the project, I could barely sit still with happiness, thinking: *"Maybe I am good enough…"* This allowed me to participate as myself.

The moment of bliss passed quickly, however, in learning about the general wards' work conditions. This "collective lesson learned" emphasized the need for the project to support the general wards when receiving patients from the ICU, as these patients are usually the healthiest leaving the ICU but become the sickest entering the general ward. During the second transition, I learned not about of the general wards' work contexts but also that it seemed possible for the nurses to collaborate and even respect each other's work, regardless of the ward with which they were affiliated.

The third transition also reflected my limitations, as I originally thought that I knew what the nurses wanted; however it became clearer to me that the consequences of a PD project meant lack of control. At the end of the second design workshop, the participants wanted another workshop. They wanted to test their design before it was implemented in their wards. At first, I thought, "*Hey, this is my call—I'm the one who decides if another workshop is needed!"* Now I see that this is exactly what is needed for the project to be fully implemented in all wards—the nurses must have ownership in and participate for the task and the project.

5. DISCUSSION

This paper offers a novel perspective for considering participation in PD through genuine participation. It decenters–without excluding–the more traditional pragmatic and political angles and makes room for considering participants as individuals and collectives [8-10]. Genuine participation recognizes the need for reflective processes that contribute to the quality of participation and acknowledges

that the processes between the starting point and the end-product are as important as the project itself. The processes of becoming and collective learning support one another, and their intertwining was evident in the analysis of the empirical case through the lens of genuine participation. Mutual learning seemed insufficient for the analysis of this empirical case. Furthermore, the empirical findings indicated that the biggest insight for the participants emerged when they shared and learned collectively. Collective learning differs from mutual learning in that it is not restricted to the two customary parties of users and designers/researchers. It stresses the importance of the participants also learning from their fellow participants to design as and with themselves as equals in a heterogenetic group of participants.

This paper argues that the processes of becoming and collective learning (for both users and researchers) are important in terms of the quality of participation. These processes facilitate the journey toward genuine participation, with individuals participating *as themselves*, *with themselves*, and *for the task and the project* [8]. However, one cannot participate genuinely *for the task and the project* without having gone through the transitions toward participating *as themselves* and *with themselves.* It is as a result of the transitions that participants no longer have to pretend to know more or to be better; instead, they come to participate as themselves (first transition), and they have to be present and reflect on what is at stake to participate with themselves (second transition). It is through these transitions that the facilitating participant can hope for transcendence toward genuine participation for the task and the project (third transition).

The PD researchers acknowledge their influence in the design field [3, 4, 6, 8]; however, based on our findings, the complexity of facilitation needs to be further explored in relation to the quality of participation. How can the researcher be genuinely participating if he/she has not gone through the same processes of becoming and collective learning within the group?

Participation in PD is thus not only of a political and pragmatic nature, as argued in earlier PD literature; it is also based on acceptance and openness. The participants need to engage in both self-reflection and collective reflection to genuinely participate. Moreover, the PD researcher also has to reflect on him/herself as an individual and as part of the group, allowing the group to participate genuinely as equals.

6. CONCLUSION

This paper applied the notion of genuine participation, thereby offering a novel perspective on participation for PD research by illustrating the empirical case and the researcher's own journey, as well as how genuine participation relates to mutual and collective learning and the notion of becoming. It recognized that regardless of their assigned role (e.g. users, designers, researchers), participants need to engage in a reflective process to be able to engage in high-quality participation. It is a premise of this paper that for the participants to willingly participate *as themselves*, *with themselves*, and *for the task and the project* as a collective group, mutual and collective learning must take place, thereby supporting the journey of becoming genuine participants.

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