

Participatory Design with Health Consumers

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Abstract

Participatory design methods can help create usable and useful systems by involving users directly in the design process. Traditional participatory design approaches have been adapted to work in health contexts and we present lessons we learned while designing with health consumers. These lessons are intended to be practical suggestions for system designers and researchers who want to create better technology by working as partners with health consumers during the design process.

User Involvement in the Design Process

In health informatics, we have heard numerous stories of technology that fails to be adopted by the intended users. Fortunately, methods for involving target users in the design process can help.^{1,2} **Participatory design (PD)** methods provide ways to involve users directly in the design process. Users are active members of design teams prototyping and making decisions alongside designers. Instead of relying on designers to understand and represent user needs in the design, users' presence during the design work allows them to represent their own needs, constraints, goals, and priorities. This involvement results in better technology as well as an improved understanding of the users. In a process referred to as **mutual learning**, users learn from designers about what is possible and how to represent design ideas, and designers learn from users about the work they do. Some researchers in our field have advocated for and successfully used participatory design for clinical and consumer-focused design projects.^{2,3,4} Traditional PD methods have been adapted somewhat to fit the health context and we present practical advice for successfully doing PD with health consumers.

Participatory Design: Practical Lessons Learned

In this section, we share the insights we gained doing participatory design with health consumers. Our findings are based on a finished project doing PD with general health consumers³ and an ongoing participatory design project with breast cancer patients and survivors.

Get participants to address one another. When participants addressed one another instead of the moderator, we learned more because they identified the differences in their perspectives and further articulated their ideas and the reasoning behind them. We suggest creating a collaborative group dynamic by emphasizing participants' role as partners in the

design process. We also recommend providing time to socialize during breaks and meeting with the same group multiple times to build community and rapport.

Guide the design without dictating it. The designer's approval of some ideas over others can influence the direction the group takes, and it is important to be aware of validating ideas and fostering participation. However, some guidance from the moderator is useful to focus the design on what researchers are interested in. The balance between guiding and dictating can be difficult to strike and researchers should be consciously thinking about when to guide the group and when to stay quiet so the design reflects the ideas generated by participants.

Use participants' language. The language used by the moderator is quickly adopted by the group. The moderator should listen, understand, and adopt the language of users because it helps to situate the design in their context, prevents miscommunication, and promotes user ownership.¹

Conclusion

Directly involving users in the design process results in technology that reflects user priorities and preferences. When creating new technology, we are often faced with trade-offs and difficult decisions. PD provides methods for making these decisions collaboratively with users based on their expertise and experiences, resulting in usable and useful technology.

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