

An Argument for Using Participatory Approaches for the Design of Online Health Interventions Targeted At Young Women

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Abstract

The Internet is becoming an increasingly important portal to health information and means for promoting health in user populations. As the most frequent users of online health information, young women are an important target population for e-health promotion interventions. Health-related websites have traditionally been generic in design, resulting in poor user engagement and affecting limited impacts on health behaviour change.

Mounting evidence suggests that the most effective health promotion communication strategies are collaborative in nature, fully engaging target users throughout the development process. Participatory design approaches to interface development enable researchers to better identify the needs and expectations of users, thus increasing user engagement in, and promoting behaviour change via, online health interventions. This article introduces participatory design methods applicable to online health intervention design and presents an argument for the use of such methods in the development of e-Health applications targeted at young women.

Introduction

Chronic conditions such as cancer, cardiovascular disease, and diabetes are the leading causes of morbidity and mortality in North America. These conditions are largely attributable to lifestyle risk factors (i.e., smoking, poor diet, sedentary lifestyle)¹ which are often established during childhood and adolescence^{2,3} and persist into adulthood. While limited, research suggests that e-health promotion interventions are an effective means of targeting behaviours such as smoking^{4,5}, alcohol use⁶, physical activity⁷, nutrition⁸, and sexual risk behaviors⁹⁻¹¹. Adolescents and young adults view the Internet as an important source of health information¹² and are amenable to engage in e-health promotion programs¹³. Their preference, however, for gender-specific design and content^{14,15} highlights the need, for example, for developers to

engage young women in the development of websites that are successfully tailored to meet young women's specific design and content preferences.

Participatory Design and Paper Prototyping

Participatory design (PD) is a software user interface design approach that is derived from participatory action research (PAR). It draws upon a variety of research methods that allow for the inclusion of multiple voices in the software design process¹⁶. Central to participatory design is the notion of democracy; PD empowers users by treating them as experts and encourages them to play a central role in design decision-making by actively participating in the design process. In contrast to other user interface design approaches such as user-centred design, which posit that design is conducted on behalf of users, PD is completed with users¹⁷. As a result, users involved in a PD process become an important source of design innovation. PD uses an iterative approach to engage users in the innovation and design process not only during the early stages of problem specification and solution identification, but also during system development and subsequent evaluation. Consequently, PD approaches have been used in several studies to design and test e-health interventions¹⁸⁻²².

An example of a PD approach is PICTIVE (Plastic Interface for Collaborative Technology Initiatives through Video Exploration) – a widely adopted paper prototyping technique used to facilitate user participation in the design process²³. Developed by Belcore in the 1990s and popularised in the same decade, PICTIVE is a low-tech approach which allows participants to work as equal partners with designers in the creation of user interface prototypes²⁴. Using ordinary office supplies, users work together on a design surface to create a paper prototype in an informal game-like atmosphere, promoting the sharing of diverse ideas and insights²³. As a result, the PICTIVE process has been described as both an enjoyable and a valuable experience by participants²³ and software engineers²⁴ alike.

The low-tech brainstorming design aspect of PICTIVE is combined with high-tech video recording of the process. A video recorder (mounted on a tripod and focused on the design surface) is used to accurately and comprehensively capture all user discussion during design sessions – thus it includes a record of the rationale users provide for each design decision reached throughout the process. The video recording from a design session is analysed by the designers in order to develop, based on the participants' discussion, a prototype of the system.

This prototype is then introduced to the subsequent design meeting and further refined on the basis of participant feedback; this process continues in an iterative fashion until all participants agree that the resulting prototype accurately reflects their needs and specified user requirements²⁵. Given the costly nature of website development, paper prototyping is an efficient and cost-effective way to test interface designs and inform design modifications; it also provides some assurances to developers that the system will be usable by, and acceptable to, target end users.

Benefits and Challenges of Participatory Approaches to Interface Design

User involvement is widely encouraged for the development of usable interface designs, and is generally associated with positive effects on user satisfaction²⁶ coupled with more accurate identification of user needs²⁷. Damodaran suggests that effectively involving users in the quantitative aspects of the design process (paper prototyping) leads to benefits such as: (1) improved systems since they are more accurately based on user needs; (2) the prevention of development of costly systems that are not relevant or engaging to the user; and (3) increased user engagement with, and sustainability of, the final system.

Although limited, evidence suggests that developing effective e-health promotion interventions for young women is contingent on understanding their specific views about design, content, and navigation^{9, 14}. For this demographic, consultation with representative young women would help developers identify important system features to include and others to avoid. It would thereby ensure the effective presentation and inclusion of appropriate website functionality, and typically lead to increased (a) levels of user acceptance and (b) likelihood that the developed website will ultimately be successful²⁸.

Involving users early on in the interface design process enables designers to better understand user requirements²⁷. This increased understanding typically results in systems that are more relevant and engaging to target users and that increase user satisfaction²⁶ and the likelihood the system will have a sustainable impact on target behaviours. For instance, the usability of health-related websites can be impaired by issues like poor health literacy²⁹⁻³²; related to this, research findings suggest that participation of, and consultation with, functionally illiterate adults during the design process can result in the development of applications which present more appropriate and user friendly interfaces to users³³.

The fact that PICTIVE design sessions are videotaped is advantageous in that the video records provide a “social record” of the design process. Compared to other forms of record keeping (e.g., note-taking) video records are an effective means by which to reassure participants that their views have been captured without being too intrusive³⁴; it also allows all team members to actively participate in the design process without some members being constrained by the need to take notes. As well as capturing the final conceptualisation of an interface design³⁵, the video records used in PICTIVE provide a comprehensive record of the conversational and physical manipulation of the paper prototype throughout the design process³⁴.

Despite obvious benefits, user involvement in interface design using a PD approach is not without challenges. Using PD approaches like PICTIVE it can take longer to reach a consensus on design decisions: consensus is a necessary requirement for design decisions using PD approaches but this is not always easily achieved, and may require substantial time to be spent by the design team on reaching agreement. PD approaches are also more inclined to encourage a focus on abstract and less technical aspects of interface design. Additionally, if the group of participants chosen is not carefully selected to represent the larger target population, there are risks associated with a small sample of users impairing relevance to more heterogeneous populations^{18, 19, 36}. PD approaches also present challenges associated with human communication, which may be particularly challenging when working with, for example, users with special needs, limited computer experience, and poor literacy. As such, designers involved in PD approaches need to be skilled at articulating to users what is required of them during the process and to possess excellent group facilitation skills.

The Future Use of Participatory Design In Online Health Intervention Design

A clear goal of e-health promotion interventions is the elicitation and sustainability of healthy behaviours. By affording anonymity, the Internet can empower young people to gain the information they need to make important health promotion and treatment decisions³⁷⁻³⁹ and thus enable them to make informed lifestyle choices. As such, there is a rapidly emerging desire among behavioural researchers to develop online health promotion strategies that target younger populations. To date, however, these approaches have only shown modest positive effects^{2, 40}, and attrition rates are highest among the most at-risk members^{41, 42}. This lack of success highlights the need to develop health-related websites that are more engaging to

young users.

Women of all ages are more inclined than men to search the Internet for personal health and fitness information⁴³, and the Internet has become the number one source of cancer risk information for young women¹². Despite a rapidly growing number of e-health promotion interventions, researchers currently have a very poor understanding of (1) how to effectively engage young female users in these online programs and (2), what factors motivate long-term changes in their behaviours. Thus, an opportunity exists for researchers to include young women in the design process for online health interventions aimed at this demographic – an avenue of research has arisen to use participatory approaches to website design in order to explore the effects of early user (specifically, young female) involvement in the development of e-health promotion strategies.

While there is a growing interest among researchers and website developers to consult with target users during the development process for online health interventions, much of the research to date does not utilise a PD approach. Most e-Health application interface designs continue to be developed based on limited consultation with target users, resulting in reduced functionality, usability, and poor user uptake⁴⁴. While health-related websites tend to be user-centred, they are not typically designed specifically by the user. Website designers often fail to involve users in the design process and instead attempt to simply interpret the needs of users. The result is that many websites adopt a generic appearance and do not effectively reflect the specific needs and preferences of given user populations such as young women. This mismatch between what sites offer and the requirements and/or preferences of their target populations highlights a growing need to get users engaged in the development process for online health interventions. PD approaches represent an ideal mechanism by which to avoid the mismatch between designers' understanding and users' needs in the design of online health applications by empowering users to become full participants in the design process²³ of health-related applications that could have a profound effect on their own lives and the lives of their contemporaries.

Although prototypes can play an extensive role throughout the design process for online health interventions, research to date has tended to focus on the role of prototypes in the formal evaluation of user interface design. In many cases researchers have simply evaluated the usability of prototype websites (in terms of navigation, design, and content) by consulting

young target users via online survey tools^{9, 14, 15}; users have not been considered integral to the design of the prototypes themselves. To date, little research exists about the use of prototypes to discover and generate designs or explore design decisions in the field of online health interventions. This underscores the need for more PD research that fully engages users – and especially young women – in the entire interface design process for such applications. The anticipated result of using PD approaches in this way will be better quality systems that are attractive, relevant, and engaging to the target user group, thereby increasing user satisfaction and the likelihood that young women will engage in desired health behaviours that will be sustainable over time.

Conclusion

As e-health initiatives continue to emerge as an important means of extending healthcare services to diverse populations, mounting evidence suggests that engaging users in the interface design process results in more effective systems which are powerful in their capacity to motivate healthy behaviour change. Although young females are the most extensive users of online health information, the interfaces to the majority of online health interventions targeted at such users fail to meet their measures or relevance and to effectively engage these users. The needs and preferences of young women have not, to date, been adequately or appropriately considered during the design of such interventions. This highlights the need to engage young women in the design process for online health interventions. An argument has been made in this article for research into the adoption of participatory design approaches – taking PICTIVE as a candidate method – with young women to design online health interventions that match their specific needs and preferences and thus stand a greater chance of engaging young women, of resulting in increased user satisfaction and adoption amongst young women, and ultimately in affecting positive health-based behavioural change in young women. Our current research is doing just that: we are adopting participatory design approaches for the development of an online health intervention to promote cervical health amongst young women. As a result of our study, we hope to deliver an online health intervention that engages young women and which affects positive cervical-health-based behaviour change. Furthermore, we anticipate being able to provide some design approach guidance to others who are actively engaged in the design of targeted healthcare applications.

References

1. Mokdad AH, Marks JS, Stroup DF, Gerberding JL. Actual causes of death in the United States. *Journal of the American Medical Association*. 2000, 291:1238-45.
2. Tercyak KP, Tyc VL. Opportunities and challenges in the prevention and control of cancer and other chronic diseases: Children's diet and nutrition and weight and physical activity. *Journal of Pediatric Psychology*. 2006, 31:750-63.
3. Windle M, Grunbaum JA, Elliott M, Tortolero SR, Berry S, Gilliland J, et al. Healthy passages, A multimethod longitudinal study of adolescent health. *American Journal of Preventative Medicine*. 2004, 27:164-72.
4. Walters ST, Wright JA, Shegog R. A review of computer and internet-based interventions for smoking behaviors. *Addictive Behaviors*. 2006, 31:264-77.
5. Shegog R, McAlister A, Hu S, Ford K, Meshak A, Peters R. Use of interactive health communications to affect smoking intentions in middle school students: A pilot test of the "Headbutt" risk assessment program. *American Journal of Health Promotion*. 2005, 19(5):334-8.
6. Bersamin M, Paschall MJ, Fearnow-Kenney M, Wyrick D. Effectiveness of a web-based alcohol-misuse and harm-prevention course among high- and low-risk students. *Journal of American College Health*. 2007, 55:247-54.
7. Marks JT, Campbell MK, Ward DS, Ribisl KM, Wildemuth BM, Symons MJ. A comparison of web and print media for physical activity promotion among adolescent girls. *Journal of Adolescent Health*. 2006, 39:96-104.
8. Kypri K, McAnally HM. Randomized controlled trial of a web-based primary care intervention for multiple health risk behaviors. *Preventive Medicine*. 2005, 41:761-6.
9. Michaud P, Colom P. Implementation and evaluation of an Internet site for adolescents in Switzerland. *Journal of Adolescent Health*. 2003, 33:287-90.
10. Lightfoot M, Scott CW. Computerized HIV preventive intervention for adolescents: indications of efficacy. *American Journal of Public Health*. 2007, 97(6):1027-30.
11. Chiasson MA, Parsons JT, Tesoriero JM, Carballo-Diequez A, Hirshfield S, Remien RH. HIV behavioral research online. *Journal of Urban Health-Bulletin of the New York Academy of Medicine*. 2006 Jan, 83(1):73-85.

12. Escoffery C, Miner, K., Adame, D., Butler, S., McCormick, L., & Mendell, E. Internet use for health information among college students. *Journal of American College Health*. 2005, 53(4):183-9.
13. Tercyak KP, Abraham AA, Graham AL, Wilson LD, Walker LR. Association of multiple behavioral risk factors with adolescents' willingness to engage in eHealth promotion. *Journal of Pediatric Psychology* 2008:1-13.
14. Gilbert LK, Temby JRE, Rogers SE. Evaluating a teen STD prevention Web site. *Journal of Adolescent Health*. 2005, 37:236-42.
15. Franck LS, Noble G. Here's an idea: ask the users! Young people's views on navigation, design, and content of a health information website. *Journal of Child Health Care*. 2007, 11(4):287-97.
16. Torpel B, editor. Participatory design: a multi-voiced effort. 4th decennial conference on Critical computing: between sense and sensibility; 2005; Aarhus, Denmark: ACM.
17. Iivari N, editor. Enculturation of user involvement in software development organizations: An interpretive case study in the product development context. third Nordic conference on Human-computer interaction; 2004; New York, NY: ACM Press.
18. Clemensen J, Larsen SB, Kyng M, Kirkevold M. Participatory design in health sciences: using cooperative experimental methods in developing health services and computer technology. *Qualitative Health Research*. 2007, 17(1):122-30.
19. Pileman S, Timpka T. Third generation participatory design in health informatics: Making user participation applicable to large-scale information system projects. *Journal of Biomedical Informatics*. 2008, 41(2):327-39.
20. Spinuzzi C. The methodology of participatory design. *Technical Communication*. 2005, 52(2):163-74.
21. Waller A, Franklin V, Pagliari C, Greene S. Participatory design of text messaging scheduling system to support young people with diabetes. *Health Informatics Journal*. 2006, 12(4):304-18.
22. Ruland C, Starren J, Vatne T. Participatory design with children in the development of a support system for patient-centered care in pediatric oncology. *Journal of Biomedical Informatics*. 2008, 41(4):624-35.

23. Muller M, editor. PICTIVE- An exploration in participatory design. Human Factors in Computing Systems Conference Proceedings; 1991; New Orleans, LA.
24. Muller M, Wildman D, White E. Equal opportunity PD using PICTIVE. Communications of the Association for Computing Machinery. 1993, 36(4):64-6.
25. Muller M. Participatory design: the third space in HCI. In: Jacko JA, Sears A, editors. The human-computer interaction handbook: fundamentals, evolving technologies and emerging applications. Mahwah, NJ: Lawrence Erlbaum Associates; 2002. p. 1051-68.
26. Kujala S. User involvement: A review of the benefits and challenges. Behaviour and Information Technology. 2003, 22(1):1-16.
27. Kujala S. Effective user involvement in product development by improving the analysis of user needs. Behaviour & Information Technology. 2007:1-16
28. McGee M, Rich A, Dumas J, editors. Understanding the usability construct: User-perceived. Proceedings of the Human Factors and Ergonomics Society 48th Annual Meeting; 2004.
29. Birru MS, Monaco VM, Charles L, Drew H, Njie V, Bierria T, et al. Internet usage by low-literacy adults seeking health information: An observational analysis. Journal of Medical Internet Research. 2004, 6(3):e25.
30. Ivanitskaya L. Health information literacy and competencies of information age students: Results from the interactive online research readiness self-assessment (RSSA). Journal of Medical Internet Research. 2006, 8(2):e6.
31. Gray NJ, Klein JD, Noyce PR, Sesselberg TS, Cantrill JA. The internet: A window on adolescent health literacy. Journal of Adolescent Health. 2005, 37:243e1--e7.
32. Stanley LD. Beyond access: psychosocial barriers to computer literacy. The Information Society. 2003, 19:407-16.
33. Lumsden J, Leung R, Fritz J, editors. Designing a mobile transcriber application for adult literacy education: a case study. International Association for Development of the Information Society (IADIS) International Conference on Mobile Learning 2005; 2005; Qawra, Malta.
34. Muller M, editor. Retrospective on a year of participatory design using the PICTIVE technique. Conference proceedings on human factors in computing systems; 1992.

35. Vertelney L. Using video to prototype user interfaces. *SIGGHI Bulletin*. 1989, 21(2):57-61.
36. Pileman S, Lindell P-O, Hallberg N, Eriksson H. Integrating the Rational Unified Process and participatory design for development of socio-technical systems: a user participative approach *Design Studies*. 2007, 28(3):263-88.
37. Valaitis R. Computers and the Internet: tools for youth empowerment. *Journal of Medical Internet Research*. 2005, 7(5):e51.
38. Masi CM, Suarez-Balcazar Y, Cassey MZ, Kinney L, Piotrowski H. Internet access and empowerment: A community-based health initiative. *Journal of General Internal Medicine*. 2003, 18:525-30.
39. Bleakley A, Merzel CR, VanDevanter NL, Messeri P. Computer access and Internet use among urban youths. *American Journal of Public Health*. 2004, 94(5):744-6.
40. Prochaska JJ, Sallis JF. A randomized controlled trial of single versus multiple health behavior change: Promoting physical activity and nutrition among adolescents. *Health Psychology*. 2004, 23:314-8.
41. Livingstone MB, McCaffrey TA, Rennie KL. Childhood obesity prevention studies: Lessons learned and to be learned. *Public Health Nutrition*. 2006, 9:1121-9.
42. May DE, Kratochvil CJ, Puumala SE, Silva SG, Rezac AJ, Hallin MJ, et al. A manual-based intervention to address clinical crises and retain patients in the Treatment of Adolescents with Depression Study (TADS). *Journal of the American Academy of Child and Adolescent Psychiatry*. 2007, 46:573-81.
43. Gray NJ, Klein JD, Noyce PR, Sesselberg TS, Cantrill JA. Health information-seeking behavior in adolescence: The place of the internet. *Social Science & Medicine*. 2005, 60:1467-78.
44. Shneiderman B. *Designing the User Interface: Strategies for Effective Human-Computer Interaction*. 3rd ed. Reading, MA: Addison-Wesley; 1998.