'ARE WE DOING IT RIGHT? EXPLORING HOW TO CONDUCT ETHICAL DESIGN RESEARCH AND PRACTICE WHEN WORKING WITH VULNERABLE PARTICIPANTS'

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ABSTRACT
As designing with vulnerable users becomes more prevalent, we need to establish guidelines to ensure ethical practices to protect both participant and researcher. Current research would advocate that design research should be conducted with end user groups to ensure that solutions developed meet the needs and expectations of those most impacted by the issues. This approach, however, may not always be ethical or appropriate in design projects at undergraduate (UG) level. Along with many of the standard ethical considerations when conducting research with vulnerable groups there are additional considerations when developing design solutions. Many design projects never reach fruition or may take years to develop a functional design requiring participant involvement over the course of the project. Student projects are not always focused on the implementation of final designs.
This paper explores several case studies of UG product design projects where vulnerable participants have been involved at various stages and to varying degrees. Case study analyses follow a description of these projects. The discussion unpacks key questions such as: when is it appropriate to involve participants? What are the most useful methods to work with participants? When are alternative methods of research and testing sufficient? How can expectations be managed? And what is the payback for people to participate? The paper concludes by proposing a guide for *how* and *when* to involve users as participants in the UG design process.

Keywords: Design research, ethics, product design, design education

1 INTRODUCTION

The impetus for this article stems from the researchers' experiences working with UG students on the BSc. Product Design & Technology programme at the University of Limerick and observing the disconnect between the emergent need for ethical design practices [1][2][3][4] and the limitations of UG students when managing complex engagements with vulnerable participants and recognizing situations where participant involvement is not necessary to move a project forward.

Many vulnerable groups may initially be very excited at the prospect of designing solutions that can improve their quality of life. They may be willing to engage in design projects as research participants or as co-designers across the various design stages. However, there is a risk that these participants may invest their time, knowledge and expertise with great expectations, but end up with little in return. A major ethical concern is that they may feel used, exploited, and let down as projects don't reach full completion, fail to reach the marketplace, or indeed reach the marketplace without addressing the original user needs. Including vulnerable participants in UG design projects must be beneficial to participants beyond the goals of the project, otherwise alternative methods should be employed.

This paper explores several case study projects from UG projects where designers have worked with vulnerable participants across different stages of the design process. The case studies are analysed to uncover the successful ways in which the designers engaged with and involved participants in their design process. Also explored are the ways in which this participation could have been improved or even removed if the burden of participation became overly complex or time-consuming with little reward for the people involved. The researchers collated the key lessons into a guide to which UG tutors

can refer as they set design curricula and that student designers can follow as they begin design projects that tackle sensitive issues for potentially vulnerable people.

2 LITERATURE REVIEW

Involving users and experts as participants in design research and design projects is seen as an essential part of the design process to create relevant and necessary solutions [1]. Every participatory design project must be built on a robust ethical foundation and conducted with integrity and rigor [5]. However, when people are involved in a participatory capacity (as experts, users, and other key stakeholders), the parameters of the project are often dynamic and changeable [6]. As such the standard ethics procedure within academic institutions might not be nuanced enough to cover the diversity of activities across the entire design process with the dynamic needs of the participants often overlooked. A participant can be involved in more than the initial primary research stage, having a repeated role in the subsequent stages of ideation, concept development and implementation across a practice-based design and research project. Conversely, the ethical approval process might be protracted and overly complex for shorter projects particularly at UG level [7]. As such the role of the participant needs a clearer definition and factors impacting and affecting their involvement must be considered carefully at the outset of any design project.

Working with users as participants introduces a complexity to design projects and this is further magnified when the participants are classified as vulnerable. Unfortunately, there is no consistent definition of a *vulnerable participant* in a research or design context available across international policies [8]. Vulnerable participants can include racial and ethnic minorities, people with additional physical or cognitive needs, elderly individuals, and children [9]. Vulnerability is individual and context dependent, and everyone may be impacted by different and often multiple vulnerabilities [10]. The NHS defines a vulnerable adult as *'any adult (person over the age of 18) unable to take care of themselves or protect themselves from exploitation'* (ibid) whilst the Irish Health Service Executive (HSE) offer the definition of a person who *'may have difficulty and need support in making decision'*. These vulnerabilities thus may affect prospective participants' ability to understand, consent and participate in a design project [11].

Whilst the inclusion of vulnerable participants can add perceived complexity to a project, every effort should be made to include eventual users as participants in design projects. Exclusion doesn't serve either the person or the design process as key insights, needs and perspectives may be missing, and the final outcomes not fit for purpose as a result [12]. Vulnerability must be viewed beyond an individual's ability to consent, but more as a relational factor stemming from power imbalances, potential for harm, cognitive ability, interpersonal relationships, cultural variances, and social imbalances [7][13]. The broadening of inclusion factors will ensure better and more responsible engagement with users and create the potential for an elevated level of trust with participants to continue to engage in design research and testing.

Designers must explore the potential varied vulnerabilities of their participants ahead of the project and develop protocols that are cognizant of, and work to eliminate, minimize or rebalance any risks. They can then put protective measures and protocols in place to decrease the likelihood of harm to a participant and instead empower and promote agency for the participant [7]. Several researchers have highlighted that participants must gain from their involvement and these *user gains* may have personal and/or collective benefits. In addition to reimbursement for expenses and time, non-financial payback can include participants building their knowledge, feeling empowered, gaining agency by having their voices heard, pride in participating and the experience of working with others and potentially helping others in similar situations in the future [13] [14].

Whilst UG design students are encouraged to involve users in all stages of their design project, the complex nature of participatory methods with vulnerable users presents challenges [7]. Ethics cannot be overlooked in educational projects to produce competent and ethically aware professional design community (ibid). At UG the designers are still amateurs, they might not have the skills to manage sensitive situations, their projects are not likely to develop into fully realized designs and testing might be exploratory without leading to a specific solution. Modified Ethical Approval processes can be developed for UG projects, but what appears to be missing from current research are practical guidelines for design students to help them plan and implement rigorous and responsible design projects and to offer workarounds when access to participants is not available or advisable.

3   METHOD

A number of undergraduate product design projects were chosen as exploratory case studies. The projects are the work of final year UG on a [course name removed]. Therefore, a certain level of design experience and standard of work was assumed. Each case study was chosen because the intended users were classified as vulnerable and in some or all cases participants were involved in the design process at different stages. The level of involvement varied across the projects due to access and availability of participants, designer engagement and project direction.

The case studies were retrospectively studied. The main sources of data were the project process books which document the entire project in both visual and written format. The process books were analysed, and this data was triangulated with notes from design tutors taken during the projects. Through examining these cases the researchers could explore the process undertaken by the designers for research and design development, the methods they used when working with participants across all project stages and the measures undertaken or overlooked, when working with these vulnerable participants.

3.1 Case Studies

Each case study was chosen because the designers were working on topics that were considered sensitive and therefore the intended users were classified as vulnerable users.

Table 1. Case Studies

Case study	Project Theme	Types of participants	Participatory methods used	Alternative methods used
1	Menstrual cup and cleaning system	People who menstruate. Clinical experts	Purposive sampling. Interviews. Focus groups.	Forums & online blogs. Simulated testing with proxy user.
2	Active Birthing device for homebirths	People who have given birth. People who may give birth in the future. Experts & clinicians in birthing process.	Snowball sampling. Interviews & Focus Groups Expert interviews. User testing	Forums & online blogs. Simulated user testing with proxy users. Retrospective interviews (past experiences).
3	Time management and scheduling device for young adults with ASD (Autism Spectrum Disorder)	People with ASD. Carers & guardians of people with ASD. Service providers for people with ASD. Experts in ASD.	Convenience sampling. Interviews. Storytelling. Journey mapping.	Simulated testing with proxy users. Empathy research. Online forums.
4	A navigation device for people with visual impairment	People with visual impairment. Experts. Service Providers.	Interviews. Observations. Journey mapping. A Day in the Life	Empathy research. Simulated testing.
5	Way-finding system for dementia center in the context of destigmatization	People with Alzheimer's, Residential care providers. Professional carers. Familial carers	Site visits. Observations Expert seminar. User interview. Guided tour. Expert interviews.	Journey & empathy mapping. User testing with proxy (non-vulnerable) participants
6.	Applying music as a learning tool to develop social, communication and musical skills, for children with ASD	People with ASD. Experts (music therapists, Special needs assistant, community music teacher).	Interviews. Day in the life. Role-playing & evaluation of concepts with users (teachers & children).	Journey and empathy mapping. User testing with proxy (non-vulnerable) participants. Role play

4 FINDINGS

In the following section we reflect on the findings from the case study analyses which are briefly discussed and followed with guidance for both design tutors and students.

4.1 Ethical 'Approval'

UG research design projects should undergo some form of ethical review. At a minimum, plans and protocols for how and when participants are involved should be prepared, project purpose and participant role(s) clearly explained, and consent forms signed by participants or guardians. Design educators can manage this process, but they would require ethics training themselves to ensure they can make informed decisions on the risks involved. Ethical approval can therefore be a less rigorous process with the tutors acting as the key decision-makers in the process but students gaining experience in ethical practice [7].

Guidelines:

- *Ethical training is essential for design educators.*
- *Formal but 'lighter' ethics approval must be sought that outlines plans for participant involvement, highlights any potential risk and describes measures to overcome these.*

4.2 Recruiting participants

Recruitment of potential users as participants proved difficult for UG designers and was further complicated when the topic was sensitive, and the potential users identified as vulnerable. The most common method was convenience sampling [15] where the designers drew on existing networks (personal and professional) to recruit users, experts, and other stakeholders. This was often difficult for students as their own networks were not extensive.

Guidelines:

- *Close tie participants should be balanced with objective or critical participants at key points in the design process (e.g., user testing & evaluation)*
- *Caution needs to be exerted to avoid 'over-using' vulnerable participants across long duration projects. Proxy users could be used to step in for early-stage testing and evaluation.*
- *Snowball recruitment is very effective for expert participants.*
- *Access to participants can be made through liaison and support groups or other stakeholders.*

4.3 Gatekeepers

Direct access to vulnerable users wasn't always possible across all the cases examined. Where access was possible it was typically through a gatekeeper or advocates who had an implicit understanding of the users, their needs, and the most appropriate and sensitive way to engage with them. This person was often a professional service provider or a family member who could also offer insights as a key stakeholder in the area. An example of a gate keeper would be for example a charity such as the Alzheimer's Society where the society can provide guided access to participants. Indeed, many of these gatekeepers were involved in later stage testing and evaluation of concepts if it wasn't appropriate to involve users at these stages.

Guidelines:

- *Gatekeepers or Advocates are essential for engagement with vulnerable participants. This protects both the participant and the designer.*
- *Gatekeepers can have deeper involvement in the design process providing expert feedback throughout.*

4.4 Alternative participants

Mapping the key stakeholders and relationships at the start of most cases, helped designers to identify where proxy or alternative participants could be used in place of vulnerable participants. In Case 1 the designer conducted retrospective interviews with people who had experienced the situation but were no longer considered vulnerable (e.g., former patients). This proved a very useful method of conducting research, reviewing ideas and testing concepts as the risk to the person was eliminated but valuable insights and feedback were garnered.

Guidelines:

Alternative participants might include:

- *Proxy users.*
- *Participants who have experienced an issue but who are no longer vulnerable, for example someone who was a patient but is no longer undergoing treatment or care.*
- *Liaison with support groups, charities*
- *Experts such as those providing services or care for the vulnerable participants can provide user insights where users themselves cannot.*

4.5 Workarounds - Alternative methods

In some cases, the designers independently assessed the need for the participants to be involved to avoid 'overuse' or participant fatigue (Figure 1). Instead, they used workarounds for research and user evaluation and testing that provided sufficient results to make decisions and move the project forward. This dynamic approach to participant involvement can overcome issues where access to the participants is restricted or indeed changes throughout the project process. This is particularly important at UG where the novice designers are at greater risk of mishandling sensitive or challenging situations.

Guidelines:
- *Workarounds should be the first choice where it yields the same results as participant involvement.*
- *Research workarounds: Expert & Stakeholder primary research; Online Forums & Blogs; Empathy research; Scenario Building; Role Play*
- *Ideation & Concept testing workarounds: Proxy User Testing; Simulated Testing; Journey Mapping; User Stories. Role play.*
- *Participation of users is dynamic and must be reviewed at various stages of the process to avoid over-burdening participants whilst also recognizing their interest in sustained involvement.*

Figure 1. Examples of alternative methods (a. personas, b. proxy users, c. vulnerable user testing, d, user journey mapping)

4.6 Giving back

The participant's expectations were not always managed correctly. Feedback loops were not two-way, participation was not acknowledged and little in the way of payback to the participants was considered. Where the designer could 'reward' the participants, buy-in was stronger e.g.one designer gave sweets to young users to thank them for their participation in the concept testing stage.

Typically, UG projects do not develop into fully realized designs, and at times the participants were not aware of this when they became initially involved in the project. This led to disappointment and at times disengagement from the process once the limits of the project were explained.

Guidelines:
- *Designers must be explicit about the type of project being undertaken (UG college project) and manage the expectations of participants accordingly.*
- *Acknowledging the participant's input through continuous feedback loops demonstrates respect and can strengthen involvement.*

5 CONCLUSIONS

Responsible human and life-centered design must involve the key stakeholders in the development of solutions that affect their lives. And the voices of vulnerable participants are as important in this process. However, what is also clear is that designers must conduct these interactions in ethical and sensitive ways and to do this they must develop good practice from UG to carry through to their professional work. Sometimes it is not appropriate to involve vulnerable users in design research, particularly repeatedly over the course of a project. This research has provided a set of guidelines for UG design students and educators when working with vulnerable participants whilst also providing information on alternative research and testing methods that can be applied when it is inappropriate to use vulnerable participants.

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