26TH INTERNATIONAL CONFERENCE ON ENGINEERING AND PRODUCT DESIGN EDUCATION
5-6 SEPTEMBER 2024, ASTON UNIVERSITY, BIRMINGHAM, UNITED KINGDOM

APPLYING A FRAMEWORK TO CONDUCT ETHICAL DESIGN RESEARCH AND PRACTICE WHEN WORKING ON SENSITIVE TOPICS WITH VULNERABLE PARTICIPANTS

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ABSTRACT
In a world where generative AI has become pervasive it is important that we maintain ethical standards when conducting design research and practice and even more so when that is around sensitive topics and or with vulnerable participants. This paper builds on previous research [1] where a framework was developed to guide students when conducting research and practice. This paper explores how the framework is adopted across four case studies of student design projects where the topics have been sensitive and involved vulnerable participants at various stages and to varying degrees. Case study analyses follows a description of these projects in applying the framework.
This paper firstly reintroduces a framework developed by the authors that guides design students when conducting design research. Case studies are presented showing how the framework was implemented and an analysis follows where a discussion unpacks key questions around the efficacy and effectiveness of the framework. These questions address how useful the framework is in guiding the student as to when it was appropriate to involve participants; how it did or did not provide the most useful methods to work with participants; what alternative methods of research and testing are appropriate and sufficient; how participant's expectations were managed, and guidance around means of payback for people's participation. The paper continues by evaluating the appropriateness and usefulness of the framework to facilitate and guide students over the course of a project while also protecting vulnerable participants, before concluding by offering a revised version of the framework.

Keywords: Design research, ethics, product design, design education, vulnerable participants, sensitive topics

1 INTRODUCTION
This article builds on a previous study [1] where a framework was developed to guide design students when conducting research and practice. The application of this framework is evaluated in this paper to understands its ability to act as an ethical guide to support design students and supervisors when researching and designing with vulnerable participants on projects where the topics may also be sensitive.
Current research advocates 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 [2]. When conducting design research around sensitive topics we need to establish guidelines to ensure ethical practices to protect both participant and researcher [3] and participatory design projects must adhere to robust ethical principles and be conducted with integrity and rigor [4]. However, when people are involved in a participatory capacity (as experts, users, and other key stakeholders), the parameters of design projects are often dynamic and changeable [5]. Standard and generic ethics procedure within academic institutions might not be sufficiently flexible to cover the unfolding and diverse activities across the design process and the changing role of the participants. Conversely, the ethical approval process might be protracted and overly complex for shorter projects particularly at UG level [6]. Therefore, there needs to clear rules of engagement for researchers and supervisors when involving participants at the outset of design projects which considers the different roles of the participants across

the full project with the possibility of alternative participants and methods to be employed if deemed more appropriate.

2 METHOD

2.1 Case Studies

Four undergraduate product design projects were chosen that involved both sensitive topics and the involvement of potentially vulnerable participants. The projects are the work of final year UG on a BSc. Product Design & Technology. Therefore, a certain level of design experience and standard of work was assumed. The level of involvement of participants varied across the projects due to access and availability of participants, designer engagement and project direction. The case studies involved interviews with each of the students and their project process books which document the entire project in both visual and written format were also a source of data. The process books were analysed, and this data was triangulated with transcripts and field notes taken by design tutors during interviews and over the course of the projects. Through examining these cases the researchers could explore the process and methods undertaken by the designers when working with participants across all project stages and the measures undertaken or overlooked, when working with these vulnerable participants.

Case study	Project Title	Types of participants	Participatory methods used	Additional and alternative methods used
1	Menopause - Relieving people of daily discomfort & creating awareness of symptoms & treatments.	Women who are in perimenopause or menopause. Peers and own network.	Convenience sampling Purposive sampling. Interviews. Focus groups. User diaries	Instagram, Forums & online blogs, podcasts. Simulated testing with proxy user.
2	Exploring design opportunities related to a more positive breastfeeding experience, for mother and child.	Women who are breastfeeding or have breast fed within the past 5 years. Experts & clinicians in birth and postpartum care. Own network Proxy users	Purposive sampling. Snowball sampling. Interviews, survey observations, 'show me' with use of current products. Expert interviews, user diaries, User feedback and testing	Forums & online blogs. Scenario role play. Simulated user testing with proxy users.
3	Postpartum Recovery	Women who have given birth between 3 and six months prior to the research. Experts & clinicians in birth and postpartum care. Own network	Purposive sampling. Snowball sampling. Survey, Interviews, Expert interviews, Journey mapping.	Simulated testing with proxy users. Empathy mapping. Social media, Online forums. Testing with self,
4	Menstruation – a solution to aid in dealing with symptoms	Women who are menstruating	Convenience sampling, Purposive sampling and Snowball sampling Survey, Interviews, focus groups.	Online forums, Empathy research. Simulated testing.

3 FINDINGS

3.1 Ethical 'Approval'

Ethical approval was sought for all projects and was completed at a school rather than faculty level for expedience. We found that all student researchers demonstrated deep sensitivity and empathy for their research participants:

> "A lot of the topics they discussed with me they never discussed with anyone before, I wanted to make sure the participants felt comfortable and at ease, so I took a more conversational approach to the interview questions."

Extra care was also taken to consider the well-being of the participants, for example in one case the health service executive contact details and mental health hotlines were supplied should participants be affected in reliving these experiences. However, one observation made was that it is important to protect the researcher as much as the participants. many young researchers will not have the experiences of their participants and we found that our participants were impacted by the stories that they heard.

> "I stopped kind of researching things … because I was a little bit like, Oh my God! Literally because it was just so like, I'd never want children."
>
> "I had to like, emotionally withdraw myself from that because I'm like, ok, that's very traumatic and that freaks me out as a person."

The students also stated that it was very important to be well informed on the topic in advance of undertaking the research to be sensitive and aware of what participants may have experienced and to also prepare themselves for what they might hear.

> "I do feel like you needed, like I needed to be educated going into those conversations. Like, if I did not really understand my research, I wouldn't have been able to, like, lead the conversation."

In some cases, it was also not appropriate to target somebody who was having a difficult experience for example someone who has just had a baby and was still in recovery. In this case it was agreed that the researcher would only interview participants within six months of recovery (Case 3).

The following are revised guidelines for ethical approval in bold:

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.*
- ***Researchers should be made aware by their supervisor /tutor that the research stories may impact them and that they must consult with their tutor to agree a pause or alternative methods or topic.***
- ***In advance of primary research researchers need to be well informed on the topic.***
- ***Avoid recruiting participants as they are experiencing a difficult experience and recruit those who can contribute to the experience when it is over.***

3.2 Recruiting participants

All students followed convenience sampling and recruited from their own close networks, choosing a topic that had a personal stake for a family member or close contact. All researchers applied snowball sampling where at least one participant recruited another. However, in two of the four cases the researchers did not approach any experts, organisations, or anyone outside of their own network. Some students felt uncomfortable about approaching people when the topic was so sensitive or the participants vulnerable. This may also be a confidence issue with younger researchers. All participants felt that they couldn't keep going back to their initial interview participants to participate in evaluations and testing.

> "I think since they gave me their time and they did find it interesting; I think they more wanted their story to be told than continue with the project."

All students used surveys as a means of recruiting people for interview by asking people to include their email address if they were willing to be contacted for an interview. This was a successful method in all cases, even if some students didn't follow up with further contact.

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.*
- ***Assessment and grading should consider different project types and that some students may not be able to access or feel comfortable enough to recruit participants therefore alternative methods such as social media accounts, blogs and forums should be considered as alternatives to primary research.***

- ***Tutors/supervisors should ensure that the researchers have direct access to the participants.***
- ***Participants can be recruited for interviews through surveys.***

3.3 Gatekeepers

To gain direct access to vulnerable participants about sensitive topics at times it was necessary to go through gatekeepers as per the framework guidelines. In Case 2 the researcher approached The La Leche League of Ireland a non-profit organisation dedicated to supporting mothers who want to breastfeed or provide their infants with human milk. Through this organisation, the researcher gained direct access to breast feeding mothers who were happy to assist the researcher. However, two of the lactation consultants did act as gatekeepers by cautioning the researcher about imposing design solutions that could potentially undermine or patronise mothers' natural instincts and abilities. This was very useful feedback for the researcher who was very conscious of this at the solution phase.

> "One person did actually kind of warn me, that you might receive backlash as you go about this, because you're coming from a design point of view. She said, you know, there is a little bit of like an anti-design movement maybe in breastfeeding. It's maybe coming from like the formula companies and things like that. That's just, you know, people trying to promote I guess things outside of breastfeeding."

While the other researchers may not have recruited through organisations to access a gatekeeper, they tended to have one close contact from their own network who acted as a gatekeeper and connection to other participants. In Case 3 the researcher recruited a physio through a friend of her stepmom. The stepmom who was herself nine months post-partum, was the main participant and helped to recruit other people from her friend group.

> "I had my mom actually read through my questions as well to make sure that she considered them empathetic."

Interestingly the close contact gatekeepers were also the ones that the researcher felt that they could return to over the course of the project to evaluate and test solutions.

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,*
- ***Gatekeepers can provide independent evaluation on the appropriateness of solutions being proposed.***

3.4 Alternative participants

In all of the cases the researchers needed to recruit alternative or proxy users and in some of the cases to compliment the targeted end user. In Case 3, the designer conducted retrospective interviews with people who had experienced post-partum recovery in the past but were no longer considered vulnerable (e.g. former patients). In most other cases the researchers relied on close friends, family, and their student peer group. They found it was easier to ask more of these close tie connections questions on sensitive topics. The participants found that as the projects developed, they were more inclined to ask the proxy users to test solutions for them. There were several reasons for this: the researchers felt uncomfortable about repeatedly asking for input from the people who participated at the research stage; the researchers felt that it would not be appropriate to use low fidelity or rough prototypes with end users or ask them to iteratively test minor changes. Many of those participants were not always accessible or nearby and in one case the participants while "happy to have their stories heard" were not interested in following the design phase when they did not see an outcome for them.

> "But I don't think I'll go back to people who I went to for ideation and concept development because I think like for designers it can feel like it's moved on a lot, but maybe for a user group it's as if the project hasn't."
>
> "I haven't tried that on other people. I think when I have more higher fidelity models I will."

Guidelines:

Alternative participants might include:

- *Proxy users, **family, friends, and peers.***
- *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.*

3.5 Workarounds – Additional and alternative methods

In all cases the students used additional methods during interviews with participants and when it was not possible to use participants. In Case 2 the researcher created a series of hypothetical scenarios in relation to breastfeeding situations and asked the participants to speak around these. In Case 3 the researcher used existing menstrual products as a talking point to open the conversation on menstruation.

> "Scenario role-play was a useful technique to understand more about the obstacles that are in place for breastfeeding mothers."

During testing at the ideation and concept development phase participants employed a variety of methods to simulate testing. This involved creating rigs to recreate the human anatomy (Case 1), Creating a liquid to replicate blood (Case 4), and using minimalist clothing such as leggings to test a perinium plaster solution (Case 3). In all four cases the researchers used proxy users to roleplay with solutions. However, testing could only be done to a point. In Case 1 the student developed a vaginal applicator to release hormones. In this case the proxy user could only role play using the device to the point of insertion and wearing clothes, and therefore a simulator to test the insertion had to be created.

3.6 Giving back

In all cases the researchers, through their consent forms with participants made it clear that they were working on student projects which managed the expectations of the participants that there would not necessarily be implementable solutions. The researchers found that some participants wished to be informed about the project progress and that it was important to ask this at the end of a survey or at the end of an interview. Feedback was given at stages via WhatsApp and text. Reimbursement of participants was found to be dependent on the relationship of the participants to the researcher and the nature of their participants. Participants not connected to the researcher's network were bought chocolates or tea/coffee. Peers in a classroom were able to participate in each other's projects, quid pro quo, so reimbursement was not necessary.

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.*
- ***Participants can be asked on surveys and during interviews if they would like to receive feedback on the project and on the preferred format for this feedback.***
- ***Reimbursement is advisable in the form of a simple box of chocolates, a coffee or tea or a return favour.***

4 CONCLUSIONS

In this study we applied an ethics guide previously developed by [1] to student research projects involving sensitive topics and vulnerable participants. This paper explored how the framework was adopted across four student design projects. The findings overall showed that the guide was a robust framework to guide student researchers over a very nuanced process. The process of managing sensitive topics and vulnerable participants requires deep sensitivity and empathy by the researchers. In student projects this requires careful management by supervisors and the framework can provide support for that. We found that the researchers also require protection and supervisor/ lecturers need to protect the student and allow for flexibility for alternative methods to be employed or to encourage a project to pivot in a different direction.

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