Participatory Design in Sensitive Contexts: A Proposal for a Conceptual Framework

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There has been an increasing focus on Participatory Design (PD) and design research involving 'vulnerable groups' and sensitive topics in recent years. Existing approaches, however, focus on working with discrete 'vulnerable groups' and/or sensitive topics, with limited work capturing shared learnings and key principles across these. In this position paper, we discuss our work specifically focusing on enabling participation from people perceived as vulnerable to engage on sensitive research topics, sharing key themes from project examples across three different contexts. We present a proposal for a conceptual framework synthesising key principles for Participatory Design in Sensitive Contexts. The framework emphasises: valuing lived experience as expertise; rights-based ethos foregrounding the political, ethical and social commitment of PD; asset-based design promoting individual and collective agency, voice and empowerment; and attuning participation with a focus on relationships, dynamics of engagement and wellbeing, to create appropriate conditions for genuine participation and transformation.

Keywords: participatory design; vulnerable groups; sensitive topics; Participatory Design in Sensitive Contexts; rights-based ethos; asset-based design; genuine participation; transformation

INTRODUCTION

Recent years have seen a growing interest in participatory design (PD) and design research involving 'vulnerable groups' and sensitive topics. 'Vulnerable groups' have been historically associated with 'weakness', 'dependency' and 'victimhood' (Wisner, 2016). A similar negative understanding is commonly reflected across design disciplines when it relates to participation of people perceived as vulnerable due to 'a lack of social, political, economic and cultural capital' (Selloni and Rossi 2019) or 'psychological or physical capacities' (Tutenel and Heylighen, 2021). While contemporary understandings of vulnerability acknowledge the subjectivity in the context and perspective of those who are 'doing the defining' (Aldridge 2014, 2015), participation continues to be widely viewed as a 'potential risk' to people's wellbeing (Aldridge 2014; Lindberg 2018), 'something to be avoided or reduced' or 'a problem to be solved' (Tutenel and Heylighen, 2021). Challenging this paternalistic mindset centred around safeguarding that often creates barriers to participation, there is a shift towards enabling participation by prioritising rights and agency of people with lived experience (Benzon and Blerk 2017). This requires moving from a problem-focussed view to supporting agency and choice (Zarowsky et al. 2013; Bennett and Roberts 2004 in Butler 2015); developing capacities that foster empowerment (Wisner 2016; Zamenopoulos et al. 2019); critically reflecting on the relational nature of vulnerability (Benzon and Blerk 2017), and foregrounding 'an ethic of care' (Manzo and Brightbill 2007 in Gieben-Gamal 2019). This aligns with wider developments in design related to agency and power when addressing social concerns, including sensitive topics (Pierri 2017). Some PD practices involving discrete 'vulnerable groups' and sensitive topics are beginning to promote these views, however, generic models and frameworks that explicitly acknowledge this shift and enable participation are lacking (Dietrich et al.

2017; Aldridge 2015, 2017; Lindberg 2018).

Over the last seven years our practice at The Glasgow School of Art has focused on developing a participatory design approach for engaging people with diverse expertise and perspectives to co-design future health, care and wellbeing (futurehealthandwellbeing.org). Our design research in this context particularly focuses on enabling participation of people with lived experience of a range health and wellbeing areas to transform current services, systems, models and strategies by instilling a person-centred ethos. Within this wider context, projects specifically focusing on enabling participation from people perceived as vulnerable to engage on sensitive topics has motivated us to write this position paper – to respond to a salient gap in theory and how these are enacted through examples from practice on creating conditions to enable participation and designing engagement in these contexts by sharing our experiential learning.

The aim of the paper is to initiate dialogue with wider PD practitioners and design researchers on ways of enabling participation from people perceived as vulnerable to engage on sensitive topics. We present the emerging themes and learnings from our reflection alongside related literature on creating appropriate conditions to enable participation from people perceived as vulnerable to engage on sensitive topics. Finally, we present a proposal for a conceptual framework for 'Participatory Design in Sensitive Contexts' that embodies these themes and learnings. The framework reflects our position based on our experiential learning on creating appropriate conditions for genuine participation and transformative outcomes through: valuing lived experience as expertise; rights-based ethos foregrounding the political, ethical and social commitment of PD; asset-based design promoting individual and collective agency, voice and empowerment; and attuning participation with a focus on relationships, dynamics of

engagement and wellbeing. We invite other practitioners and researchers to share their experiences and reflections to inform further refinement and iteration of this framework.

REFLECTING ON OUR PARTICIPATORY DESIGN PRACTICE

The themes and learnings have emerged through a combination of organic reflection embedded in our shared practice over seven years and a structured reflection process synthesising themes from three different project examples. Organic reflection involved reflection in situ during the iterative development of PD approaches and co-design processes tailored to each project context, and tacit knowledge sharing across these that has shaped our overall practice. Structured reflection included critical consideration of three project contexts and co-design processes together in retrospect, to identify shared themes in the approaches and learnings on designing the appropriate conditions to enable participation.

The three project examples were chosen based on how well the values underpinning the purpose of participation and sensitivities of engagement of people with lived experience, and emerging outcomes were aligned with each other (Table 1). A key focus across these projects was to enable 'genuine participation' – ensuring participants' legitimate involvement as partners in the design process (Cozza, Cusinato and Philippopoulos-Mihalopoulos 2019) and explicitly acknowledging participants' expertise by creating a meaningful frame for participation that reflects their everyday lives (Iversen and Brodersen 2008). In addition, the design of engagements within these projects also foregrounded the design process to enable transformation by considering outcomes that bring about positive changes for the participants beyond simply the project output (Selloni and Rossi 2019).

Table 1. Three project examples from our PD practice

Project	Topic	People	Purpose of participation and sensitivities of engagement
Co-designing a game-based learning tool	Online safety	Young people with learning disabilities, Local Area Coordinators providing training	Engaging young people with learning disabilities to share personal experiences related to online behaviours, while ensuring equal voice by overcoming existing learner-trainer power dynamics and communication differences.
Exploring the future of transitions in palliative care	Palliative care	People with lived experience of palliative care, practitioners, academics, policymakers	Engaging people with lived experience of palliative care to share their journey and aspirations for the 'future' whilst acknowledging the uncertainties when living with a life-limiting condition, and foregrounding these experiences in the context of multidisciplinary, multi-stakeholder participation.
Co-designing care and emotional	Miscarriage	Women with lived experience of miscarriage,	Engaging women to share their experiences of accessing and receiving support whilst

support around miscarriage		practitioners	acknowledging, being mindful of, and supporting personal ways of coping with grief.

EMERGING THEMES AND LEARNINGS ON CREATING CONDITIONS FOR GENUINE PARTICIPATION AND TRANSFORMATIVE OUTCOMES

Valuing Lived Experience as Expertise

Enabling voices of people with lived experience, particularly those perceived as vulnerable, and positioning and valuing lived experience as expertise is a key ethos of our practice. There is a further focus on supporting expression of a diversity of voices and an authentic and respectful representation of voices acknowledging the depth of participant's experiences. Wider literature highlights the role of autobiographical forms of engagement in understanding the subjectivity and complexities of people's lived experience (Goodson 2013 in Aldridge 2015; Agyeman 2008). Individualised or subjective methods, particularly narrative techniques, have been suggested when working more inclusively (Aldridge 2015). Personalised, 'bespoke' methods incorporating different narrative approaches (e.g., spoken, written or visual) enable empowerment through legitimising these lived experiences (Bjorgvinsson et al., 2012). When engaging people on sensitive topics, we have observed that understanding and integrating personal motivations at the outset to inform the design of the engagement is crucial for ensuring personal meaning and purpose to participation. We develop design tools and visual artefacts that make participants' expertise visible and tangible by embodying their lived experiences, enabling empathy and exploration of topics in a

mutually respectful and sensitive way during co-design. Further, supporting participants to express their stories in their own ways, and involving them in identifying and validating emerging themes from a lived experience perspective is a key focus when designing engagement. We found that this is essential for avoiding conflicting interpretations or misrepresentation in translation, by valuing what is 'true' for participants as authentic and significant for the wider context (Aldridge 2014, 2015). This also supports multi-dimensional participation where participants can adopt roles such as narrator, social actor and self-advocate (ibid).

For example, when engaging with women with lived experience of miscarriage (Raman and Tulloch 2018), participants reflected on their individual experiences of care following miscarriage and personal ways of coping with loss. Craft materials and bespoke cut out 'charms' (e.g., heart, hand, feather) supported participants to visualise and express their emotions and feelings, and participants associated their own personal meaning to these artefacts. These were then used to create a visual narrative of their care journey, enabling participants to develop a shared vocabulary and express their lived experiences through this process. This created ownership in the representation of their personal stories, and participants used these visual narratives to share their lived experiences with health professionals during a subsequent co-design session. In this session, health professionals and women with lived experience also created visual artefacts to communicate their personal motivations related to participation, enabling empathy with each other's experiences and perspectives on the topic. They further built on these visual narratives and artefacts when working together to co-design future experiences of care and support.

Figure 1. Individual and collective meaning making, expression of lived experience and co-design of future care. Image credit: Hannah Laycock, Louise Mather

Committing To and Sustaining a Rights-based Ethos

Our approach to participation is underpinned by a rights-based ethos. It is founded on the inherent political and ethical commitment of PD (Bjorgvinsson et al. 2012) to democracy and inclusion of people with lived experience, including those perceived as vulnerable, when addressing social issues. When designing engagement, the focus is on promoting and respecting participants' choice to take part and designing appropriate ways of engaging to enable this. Previous literature highlights committing to participant integrity and wellbeing, acknowledging participant sensitivities, and developing tailored and multi-method approaches that enhance ability and facilitate individual voice as being key to enabling participation (Aldridge 2015; Lindberg 2018). In addition, 'sensitisation' to unpredictable situational challenges, balancing of risk and empowerment, and participant wellbeing is crucial (c.f. Lindberg 2018; Agyeman

2008). The advice to 'err on the side of caution' when faced with practical challenges to equal participation (Lindberg 2018), however, is at odds with a rights-based approach in our experience, as this could lead to reduced participation or exclusion. Therefore, we argue that the commitment should be to both supporting *participants' choice* and to *designing ways* to enabling this by being responsive in practice.

For example, when engaging with young people with learning disabilities (Raman and French 2021), researchers met young people in a social setting familiar to the young people to introduce the project and invite them to take part. Engaging in this informal setting was seen by young people as a 'stepping stone' for participation, and enabled researchers to develop sensitivity towards personal preferences and individual abilities of participants early in the process. Working collaboratively with the Local Area Coordinators who have an existing knowledge of participant preferences further supported development of a multi-method approach integrating simple language, minimal text, visual and verbal forms of expression (e.g., stars and smiley stickers Lego, role play) across design activities. This enabled participation by offering participants choice around engaging and sharing experiences in a way that was most comfortable to them. Young people felt that materials such as Lego supported them to express themselves without feeling judged when sharing their online experiences. Designing activities and tools to be emergent and curated in response to participants' preferences and feedback on engaging with these, rather than following a pre-determined process, enabled participation from the young people across all stages of the co-design process.

Figure 2. Use of multi-method approaches for expression of individual experiences while supporting collaboration. Image credit: Louise Mather

Embodying Asset-based Design

Asset-based approaches focusing on and harnessing community assets have been suggested to support engagement and create outcomes of direct social benefit in PD (Broadley 2020). Adopting an asset-based mindset and extending this to the design of methods and tools is an important characteristic of our PD practice. This includes an asset-based framing of people with lived experience and sensitive topics embodied in the choice of language, format, tone and aesthetics of engagement methods and tools, alongside an asset-based mindset when framing wider questions and topics for engagement. When designing engagements, our focus is on empowering participants to recognise individual and collective assets through creative exploration and reflection to enable participation. In our experience, using asset-based metaphors support sensitive and reflective expression of participants' personal experiences, enabling an authentic

representation of lived experiences that challenge 'outsider' perceptions of 'vulnerable groups' and sensitive topics (French and Raman 2021). Visual methods and sharing of lived experience using asset-based tools have also been highlighted by our participants as valuable in supporting self-reflection and 'making sense' of difficult experiences through creative expression.

For example, designing engagement materials and tools to enable participation from people with lived experience of palliative care transitions (French and Raman 2021) involved careful consideration of the aesthetics enabling sensitive engagement with the topic. Sharing of personal experiences were supported through combining abstract and imaginative metaphors and a narrative approach visualising participants' 'journey' of transitions. This included – 'doors' of different shapes, sizes, opened, closed, ajar to allow participants to express positive and negative experiences of transitions; 'keys' to unlock closed doors and access support; 'Russian dolls' to express people in participants' care circle; 'magic potions' revealing individual assets that supported participants during transitions; and 'rainbows' for their hopes and aspirations. A 'Stories of Transitions' tool capturing vignettes from the visual interviews was created to foreground participants' lived experiences when engaging with practitioners and policy-makers in subsequent co-design sessions. This supported reframing of perspectives and richer asset-based dialogue on what mattered to people with lived experience when designing future services.
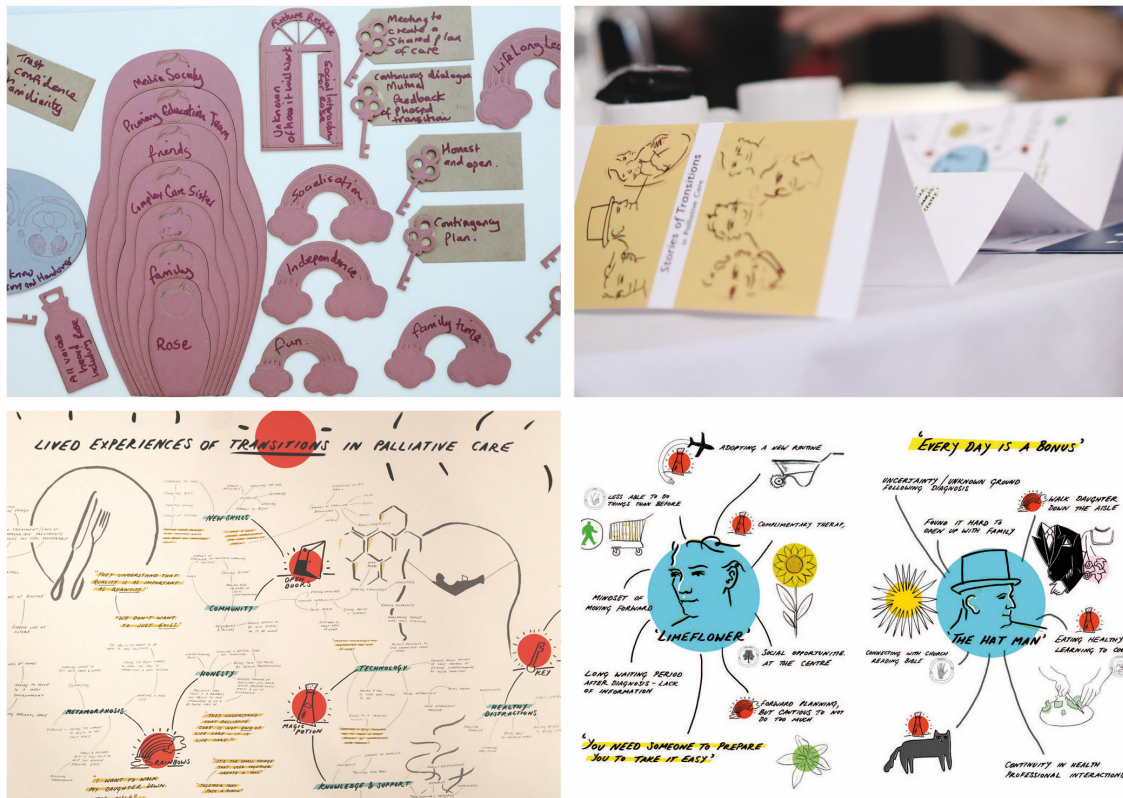
Figure 3. Tailored asset-based metaphors to enable reflection and expression of personal stories. Image credit: Louise Mather, Illustration credit: Tessa Mackenzie

Attuning Participation with a Focus on Relationships, Dynamics of Engagement and Wellbeing

Fostering collaborative relationships that support equality, trust, respect and empathy is a key aspect of our work (French et al. 2016). Collaborations involving a diverse range of voices require a recognition and balance of power dynamics to facilitate relationships that support positive engagement. Therefore, when designing engagement, we place emphasis on contextual preparation and devoting time from the start to build trust and relationships based on a mutual understanding and respect for personal and shared motivations and expectations around outcomes of participation. We believe this is important for relational engagement and to create conditions for participation that are appropriate to the people and topic. While empathy with participant's experiences and needs has been widely recognised as fundamental in participatory design processes, we

highlight a further need for *attuning* – i.e., nurturing a situated mindset with heightened awareness and response. This further translates in practice through attuning the tools and artefacts to support meaningful engagement, and social organisation of the space attuned to the tone and dynamics of the engagement (e.g., scale and format of engagement – intimate one-to-one or larger groups, seating arrangements, objects and aesthetics of the space, refreshments). Intimate individual and small group engagements form an important part of the early stages of the process in our work, to build trust and empathy for respectful and sensitive sharing of personal lived experiences.

For example, in both the projects involving people with lived experience of palliative care (French and Raman 2021) and women with lived experience of miscarriage (Raman and Tulloch 2018), the scale of engagement was crucial to support the inclusion of people with lived experience. One-to-one or intimate, small groups were chosen for early engagements with participants. In the former example, the programme was designed to include multiple engagement formats to support participation and choice. This involved one-to-one engagements with people with lived experiences and larger seminar and workshop sessions with wider stakeholders, giving the choice to people with lived experience to participate in larger sessions in person or through sharing of the visual narratives created in the one-to-one engagements. It was important to work with practitioners and researchers with previous contextual experience in selecting the venue for the one-to-one engagements ensuring this was comfortable and accessible, and also as part of building a trusting relationship with people with lived experience of transitions. Staff at the venue further recommended a room usually used for relaxation and quiet time. The set-up of the room was adapted to ensure that in addition to comfortable seating, one of the researchers could sit alongside the participant to enable collaborative making as well as to remove the dynamic of

'interviewer and interviewee' imposed when sitting across from each other. In the latter example, the venue was a private room within a public building and each element added to the room was carefully chosen, including small round tables for dialogue and collaboration. Alongside this, a comfortable corner with relaxed seating and materials such as books and soft furnishing created a more reflective and private nook if participants wished to take a break during the engagements. Refreshments available throughout the process created a comfortable personal and social experience, helping to set a relaxed pace and tone. The aesthetics of care also translated into the choice of materials and colour palette of tools and artefacts designed for the engagements.

Figure 4. Attuning the space, tone and dynamics of engagement. Image credit: Hannah Laycock

There is also an emphasis on *designing* time throughout the participatory process to facilitate an emergent form of engagement, in line with generative approaches in

design research (Sanders and Stappers 2012). Flow and pace of engagements are informed by what is comfortable to the participants in expressing themselves (Rajapakse et al. 2019), and a situated response to participants' needs 'in the moment' (Raman and French 2021) to prioritise wellbeing. We found that this emergent nature, however, can pose challenges related to the duration of participation (particularly around 'endings') and uncertainty related to expected outcomes. Therefore, we believe ensuring transparency around expectations related to time and fluidity in the process from the outset and communicating the indicative stages involved is particularly important. One of the ways we currently mark project endings is by sharing back the outcomes in the form of lay summaries and videos capturing experiences, key findings and recommendations.

For example, on receiving the lay summaries and video of the project co-designing care and emotional support around miscarriage, women with lived experience and health professionals who participated expressed their appreciation and feedback on being able to be involved in the process. A small deck of postcards with quotes capturing perspectives of women and health professionals were also created and sent to all participants and shared on social media during a baby loss awareness campaign. In addition, visual artefacts created by participants during the process, e.g., 'charms' visualising experiences, were offered as a 'memento' or token to show appreciation for their time and as a reminder of their engagement. Whilst these created more tangible forms of 'endings and legacy', feedback from participants suggested that positive experiences as a result of participation and empowerment also extended beyond the project to benefit people's personal and social lives.
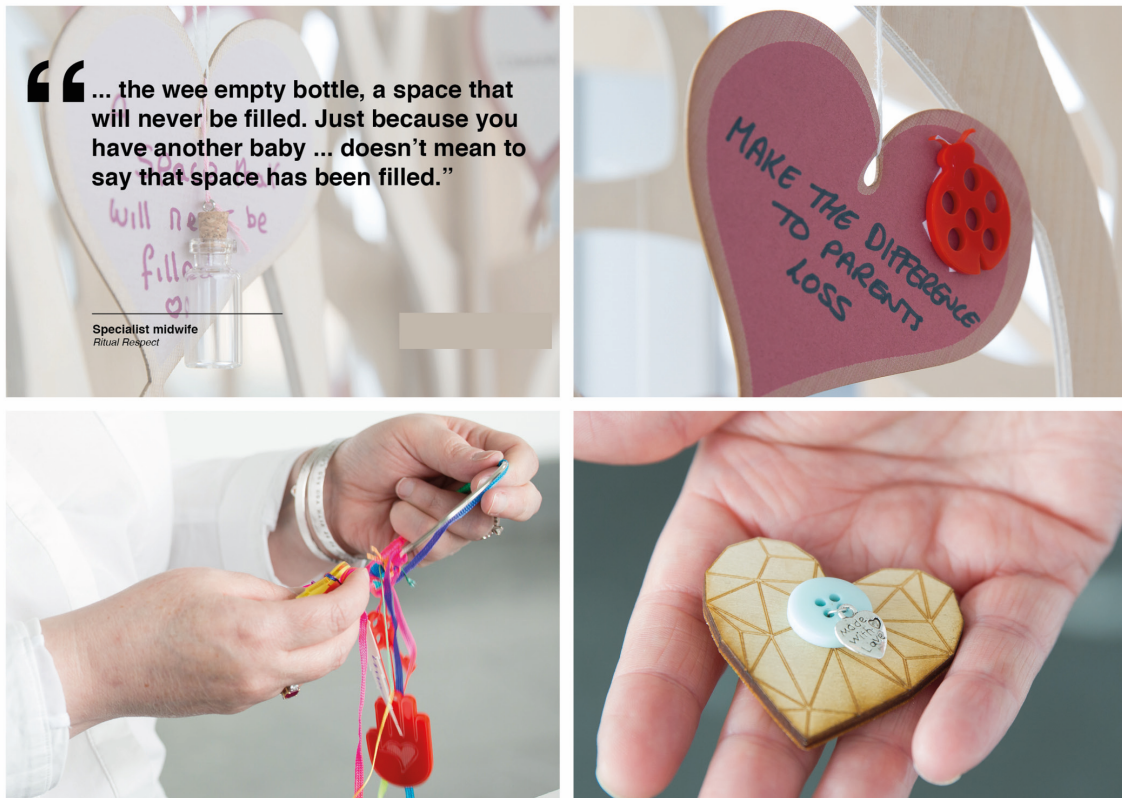
Figure 5. Visual artefacts marking endings and supporting legacy. Image credit: Hannah Laycock

However, we acknowledge that these do not fully address the ethical dilemma around "temporariness", i.e., fostering a trusting and empathetic relationship and leaving that relationship honourably (Fahie 2014). In our experience, there is a tension between the significance placed on time spent at the beginning building trust and relationships, and the time-bound nature of projects due to external constraints such as funding. We have also observed the need for responsibility towards recognising and preparing for potential longer-term impacts of participation and participant wellbeing, e.g., additional forms of support that may continue beyond the duration of engagements. However, we found that it is challenging to envisage the extent of this support due to the personal nature of experiences and individual needs, and recommend this as an area for future research.

A CONCEPTUAL FRAMEWORK FOR PARTICIPATORY DESIGN IN SENSITIVE CONTEXTS

The above themes have emerged from our reflective process and has informed the development of a proposal for Participatory Design in Sensitive Contexts framework, which foregrounds key principles focusing on genuine participation of people perceived as vulnerable and enabling transformative outcomes (Table 2). The framework aims to shift mindsets on participation and designing engagement in sensitive contexts by emphasising – genuine participation focusing on individual voices (personal experiences), collective voice (shared experiences) and collaborative voice (visibility and legitimising of experiences from multiple perspectives); as well as personal, collective and social transformations. Within the examples shared from our practice above we have illustrated how a specific principle was embedded in the design of engagements. However, it should be noted that in practice multiple principles were integrated in the design of the engagements and, therefore, we would like to highlight that the principles should be considered as intertwined with each other rather than as working in isolation.

Table 2. A conceptual framework for Participatory Design in Sensitive Contexts

Key principles	Enabling genuine participation	Enabling transformative outcomes
Valuing lived experience as expertise	Reframing participation building on personal meanings and motivations, and embodying lived experiences using visual tools and artefacts. Enabling empathy and reflection using visual tools and artefacts to create a shared vocabulary and explore different perspectives. Supporting multi-dimensional participation and authentic representations of lived experiences.	Empowering people with lived experience and creating ownership in shaping narratives to challenge and transform wider social perceptions.
Committing to and sustaining a rights-based ethos	Enacting the right to participation by promoting and respecting individual choice to participate, and designing situated, tailored multi-method approaches to enable this.	Enabling participation and changing mindsets to respect the agency and choice of people with lived experience related to voice and wellbeing.

	Enabling and sustaining participation through an emergent process that is sensitive and responsive to participant wellbeing.	
Embodying asset-based design	Asset-based framing of people with lived experience and sensitive topics embodied through language, format, tone and aesthetics of engagement to support sharing of personal experiences. Empowering people to recognise individual and collective assets through creative exploration and reflection using asset-based metaphors and visual tools. Enabling an authentic representation of lived experiences and reframing perspectives from an asset-based mindset.	Manifesting outcomes that matter to people with lived experience to support personal and social flourishing.

Attuning participation with a focus on relationships, dynamics of engagement and wellbeing	Adopting a situated mindset with heightened awareness and response 'in the moment', along with attuning the space, tone and dynamics of engagement bespoke to the people and topic. Designing time to build relationships and trust and creating conditions to support an emergent form of engagement through flow and pace informed by people's preferences and needs. Emphasising personal and collective wellbeing by preparing for potential long term impacts through embedding trusted forms of support during and after engagements.	Nurturing personal and collective wellbeing through relational and respectful engagement enabling personal, psychological and social benefits for people with lived experience.

The key principles emerging from our work highlight a similar focus to previous work in relation to participant's expertise, rights, abilities, voice, wellbeing, and situated design to enable participation (Lindberg 2018; Aldridge 2014, 2015; Rajapakse et al. 2019; Agyeman 2018; Bjorgvinsson et al. 2012; Selloni and Rossi 2019). The

Participatory Design in Sensitive Contexts framework makes further contribution by focusing on how the key principles inform ways of designing engagement to enable genuine participation of people perceived as vulnerable and transformative outcomes beyond project outputs.

A key contribution of this paper is the development of a rights-based ethos for Participatory Design in Sensitive Contexts. We invite future research to explore a rights-based approach to participation more widely, and in design research specifically we call for an emphasis on translating the ethical commitment to inclusion by designing *ways* of enabling engagement in practice. This would also require further research to acknowledge the dilemma of temporal and relational participation when adopting a rights-based ethos, to create awareness and acceptance of flexible and novel approaches to PD and public engagement.

The framework also introduces an embodied asset-based design, moving beyond asset-based approaches being *applied* to inform the design engagement and outputs, towards *embodying* asset-based design through reframing of people, topic and outcomes to enable genuine participation and transformation. Whilst there is an emerging focus on design for wellbeing through the developing field of positive design, the focus currently is mainly on 'positively designed' products that enhance wellbeing (Petermans and Cain 2020). Shifting this limited focus from wellbeing supported by the outputs of a design process to the impact of participation in co-design, our future research aims to further understand and define an *embodied* asset-based design process. This will focus on what matters to people with lived experience to enable genuine participation and transformative outcomes when designing for wellbeing.

The framework offers specific contributions related to contextual attuning and wellbeing, by highlighting the importance of focusing on the relational and temporal

nature of participation. Attuning extends from the design researchers adopting a situated mindset with heightened awareness and response 'in the moment' to considering potential long term impacts of engagement.

FUTURE WORK

In developing this position paper, additional focus areas related to Participatory Design in Sensitive Contexts have emerged that require further research. This paper has focused on sharing our position based on a reflective process synthesising learnings and experiential knowledge from our PD practice, and proposes a framework building on this process. We invite other practitioners and researchers to share their experiences and learnings to inform further refinement and iteration of the proposed conceptual framework or share additional frameworks, to address the gap in theory related to shared learnings and key principles and how these are enacted through examples from practice across multiple sensitive contexts. There is further scope for a systematic study comparing approaches, methods and tools related to participation of people perceived as vulnerable and their engagement in sensitive topics across different contexts.

CONCLUSION

The proposed Participatory Design in Sensitive Contexts framework responds to a gap in theory and how these are enacted through examples from practice on creating conditions to enable participation from people perceived as vulnerable on sensitive topics. The framework emphasises: lived experience as expertise; rights-based ethos foregrounding the political, ethical and social commitment of PD; asset-based design promoting individual and collective agency, voice and empowerment; and attuning participation with a focus on relationships, dynamics of engagement and wellbeing. Enabling genuine participation and outcomes towards personal, collective and social

transformations are central to the framework. We invite further dialogue with other design researchers and practitioners on what 'genuine participation' and 'transformative outcomes' mean in the practice of PD across diverse sensitive contexts. In applying and refining this framework in practice, we also highlight the need for adopting a situated, 'in the moment' and emergent approach attuned to the people, topic and outcomes in each context.

The Participatory Design in Sensitive Contexts framework draws on learnings and principles by reflecting on our PD practice. We acknowledge that while it represents shared learnings and experience across three diverse sensitive contexts, there may be additional considerations that emerge with other contexts and practices. There is a need to develop a critical positioning of the proposed framework within wider literature in design research and PD practice in the future. Further contributions from the design research and practitioner communities are required to critique the principles within the proposed framework, and share additional principles and examples of translating these in practice, to enable systematic development of a shared future framework.

DISCLOSURE STATEMENT

No potential conflict of interest was reported by the authors.

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