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What began as a pragmatic honour's year project towards death, dying and beyond, became a source of constant curiosity and is now part of his PhD research in collaboration with Marie Curie Hospice Liverpool; exploring how, why and should technology and artificial Intelligence play a role in the future of hospice care. And what many forms those technologies could take to strive towards a 'good death' in the modern age. Andrew's PhD is funded by Doctoral Network in AI for Future Digital Health.

Influences in Eliciting Authentic Answers in Design Inquiry and Imagination: through the lens of participatory design workshops

Andrew Tibbles

Abstract

Observations from participatory design workshops have resulted in a personal scepticism on the authenticity of participant contributions. This may be due to a participant being unable to express their lived experience or simply they have not examined them critically before the workshop. Secondly, the social desirability bias present within a group dynamic is prevalent in these workshops, described from the perspective of the facilitator and participant. Participatory design workshops have unconscious values present in their tools which may need to be consciously chosen to obtain authentic contributions at the risk of biased results. Group dynamics in participatory workshops may be used to reinforce dominant narratives, or as a way to evidence and challenge them.

Keyword

Participatory Design Workshops, Authenticity, Rigour.

Introduction

Participatory Design and its branches such as the many forms of co-design are becoming increasingly popular in and outside of the field of design for their ethical underpinnings of involving those who are being designed for in the process. This is especially relevant for those who are socially marginalised where a non-marginalised designer simply would not know the barriers they

face in life. So, it cannot be enough to simply involve a person in participatory design; they must also be, to the best extent we can, understood. To begin to understand another's experiences we cannot perform simple tokenism in participatory design, there must be a level of depth to the engagement which allows participants to give reliable and authentic contributions.

As design shifts to tackling more societal level and complex systemic problems with participatory methods, it requires a broad representation of stakeholders and interdisciplinary teams to design and coordinate together. How much does a designer influence reflective practice through the tools of their craft and how authentic can contributions be in a group setting with those who hold a position of power to change systems? This does not necessarily refer to the people in a position of power overriding or not listening and engaging with the stakeholders, but it is true that those able to make change may not feel free to express their insights in case there is a loss of trust from those they wish to help. For instance, a healthcare professional may not suggest, in a group setting with stakeholders, that some patients' lives were not worth continuing because of the quality of life they are likely to have after a specific life-saving treatment, despite their experiences.

Can participatory design elicit authentic answers?

This article is not intended to be an authoritative answer to this question but a discussion of the methods of participatory design with these points in mind. These have come from professional experience of using various methods to answer difficult and intimate questions that may well be answered in another discipline, but I have yet to find it for the field of design.

What is participatory design?

As a quick definition, participatory design methodology sees knowledge-making as occurring through the interaction among designers and stakeholders, practices, and artefacts (Spinuzzi, 2005). Many participatory tools and techniques are now available to design researchers to apply to different contexts and populations (Sanders et al., 2010).

What do we mean by authentic answers?

Getting to know the unknown

In this case, authentic answers are when participants of research or design express the genuine reality or desire of an experience. Why doesn't this happen? Sometimes the person may not have the ability to express themselves fully or articulately, a strong potential with any form of language. Other times, the question is asking about experiences and emotions they themselves do not know because they may not have the capacity to understand and articulate the experience or ever given time to examine it. This is what Marc Steen quoting John Dewy describes as primary experiences of "gross, macroscopic, crude subject-matters'' (i.e., experiences that come "as the result of a minimum of incidental reflection") which then can be developed through reflective practices resulting in secondary experiences of "refined, derived objects of reflection" (i.e., experiences "in consequence of continued and regulated reflective inquiry." (Steen, 2013)

Participatory design can be considered a reflective practice of inquiry and imagination. However, the process is not without influence. Designers understand that designed elements such as graphics, objects, interactions and environments hold perceived

values and affordances both in their materials and culturally. Participatory design is a combination of communication methods between stakeholders to come to a joint decision. There is a minimal amount of materials required for this, most commonly a large blank canvas (e.g. a wall or A2 paper), a mark maker (e.g. marker pen or digitally a keyboard or pen pad), potentially smaller interchangeable elements (e.g. post-it notes) and a facilitator - this is so a collective thought process and the decision can be reached on a reasonable human scale. These materials used are not usually considered inherently valuable and are used with an iterative process towards valued understanding. However, I argue that with other materials with different affordances and values, you would receive a different thought process and therefore collective decision. For example, if the large canvas was a courthouse wall, our mark maker; chisels, and our smaller interchangeable elements; wood blocks. This is an extreme scenario but enough to illustrate my point that designed elements may influence research outcomes.

An element emitted from the example that may be able to both mediate or exacerbate some of these tensions is the facilitator. In a workshop, a facilitator aims to be neutral in their approach, so as not to influence decision-making in a particular direction, but they are not infallible. However, in a personal account of myself facilitating an art performance piece guiding participants to answer an uncomfortable and intimate question, I remain neutral in my question and tone but my environment and myself are used as tools of influence.

A personal account of getting to know the unknown

This topic of discovering authentic answers goes back to my undergraduate studies. My final year project was The Aquatic

Grave, an underwater burial system in the waters surrounding the islands of Scotland. This project was conceived for ecological reasons and to make sound design decisions, I had to talk to a lot of experts outside of my field. From anthropology to marine biology, contributed to the final grave outcome which is deceptively simple, low-grade steel boxes with some small holes cut in the bottom and top.

As a form of thank you for helping me, I proposed that I put their names on the graves. I know what you're thinking, "Wow! What an amazing thank you!" but hold your applause. As part of the service, I had designed a way that visitors could go to the grave in a small boat and listen to what the dearly departed had to say, this required the dearly undeparted to reflect on what they'd like visitors to their grave to hear and I had to record it. The interaction of me recording what they'd want people to hear when they had passed was, to me, fascinating.

I remember those who were already comfortable with public speaking were easily able to address the world with who they were and their advice or philosophy, others simply couldn't talk about how they were feeling in front of me but became overwhelmed in private without guidance. I distinctly remember a lecturer at the time, it was just me and him in the department office, and his voice note addressed his children and wife. It was profoundly personal, spoken with beautiful eloquence while tears formed in his eyes. I don't know if this was something he had thought about beforehand or wrote this speech out, but it was moving.

I experimented sparsely for a number of years for ways to capture the clarity and intimacy he was able to summon, seemingly at the

drop of a hat, and to eventually guide others through knowing the unknown.

My first failed attempt was during a death cafe, these are open forums where people can comfortably and confidently speak about death and dying. It isn't typical to have themes or the facilitator to bring a task, but I thought it was a good opportunity to experiment. I asked the group the same question, what would you like people to hear after you die? I rolled out a large piece of paper and gave out pens. This resulted in tense joke-making and people creating quips and one-liners to diffuse the unease and to gain a chuckle. Surface-level responses that I don't believe given a chance they would honestly want loved ones to hear, but this is also my bias creeping in. Famously, the comedian Spike Milligan's grave has an Irish saying on it "Duirt mé leat go raibh mé breoite" translating to English as "I told you I was ill", so perhaps a zinger would be enough, but I wanted to search for more nourishing responses.

My second failed attempt was while I was working for a creative office working space and so had access to willing victims. I decided to try one-on-one style in a private space. The place still had some rubble on the floor, a cold fluorescent tube light and the sound of a flushing toilet from the floor above was very pronounced in the pipes. I scraped a table in from anywhere I could find one along with some uncomfortable wooden chairs. I situated myself and interacted with the person differently each time, sitting in silence and keeping comfortable eye contact, leaving the room after pressing record, and being conversational, but there was a marked difference when I balanced all three. I set up a screen between me and the person. I asked simple guiding questions, being more formal than conversational. They knew I was there but they couldn't see me so they wouldn't look to me

for reassurance or try to read my body language. The first screen was just a sheet of ply I found. The person I was interviewing said they'd like to be able to see some part of me so they didn't feel like I had left the room. So I made a 'confession' style screen. Cutting a pattern into the wood that would let the person know I was there, but they were not able to see my face or read my expression.

I had a vision of what I wanted to do next with it but did not find the time or resources to realise it. A few years later, an opportunity arose to further the experiment but as an artist performance piece this time. The environment was an old semi-circle operating theatre in Edinburgh with high ceilings and rows of stepped bench seating. The set-up was a tall white sheet of fabric that, at a guess would say reached the ceiling at four metres high, spotlights pointed onto the sheet, and I lit tea lights around the room with incense. I would sit on the side of the sheet with the straight wall to my back, and my participants would sit in the open circle. The chairs were wood with a deep red leather cushion, the reality of the situation was that if it weren't for the sheet between us, we would be sitting uncomfortably close to each other (Figure 1). To play my performance, I shaved my head, went barefoot and donned a black robe, leaning into the idea of the religious authority figure of the confession booth (Figure 2).
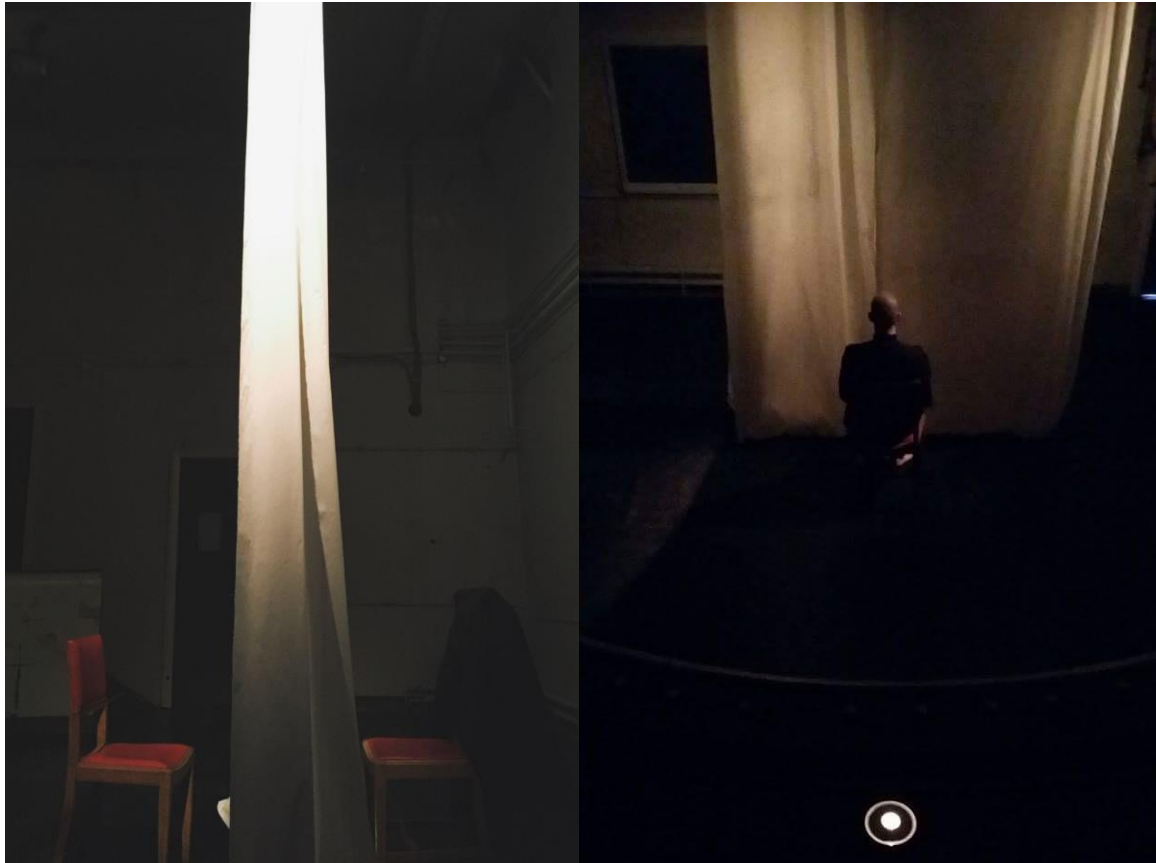
Figure 1. (left) Im'mortal art piece performance set up.
Figure 2. (right) me in situation and in costume.

Rather than my opening question being, "What would you like to be heard after you've died?" I asked if they wanted to be immortal, and most answered no, and then I would respond that at some point they did in fact wish to die, which, granted, is an odd logic or at least an odd way to put it. I continued to ask; how would they imagine their death, if they believed in an afterlife, if they could create their own afterlife what would it be, if not, I asked when they last felt serene and we would use this memory, from the afterlife they had received an opportunity to speak to those who remained, who did they see and what would they want to say to them. Remaining silent for a little longer than I would usually be comfortable with and them not being able to see this, I believe allowed for turning points and a deeper analysis of their own emotions and thoughts. The answers were surprising, they would often be analytical reflection and introspection, while as we

moved through the questions, they were more fluid and almost instinctual, surprising the participant themselves by how confident they felt about their answer. I know people felt deeply about the performance piece as many did cry and thank me afterwards - sometimes with a strong hug. But can I say that these were particularly authentic answers or did I provoke an emotional response by influencing their reflective practice? Although in this case, we were not designing a thing through a method of participatory design, we were crafting a sentiment together through reflective practice and the findings and experiences apply to participatory design practice and tools.

Hiding the known for the desired

Participatory design is conducted with the belief that contexts and situations can be improved with communication and collaboration with stakeholders. This assumes that people will naturally give forth honest information through inquiry, however, participants may know how they feel but wish not to express it due to how they may be perceived by others, this is described as social desirability bias, which I've found is not a common consideration for design research. In Nicole Bergen and Ronald Labonté's paper "Everything Is Perfect, and We Have No Problems": Detecting and Limiting Social Desirability Bias in Qualitative Research, their introduction states several situations where social desirability bias appears and the problems that arise from it. These situations can all be something present within a participatory design workshop such as; in sensitive or controversial topics, situations where there are widely accepted attitudes, behaviours, or norms, and individual characteristics such as social (and I will add organisational) position, gender, and personality traits (Bergen &

Labonté, 2020). This can lead to research concluding a false conclusion and reinforcing dominant narratives.

A personal account of hiding the known for the desired

I have already mentioned these experiences as my first failed experiment, and it was certainly present in other experiments I did. The first failed experiment was the group of participants who did not wish to engage in reflective practice and to be vulnerable in front of strangers, and opted for a group-pleasing answer. This is a textbook example, which I understand the desire to do as a confessed people pleaser. Secondly, as an interviewer, my participants would look to me for reassurance that this is what I was looking for from them hence when I went behind a screen and became present unseen, participants would open up or allow a pause for further thought to develop. In these instances, participants were trying to appease me while I was questioning them.

I have been a facilitator of group workshops for several years, mostly these have been educational, but there have been many participatory design workshops, in which I have played both roles of facilitator and participant. There's no one fluid account or story from which to draw here, but a series of incidents in different locations, under different settings, and aiming for different outcomes.

As a facilitator

My most recent ventures have been examining future hospice care and the role of technology, typically robots, within them. I find this bias much more difficult to spot because the answers themselves feel genuine. There has been a common theme throughout my recent workshops where I have been asking

groups of stakeholders to imagine desirable features of hospice care with three users and how technology can support each of their needs; the patient, the family, and the staff.

Increasingly, healthcare services are becoming, if not already, patient-centred in their service approach. Hospice models may also subscribe and say that they base their practice on this thinking, but through my personal experience of being in a hospice studying the system, it goes beyond patient-centred care. Hospice care systematically assesses and cares for the state of those close to the patient, sometimes also the patient's carer, and their health physically and mentally. Two of the three users mentioned are in practice accounted for and are two different but linked centres of care. It's when we came to the point in the workshops when we asked what the staff found desirable and how they would like to be supported in future that the bias potentially crept in.

Hospice staff work hard for what is increasingly unsatisfactory pay. It is a difficult job physically and emotionally, and you need genuine compassion for human beings to be able to perform it. From passing comments and interviews, the majority of medical staff prefer hospice work to hospital work because you are granted the opportunity to care for the person, the human, and not simply the body. This is something that they find desirable in their work. Consistently throughout the workshops, however, a familiar dominant narrative appeared; that the technological interventions they imagined would simply replace them, which was bizarre considering up until this workshop this was a huge fear for both the staff and the patients that they would lose human connection, which was considered vital and highly desired for their work. In our participatory workshop, they imagined they

were workers and they were here to do a job not to be fulfilled or have their desires met.

Perhaps by wishing to be seen as caring, potentially selfless or professionally patient-centred, they omitted how they felt they fulfilled the role and how they could be supported. It is worth noting that there was not one level of organisational hierarchy in the workshop, so when imagining themselves in the situation, they didn't want to bring up anything that sounded like a complaint or criticism to the managerial level. This is of course all speculative and I can only assume why during the workshops, staff wrote themselves out of a desirable future for hospice care.

As a participant

Because of my professional background and my personality type, when I have been involved as a participant in participatory design workshops, I've had to be very conscious of not becoming a defacto facilitator. As I empathise with the goals of the researcher, I know how I would like participants to be involved in a workshop and dead-stare-silence is excruciating, but as I've tried to break the silence by asking others questions, input, or pitch ideas to help get things rolling, my contributions sometimes end up being the majority of it. Other participants were quite happy to relinquish their input to someone with seemingly more enthusiasm. The conundrum also lies on the other side of this line - by keeping quiet and sitting in the uncomfortable silence waiting for someone else to take the lead, I hide input or disengage from a potentially valuable reflective practice for others. In both these cases as a participant, group dynamics can quickly form and the potential for groupthink grows.

In defence of participatory design from my experiences, these have been short or day workshops and not recurring participatory

design development over weeks or months. Which over a lengthier period may allow for participants to open up, reflect further and respond more authentically. During a longer period, using participatory design problems and solutions can co-evolve, simultaneously being explored, developed and evaluated in an iterative process.

Conclusion

Summarising the above and two questions to consider about the rigour of design knowledge building in the area of participatory design.

Design values present in the creative tools and environments that participatory design uses, along with the presence of a facilitator, have an impact on the reflective practices of individuals. However, do we aim to minimise these for authentic answers to emerge on their own, if they can, or do we create practices and tools with values embedded that may encourage and guide participants towards authentic answers and risk bias results?

The group setting of participatory design can be a hindrance, at least for short-term interventions, as group dynamics if not already present, form quickly and there is no time to undo or reflect further on those dominant narratives. So, are short-term participatory workshops as a form of design inquiry or imagination reinforcing potentially harmful narratives or a way to identify and challenge?

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