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Invisible Impact: Revaluing data in design research

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Abstract: Design research as a way of understanding and responding to the world around us has grown significantly over the last decade, particularly in the domain of health. Design can offer a deep interrogation of the complexity experienced by stakeholders in a given health context, engaging in an empathic and creative way to capture lived experience as data that can inform, influence and engender meaningful change. Ordinarily, this data is valued in its contribution towards the intended study aims and is traditionally realised in project reports, academic publications, and lay-person summaries. However, this paper argues that value should be reconsidered to take account of invisible impacts, the unintended outcomes that emerge as a result of engaging and conducting a study. This paper suggests that the underpinning values of participatory design, those of empowerment and valuing lived experience create an opportunity to realise participant contributions and research data in an alternative way.

Keywords: value; participation; engagement; design research

1. Introduction

Design research as an epistemological, ontological and methodological way of understanding and responding to the world around us has grown significantly over the last decade.

Recognising the possibilities afforded by creative stakeholder engagement, for example through framing intangible and complex problem spaces and with an increasing focus on circularity, future sustainability and positive social and political impact; design research is now adopted, applied and diffused across more disciplines than ever before.

Design research is frequently aligned to the design process, foregrounding critical stages of research enquiry: define, engage, ideate, prototype, test, communicate. Such an approach can enable a deep interrogation of the complexity experienced by stakeholders in a given context, engaging with them in an empathic way to capture valuable data that can, in turn, inform meaningful change. Contrary to traditional notions of the lone designer as the problem-solver working to produce an outcome in isolation, design research is instead positioned as an enabler, an approach that can support the co-creation of a solution. Akin

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to the epistemological underpinnings of the social sciences, the value of design research is in understanding, and the inclusion of the lived experiences of stakeholders (Koskinen, 2016; Manzini, 2015). The participatory nature of design in this way can result in the collation of rich data sets of lived experience captured through creative endeavour.

It is acknowledged across the literature that research must move beyond the advancement of academic disciplines to be more accessible and impactful across social, political and civic life and as such, new ways of exploring and disseminating data are required. From a design research perspective, taking into account the intrinsic and inherent role of stakeholder engagement as a core element, real-world impact can be seen as a deeper understanding of the needs and desires of publics; as a route to engaged and informed communities; and towards the co-creation and scaffolding of meaningful change.

Across disciplines, research outputs are traditionally articulated in a body of written text. Framed around a well-established research approach, the output traditionally articulates a problem; describes the chosen methodology; presents data collected; offers a discussion of insights, and concludes with an applied meaning generated through analysis of the insights. In recent years, the demand for research that moves beyond the advancement of academic disciplines towards accessible impact has encouraged alternative means of dissemination (Collie *et al.*, 2014; Robson and McCartan, 2016). Despite this, participant-generated data is still predominantly valued in its contribution towards the intended study aims, recognised for providing essential insights and supporting research activity. The output is traditionally realised in project reports, academic publications, and lay-person summaries.

Despite a growing awareness of the potential impact of research more broadly and growth in non-traditional research outputs, dissemination is yet predominantly limited to the final reporting of research activity. There appears to be a scarcity of situations in which research findings are explored and shared in new ways, suggesting a potential space for innovation and impact. In design research, the capture of lived experience as data is core. However, the experiences captured are often limited to informing the research activity itself. Little thought is given to additional ways of re-exploring the data captured to create added value.

One domain within which design research is active, both across scholarly endeavour and in practice is health. Inclusive of medicine, care and wellbeing, design research in health offers a deep interrogation of the complexity experienced by multiple stakeholders in a given context, engaging in an empathic and creative way to capture lived experience as data that can inform, influence and engender meaningful change. However, this paper argues that the value *for* design research participants and the value *of* research data should be reconsidered to take account of invisible impacts, the unintended outcomes that emerge as a result of engaging in a study. This paper suggests that the underpinning values of participatory design, those of empowerment and valuing lived experience create an opportunity to realise participant contributions in an alternative way.

Drawing on a design research project as a case-study example, this paper discusses found poetry as an approach to recognising and articulating value in design research data beyond

traditional means. The poetic narratives of eleven people who experience chronic pain are presented, highlighting the potential of both reimagining data and extending the empowerment of research participants. The emerging value is realised in articulating notions of self; increased visibility within a community; and a broader attempt to influence and inform socio-political impacts through dissemination.

2. Case Study: The Language of Pain

2.1 Project Introduction

Chronic pain is a common, complex and challenging condition, generally accepted as pain lasting longer than three months. While recognised as a condition in its own right, it is also an umbrella term for severe pain occurring from a multitude of clinical conditions (Hepburn and Jaatun, 2018). The societal burden of chronic pain is significant, underpinned by the recognition that management focuses on promoting rehabilitation and maximising quality of life rather than achieving a cure (Mills *et al.*, 2016). As such, innovative approaches to managing chronic pain over the longer term are required.

The Language of Pain was a design research project led by The Digital Health and Care Institute that aimed to explore the potential of a digital intervention to improve the relationship between health professionals and people experiencing chronic pain. Through the translation and interpretation of interactions, it was proposed that an intervention could potentially create new learning opportunities resulting in more effective, efficient and meaningful experience for all involved.

From the beginning, the Language of Pain project acknowledged that the ways pain can be described, interpreted, understood and translated vary considerably, compounded by the contrasting literacies of medical practitioners, people experiencing chronic pain and the broader network of health professionals engaged in care delivery (Hepburn and Jaatun, 2018). To understand the complexity of the context in-depth, the project adopted a design research approach and facilitated series of participatory design workshops and in-depth interviews to capture the lived experiences of those involved.

The role of design in delivering an evidence-based and experience-based co-design approach for health has grown exponentially (Robert *et al.*, 2015), and design has a recognised role in shaping future services as well as informing new ways of thinking around health, care and wellbeing. Articulated in approaches including experience-based co-design; co-creation, co-production and co-design; the essence of participatory design for health and care is in the embodied agency that enables and values participant's engagement, underpinned by ethical principles of participation and consent; minimising harm; beneficence; and power (Kelly, 2018). Positioning design as more than just the generation of new ideas, this approach reinforces the potential value in representing invisible or under-represented voices; in engaging multiple, often disparate communities; and in communicating and translating complex contexts.

2.2 Found Poetry

The text-based data collated during qualitative enquiry is traditionally considered and coded thematically, with the application of analytical frameworks and theoretical lenses based on an underpinning disciplinary or epistemological paradigm. This involves the dissection of text to generate and apply meaning across nodes or thematic groups. This approach contributes to the creation of rich insights, informing research activity and addressing the intended outcomes of the enquiry. However, when considering emotive data sets, for example, transcripts of lived experience, such approaches often fail to capture the personal narrative or essence of a story in its entirety. Found poetry offers an additional way of interrogating data (in addition to the thematic analysis), in repurposing text to create a poem that captures the essence, or core value.

Scholars have used found poetry to represent the data gathered from participants in several ways (Faulkner, 2016; Bhattacharya, 2013; Cahnmann-Taylor, 2009; Prendergast, 2006; Ellis & Berger, 2003; Richardson, 2003; Glesne, 1997). Reflecting upon the social impact of poetry, Reilly *et al.* (2018) recognise the value in exploring relatable experiences, that represent what it means to be human, and that allows the reader to empathise in a deeply connected way. As an alternative framing of daily life, found poetry can provide space to share participant's lived experiences beyond the traditional 'static data-driven text' of research (Burdick, 2011, p3), and offers an alternative route to wider engagement and dissemination beyond the outcome of the wider research study.

2.3 Found Poetry and Chronic Pain

Chronic pain is a condition that attracts considerable public attention. Much of the debate is centred what constitutes, and is experienced under the term chronic pain and recognises that as an often invisible or 'hidden' condition, much of what is experienced is not visible externally, creating additional challenges for people trying to manage day-to-day. For participants, found poetry can offer an alternative outlet for their voices, valuing them in a way that moves beyond the aims of the initial study. In this way, found poetry of lived experience can offer an articulation of truth in a given moment in time.

Denzin (2014) also reflects on the potential impact of found poetry, describing it as a driver of change, engaging audiences with the aim of challenge and altering existing perceptions. In addition to the personal challenges associated with a long-term condition, people experiencing chronic pain must also negotiate a range of societal, political and work-related issues, constantly repeating their narrative to address the different facades of power. Responding to this, the potential impact of emotive narratives in raising awareness and framing political activism is acknowledged (Faulkner, 2018) and could offer a new way of addressing the socio-economic challenges faced.

The role of the researcher is critical in the crafting of the poetry, in rigorously re-reading paragraphs of text and curating that which both captures and represents the narrative but also aligns to the style and format of poetry selected. As such, the subjectivity of

the researcher is entirely embedded in the work. Some scholars have questioned the validity of such poetic works, questioning their structural content and whether they can be truly understood as poetry (Cahnmann, 2003; Piirto, 2009). However, drawing upon the interpretive approach to qualitative research (Lincoln and Guba, 1985); the goal is not to create high-quality poetry, but rather to enable a new way of exploring and understanding data gathered and representing participant voices in a new way.

3. Methodology

This study adopted a qualitative and phenomenological approach, recognising the ability of design to support the gathering of lived experience to better understand complex contexts. People living with chronic pain were invited to participate in one of five small design workshops that took place across three geographic locations in Scotland. Respondents were recruited via posters placed in doctor surgeries, via social media adverts and through a peer-support group for chronic pain. These workshops, similar to a focus-group approach aimed to explore of the language used to describe pain; to identify challenges and opportunities existing within current chronic pain management experiences, and to identify any knowledge gaps and potential of learning opportunities for people living with chronic pain. Each workshop lasted approximately three hours, and respondents took part in a series of making activities, including developing a visual representation of their lived experience in the form of a cartouche (Hepburn, 2019).

The workshops were audio-recorded with informed consent and transcribed, resulting in over twelve hours of content. The verbatim transcripts were read and re-read by the researcher to encourage a deep familiarity with the texts. Using Nvivo as coding software, sections of the transcript were identified, highlighted and coded by each respondent. The qualitative data was interrogated to identify common themes emerging, and this contributed to the creation of traditional academic and project outputs as described earlier, disseminated in project reports and publication. However, an additional second iteration of coding was also undertaken. This analysis highlighted words and statements per respondent to identify key themes emerging in a similar way to the first, however, what was important in this analysis was that the highlighted text was recorded in an ordered way, with no changes to the sequencing. This approach was deemed to be most representative of the narrative flow and intended meaning conveyed by the respondents.

"I've done it more to describe the way I am now as opposed to the way I was before. I do think I'm very strong, a lot stronger than I was before. That strength is coming from a desire to live as good a life as I can, and I find joy in little things whereas before, that was all lost. I went through two years of absolute hell and for that reason, I do... it took me a long time to give myself credit for being a bit of a warrior because I am a bit of a warrior. People don't realise it is actually the roll of the dice. I thought I was healthy, never had health issues, and what keeps me going is the love I have for my family and I'm looking for that key to unlock or reset my health again, just something to restart it." (Participant 1)

Figure 1 Example analysis from the transcript – Participant 1

The highlighted text from each transcript was then curated into stanzas of between two and five lines. Another reading of the curated text was undertaken alongside the transcript to ensure that the poetic narrative was representative of the essence and could be described as a true interpretation of the underpinning dialogue captured. The outcome is then presented as a piece of curated found poetry, seen in Figure 2, with the researcher allocating a title that draws on the content expressed.

As with the analysis of visual research, the synthesis of the text required an aesthetic and empathic approach. To this end, the author reflected upon the experience of engaging with the respondents during the workshop to ensure that the narratives retold the lived experience in a way that captured, and could convey to the reader the emotions involved, the feelings and thoughts of respondents. Richardson (1993, 2002) refers to this in more detail and discusses the role of ethnographic poetry in making the lived experience accessible to others, and this provided the underpinning rationale for the creation of these ten poetic narratives.

A total of eleven poetic narratives were created using this methodology. The narratives were collated into an anthology, and this artefact was shared with participants both digitally and in printed form. A focus group session was held as a follow-up event four weeks later, where participants were invited to discuss the narratives created with the researcher. The discussion was audio-recorded, transcribed and emerging themes related to value were highlighted. These are discussed further in section 6.

KEY

I'm very strong.
Stronger than I was before.

That strength
is coming from a desire
to live as good a life
as I can.

I find joy in little things
Whereas before
that was all lost.

Years of absolute hell.
A long time.

I am a bit of a warrior.
People don't realise
it is actually
the roll of the dice.

I was healthy
never had health issues.

What keeps me going
is the love
for my family.

I'm looking for that key
to unlock
reset
my health
to restart it.

A lot of people see
weakness.
It's not weakness.

I don't go out screaming
Ranting
Raving.
They see it
as weakness.

You feel it's something you've done
that's brought it on.
I don't know.

Figure 2 Example poetic narrative generated from the analysis

4. Poetic Narratives

Three of the final poetic narratives are now presented in figures 3 as an example of the content provided in the anthology. The final artefact framed the narratives with a summary of the research study, and each participant had one poetic narrative featured in the anthology. The narratives were anonymous to protect participant confidentiality.

HUMAN

The second I was born
I had these different problems.
They didn't care.
I wasn't a human.

That's how they act.
I did have a lot of problems.

All of a sudden
like a ton of bricks.
Every day became a battle
It just leaves you exhausted.

In that limbo
It's like your stuck.
There's no balance.
One day you can be fine
The next day you just can't do anything.

DICE

I used to be a warrior.
Living life with plenty strength.
Life was rosy
I was flying high.

Now I feel like a fish
In a big pond.
So many different emotions
Angry.
Sad.
Frustrated.

Every morning
you get up.
The roll of the dice
Locked in a cycle.

Night time is my worst
Pain.
Ice cold.
I just want to take off somewhere.

Emotional.
Realising your feelings.
Frustration
Every day.

SUDDEN

A human
Working away
Doing things.

All of a sudden
Wham bam
Downhill.

Touching
When you're really sore.
You just back off.
You just don't touch it.
Makes you cry.

There's days
You just burst out.
You can't help it.
You get angry.

But
You've got somebody.
Looking down on you
All the time.
Somebody's watching you.

There is actually love there
That helps.

Figure 3 Poetic Narratives

5. Findings & Discussion

Four weeks after the anthology was distributed to participants, a final focus group session was held. The session aimed to feedback the findings from the study overall as well as creating an opportunity for participants to reflect upon and respond to both the experience of participating in the design research project and the poetic narratives created. The subsequent discussion of the poetic narratives identified several emerging themes concerning notions of value, and these are now discussed.

5.1 From invisible to visible

The main finding emerging from the discussion was a revaluing of self and increased awareness of the individual contribution made to the research study. Participants initially

discussed chronic pain as a hidden condition, one that does not always display physical symptoms: *"I look ok on the outside, it's hard because people just don't understand how hard it is to look normal, how much pain I'm in"* (participant 4). This sense of "feeling invisible" (participant 2) resonated across all participants and was accompanied by associated emotional responses described as *"frustration"* (participant 1); feeling *"sad and alone"* (participant 5); *"ignored"* (participant 10); and *"...a burden on society, like I don't have anything of value left to contribute"* (participant 7).

Participants also described the challenges inherent with describing and constantly recounting their chronic pain narrative or health story. In the first instance, this referred to having to repeat what one participant described as *"the story of my chronic pain"* (participant 4) each time they visited a health professional. Another participant described the same challenge but from a social and community perspective: *"I think people forget that I'm in pain, they are so busy with their own lives that they expect me to keep up. I feel guilty having to remind them that I'm not able"* (participant 11).

Reflecting upon the poetic narratives, participants discussed how the repurposing of their data in this way offered a new perspective on their lived experience: *"It's like I'm reading about myself from a distance, I actually feel really proud that I'm living this life and doing so well"* (participant 3) and *"Are those my actual words? It's amazing, it sounds so strong...I sound so strong"* (participant 9). This appreciation of the words they had shared as part of the project (the lived experience captured as research data) represented a notion of "voice" (participant 3) and appeared to support participants to revalue the perceived contribution made to the wider study: *"I knew I talked away for ages, I just didn't think it would be useful, you know"* (participant 1), a sense of self-value that might otherwise have gone unacknowledged.

5.2 A tangible asset

In addition to the value generated through the realisation of the contribution made to the research, participants also discussed the collated anthology of poetic narratives and described it as a tangible asset that served as an important artefact.

Building upon the invisibility as described earlier, participants also referred to the physical artefacts associated with chronic pain: *"I've got walking sticks, and a chair for, when, sometimes for when I'm tired...and a stairlift, slings and bandages, you name it, like a walking pharmacy"* (participant 10) and *"...a disabled parking badge and a disability car"* (participant 6). These artefacts were predominantly discussed negatively, as barriers rather than as aides: *"...I mean, I'd rather walk without the stick, so that people don't see me as disabled"* (participant 9).

In response to this, participants referred to the anthology as a *"something positive about my condition, to do with my pain"* (participant 11) and *"...a reminder, but a good reminder you know, one that I'm happy about"* (participant 1). This suggests an articulation of value that contradicts their usual experience of assets related to chronic pain. The anthology presents a

tangible and concrete articulation of their lived experience, framed in a way that the artefact becomes a positive physical part of their condition.

Additionally, participants also described the value of the tangible asset as a tool for sharing their experiences: *"...a way for me to explain what it's like to live like this"* (participant 3). Some participants described this as a feeling of empowerment: *"I've been showing it to everyone, anyone who'll look"* (participant 5) and

"Usually I don't like to talk about my pain. I feel like people are rolling their eyes, here she goes again, moaning about her life. But now I've got something that looks professional. It's my words but it looks real, authentic. I'm really proud" (participant 4).

From this perspective, the anthology of poetic narratives appears to provide participants with an asset that can represent their experiences in a new way. Furthermore, all participants described a sense of surprise that participating in a research study would generate something positive for them: *"I was really surprised, it was so unexpected"* (participant 2); *"...you know, you take part in these sorts of things for the greater good, not thinking that anything will come of it. I was surprised"* (participant 9); and *"I didn't think I'd get anything, apart from a cup of tea like. I was delighted"* (participant 8).

In this way, the response to the anthology as an output of the research activity and also as a representation of a positive physical artefact of the chronic pain experience suggests that value was created and realised by participants, in unexpected and surprising ways.

6. Discussion and Conclusions

Participatory design strives to empower participants, using creative methods to engage support conversations that draw on lived experiences to inform and influence change. Found poetry offers an interesting approach to extending that empowerment beyond the life of a research project, and beyond the stated project aims. By reimagining interview transcripts or other written texts that capture rich lived experiences, participant data can be explored to recognise and articulate value for those involved. The emerging narratives can be curated to extend the reach of participant voices, raising awareness amongst new audiences, and offering an emotive connection to stories that are often untold.

In this case, found poetry offered an opportunity to revisit and revalue the data collated, enabling a rich interpretation of lived experience in a way that would otherwise have been lost. In addition to the creation of a body of work that is representative of a given moment in time, the poetry also became a concrete, tangible and personalised artefact for participants and acts as a way of valuing, and articulating their contribution.

Two articulations of value are described in this paper. The first explores the importance of making the invisible visible, creating new ways to express and value personal lived experiences. The second explores poetic narratives as a tangible asset and considers how they can be revalued. By curating the lived experience of people with chronic pain through found poetry, it may be possible to create a new representation, awareness and appreciation

of what it means to experience human life in this way. The poems are an articulated truth, a revaluing of the contribution of participants and offer much to support the understanding of life within a complex society. To this end, they are just as important as the traditional research outputs, if not more.

7. Limitations and Future Work

This research offered a new form of interaction and created an opportunity to revalue the data captured through traditional methods. The value discussed in this paper relates to the experience of participants and as such, is based on the small sample size of participants engaged. Planned future work will include a follow-up with participants to review the findings and consider whether notions of value have been sustained. Additionally, there is a desire to explore the use of found poetry as a design research approach in more depth, and considering the extension of the value beyond participants.

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