# Healing Fabulations: A dialogic methodology for digital codesign in health research

Recent research has highlighted the importance of responding to trauma and promoting healing when working with participants in sensitive contexts. This article presents a new methodology for design research on health topics which combines principles from narrative medicine (health storytelling) with codesign. In this collaborative, dialogic approach, participatory action research cycles of storytelling are used to inform a process of digital codesign, positioning participants as peer researchers. The resulting prototypes (termed *healing fabulations*) are a new type of design artefact which captures each participant's lived experience while also extending it into a speculative future. Discussion of the methodology shows how the approach protects participant wellbeing during research on their health experiences, addresses common criticisms of digital design research, and explores the importance of visual metaphor and aesthetic in design for health. The article concludes with a discussion of the methodology's replicability and use in future research.

Keywords: dialogic; narrative; health; digital; speculative; fabulation

## 1 – Introduction

### *1.1 – Trauma and healing*

Tsing et al. have used the concept of *ghosts* as a way of describing how environmental landscapes are 'haunted by past ways of life' (2017, G2). Similarly, people may be haunted by their previous experiences. While we often think of trauma as being confined to a particular incident or series of incidents, it can also be the result of smaller 'hauntings' over a long period of time. Chronic health conditions, for example, have been shown to be a series of incremental events and losses which cause cumulative trauma on both the individuals they affect and their wider support networks (Penn 2001).

Recent work has attempted to define how designers can address trauma in research by incorporating principles of trauma-informed care (Hussain 2021), but it has been argued that designers should move beyond a passive position of empathising with participants into approaches which actively respond to participant trauma and promote healing (Dietkus 2022).

Hirsch (2020) observes that participants may experience psychotherapeutic effects from design research methods, e.g. mutual reflection during semi-structured interviews, particularly in the context of sensitive topics such as healthcare. This not only benefits participants, but also benefits researchers by strengthening trust and rapport. However, such outcomes are rarely intentional, and the same methods may also harm participants if sensitive topics are raised without consideration. Hirsch therefore argues that it is incumbent on researchers to recognise the possibility of these outcomes: both as a way of benefitting participants through healing and also mitigating against potential harm (ibid.).

Best practice in healthcare, particularly around trauma, advises healthcare professionals to adopt a *person-centred approach* which emphasises a stance of respect, working collaboratively with patients, and building treatment plans which understand patients as individuals with unique experiences and preferences (Elliott et al. 2005; Realistic Medicine 2020). While intended as guidance for healthcare professionals, this can also act as a guide for design researchers seeking to incorporate healing into their work.

### ***1.2 – Digital design in health***

Digital design approaches, particularly of the type used in Western, corporate fields, have commonly been criticised as overly technocratic and exclusionary towards marginalised groups. Rosner (2018) argues that the ‘dominant paradigm’ of digital design:

- Targets aggregated individuals, rather than supporting relationships or communities (*individualism*)
- Presents design concepts as objective, rather than acknowledging the situated viewpoints of designers and participants (*objectivism*)
- Imagines users' experiences as universal, rather than investigating differences in lived experiences and capabilities (*universalism*)
- Directs ideas towards predefined, usually technical solutions, rather than being open-ended (*solutionism*)

Such approaches also tend to prioritise the viewpoints of designers over those of intended users, creating a power imbalance between these groups (Steen 2011).

In recent years, there has been increasing criticism of poor design within digital health systems and its impact on health outcomes, and a call for more design-led, person-centred approaches (e.g. Morrison 2019; Marcial 2014). As a result, there has been a shift towards greater inclusivity and consideration of varying needs in design for health research, particularly through the use of participatory methods (Harrington 2020).

Because of the potentially sensitive nature of health topics, researchers must carefully consider participant wellbeing and adhere to best practice in health during participatory work (Mitchell and Irvine 2008). There is also still a question of how to represent the lived healthcare experiences of users within digital, participatory research. Commonly used tools from digital design such as *personas* may be inappropriate for use within a health context because they tend to rely on stereotypes (Portigal 2008), emphasise only positive outcomes (E. Meyer and Wachter-Boettcher 2016), and fail to capture the complexity of illness experiences (Jones 2013).

## 2 – Dialogic creation of digital fabulations

### *2.1 – Narrative medicine and storytelling*

Narrative medicine, a field that has emerged over the past 30 years, uses storytelling as a methodology for healthcare by encouraging healthcare professionals to examine their patient's health journeys using literary techniques (Charon 2006). This covers a wide variety of practices, including authoring of health stories, active listening to stories by healthcare professionals, and self-reflection by both patients and professionals (e.g. through journaling).

While the narrative approach is somewhat uncommon in Western medicine, it is a standard part of healing practices in many non-Western and indigenous cultures (Dennis and Minor 2019). In terms of theoretical stance, narrative research in healthcare often sits under the umbrella of phenomenology because of its focus on individual experience – for example, the work of Smith and Sparkes (2004), who have examined narrative themes in the health stories of men with sports injuries.

The process of storytelling is one of construction and selection (Ingold 2020), a framing which takes a more active view of the illness experience than the common cultural perception. A health condition, or health story, is usually portrayed as happening to a *passive* recipient. However, the process of constructing one's health story is an *active* experience. Making this process explicit recognises the amount of 'biographical work' (Corbin and Strauss 1985, 230) required in reconstructing one's identity in a constantly changing health landscape, as well as the personal need to share one's experiences with others (Frank 2013). Sharing health stories has been shown to improve personal wellbeing and mental health (M. J. Smith and Liehr 2014), and is an important way for individuals to assert their personhood after sometimes dehumanising health experiences (Hunsaker Hawkins 1999). Within the UK, there are multiple programmes focused on capturing and disseminating health stories (e.g. Hardy and Sumner 2020; Storytelling For Health 2 2019; Trowbridge 2018), both as a way of empowering people with long-term conditions and educating healthcare professionals.

Narrative methods are already common in design research (Quesenbery and Brooks 2010), being an excellent way of incorporating complex understandings and lived experience into codesign processes (Manzini 2015). The use of narrative *within* and *for* healthcare illustrates how design researchers can build on these approaches to both protect and improve on participant wellbeing when researching health topics.

### ***2.2 – Dialogic approach***

Narrative health research is both *relational* and *dialogic*, in that it is a process of eliciting and constructing stories with participants over a period of time, and allowing findings to be cocreated from these interactions (Finlay 2009). This process can also be deeply formative (Mattingly 2009), so designers should allow participants to lead during research engagements to reduce the potential for harm. Despret (2016) describes this mindset as *going visiting*: letting the other individual shape interactions and keeping oneself open to surprises.

Arthur Frank's (2012) concept of *dialogical narrative analysis* provides a useful guide on the principles which researchers should employ:

- The research is **non-finalisable** in that 'no one…ever has "the whole story"' (2012, 103)
- The researcher talks *with* participants, not *about* them

- The researcher and the participants have *mutual recognition*, i.e. an understanding that research exists within the wider context of people's lives

In this approach, participants are positioned as co-designers and peers. By returning power and control to participants we recognise:

> …[T]he vulnerabilities involved in telling personal and emotional stories, the demands that it makes of storytellers, and the dangers that the stories might not be heard in the ways intended. (Jupp 2022, 87)

This not only reinforces value and ownership for participants within the work, but also generates additional insight through mutual reflection (Murphy, Franz, and Schlaerth 2018), adds to the depth and rigour of the analysis (Pessoa et al. 2019) and strengthens the project's ethics and consent processes (Bustamante Duarte et al. 2021).

The designer's role is therefore *fraternalistic* (Thorpe and Gamman 2011), in that they work collaboratively and with equal agency alongside participants, unlike a *paternalistic* role, where the designer assumes sole responsibility for problem solving. This allows the designer to contribute from their own practice, while still acknowledging the participant's expertise derived from their lived experience of ill health (Liddy, Blazkho, and Mill 2014). The result is a collaborative process of codesign informed by a practice of care which '…does not exist within one particular person or object of the work, but appears in-between those involved' (Thompson 2015, 45).

Analysis is done in partnership with participants, and by looking holistically at a single narrative (Lieblich, Tuval-Mashiach, and Zilber 2011) rather than thematically across many at once – a process which preserves 'the meaning and the understanding of the whole picture and purpose of the story' (Simonds and Christopher 2013, 2187). Researchers may find this approach difficult to achieve when it is necessary to identify overall thematic findings. In this case, a layered approach can be adopted where successive iterations of holistic narrative analysis are done on a single story, followed by thematic analysis across all narratives to pull out overarching themes.

The resulting narratives are a cocreated representation of the holistic, lived experience of each participant. They also extend these stories speculatively into the future by demonstrating possible opportunities for digital tools to support their aspirations for improved healthcare experiences. In tune with Tsing et al.'s *ghosts*, the story landscape is haunted not only with remnants of the past but also imagined futures: 'As artists we conjure magical figures, weave speculative fictions, animate feral and partial connections.' (2017, G12). These prototypes can be seen as a type of *critical fabulation* (Rosner 2018), which uses storytelling to create hybrid realities (Manzini 2015). In this article, I have described these new artefacts as *healing fabulations*. The term "fabulations" is used to emphasise both the narrative and speculative nature of the artefacts, differentiating these from traditional digital prototypes.

### ***2.3 – Researcher reflexivity and self-care***

Relational, compassionate inquiry requires an ongoing commitment to reflexivity and self-care, which can be emotionally exhausting for researchers as well as participants. In doing the work to care for others, we must acknowledge the personal cost this entails and extend the same level of compassion to ourselves (Dietkus 2022). This aligns to the fraternalistic view of the researcher's role, in which they are a participant requiring protection and care. Self-care activities for researchers such as yoga, mindfulness, writing, or spending time with peers should therefore be formally incorporated into the research process (Kumar and Cavallaro 2018).

There is a danger of allowing our personal involvement, biases, and reflections to crowd out those of participants, or of overstepping the designer role and attempting to take on the role of healthcare professional. While researchers might (rightly) desire to benefit participants by incorporating healing practices into their work, this should not be confused with therapy as performed by a qualified professional.

As Tronto observes, this ‘requires honesty, and a non-idealized knowledge of selves and others’ (1993, 141). The process of contemplation and re-centring, ensures that we are always working from ‘where we are’ (Puig de la Bellacasa 2017, 87) and not attempting to overstep the limitations of our own knowledge, adopt the viewpoints of others, or allow our responses to overly colour the research (Jupp 2022).

At the same time, a large part of the insight from the relational approach comes from the transformation of the researcher through the research experience, and the way that knowledge and insights become personally embodied (Finlay 2014). This requires researchers to perform a balancing act which Despret beautifully describes as:

> …[T]he possibility of becoming…**with the other**, not in the sense of feeling what the other is thinking…but rather of receiving and creating the possibility to inscribe oneself in a relation of exchange and proximity… (2016, 17 emphasis mine)

## 3 – Case study

### *3.1 – Context of research*

The methodology proposed in this article was developed during a Master of Research project which sought to understand how digital tools could be designed to support people with multiple chronic health conditions (multimorbidity) in making sense of and conveying their health stories to others. As the focus of this article is on an exploration of the methodology, the health-related findings from the research have been omitted, but are accessible in previously published work (Cummings, Bradley, and Teal 2022).

Participants were recruited by distributing information to patient support groups for chronic illness, and inviting interested parties to get in touch with the researcher via a project website. The final participant group was made up of four women and one man, each of whom was diagnosed with multiple chronic health conditions. To preserve anonymity, participants have been referred to here by their chosen pseudonyms.

### *3.2 – Fieldwork and analysis*

Fieldwork was carried out in three cycles, each of which was comprised of desk research, a 1:1 direct engagement with the participant, analysis, and digital prototyping (Figure 1). The primary methods used with participants were reflexive interviewing (Pessoa et al. 2019) – an episodic interview format composed of multiple semi-structured interviews interspersed with periods of self-reflection – and individual codesign with participants (Sanders and Stappers 2008). At each stage, I used reflexive journaling (K. Meyer and Willis 2019) both as a form of self-care and as a way to assess my biases and reactions to the emergent findings.

FIGURE1

The cycles of work also incorporated an ongoing process of dynamic consent (Bustamante Duarte et al. 2021). Participants were taken through formal consent checkpoints at the start and midpoint of the project, and were also able to privately review, consent, and respond to the data collected from each engagement between sessions. This gave them opportunities to expand on what they had said, as well as giving their own interpretations of findings from the analysis.

Before the first workshop, each participant was asked to select an object which represented their health to them as a form of object elicitation, taking inspiration from material culture research such as Buse and Twigg’s (2016) study of the handbags of women with dementia. From their selection, I hoped to learn more about what participants perceived as important in their stories and what metaphors they used in representing them. Discussion of the object also served as a starting point for the interview on their health story. The resulting stories were individually analysed using narrative analysis which holistically examined the story’s content, structure, and themes (Lieblich, Tuval-Mashiach, and Zilber 2011). The results of the analysis were then further developed through desk research and used to create digital sketches loosely illustrating ideas for a potential prototype.

FIGURE2

The digital sketches were combined with images found during the desk research to create a *mood board* of prototype concepts (Figure 2) using Miro, a collaborative whiteboarding tool (https://www.miro.com), which we reviewed in the second workshop. After discussing the mood board with the participant, we did a structured brainstorming activity (Figure 3) which further developed their ideas on the prototype, e.g. what their goals were for a prototype, potential audience, etc.

FIGURE3

The main points from the brainstorming were used to direct a codesign session with the participant, using pre-prepared imagery designed to match their concept sketches (Figure 4).

FIGURE4

Following this workshop, the discussion with the participant was again analysed using narrative analysis to build a cumulative understanding of the individual participant's health story. This understanding, combined with the concepts generated during codesign, was used to create interactive digital prototypes (*fabulations*) for each participant (Figure 5) using Sketch Cloud (https://www.sketch.com/). Participants were invited to review their prototype in the final workshop, after which they were taken through a final interview to gather their feedback on and experience of the project.

FIGURE5

Thematic analysis was used at the end of the project to determine the overall themes and health-related findings across all of the participants' stories. Each participant was also mailed an individual booklet of their story as a keepsake (Figure 6). This contained a written copy of their health story from the first interview, along with images of their prototype.

FIGURE6

### *3.3 – Feedback on the methodology*

In the final interview, all of the participants agreed that their prototype accurately represented their story and was a tool that they would find useful in supporting their health management. Three of the five participants also emphasised how 'easy' they found participation in the project. This shows that the methodology was not only effective at supporting participants (both physically and emotionally), but also in meeting the project goals for designing health storytelling tools.

Participants discussed how emotionally transformative they found it to tell their story in the project, to be listened to, and to see it written down. For many of them, it was the first time they had ever had that experience.

> It’s difficult to think back now to the first meeting, which was the most intense one… trying to find a way to relate my story to you. But, I do remember at the time thinking…that...was a useful process to go through. It’s a long time since I’ve done that, if ever. (Sharon)

> ‘Seeing my story like that, …I thought, ‘Oooh, that’s actually about me.’ ..[W]hen you see it in black and white, you think, ‘Maybe I do have a story, it’s not just thoughts.’ (Rhona)

The dialogic process of codesign and mutual reflection elicited aspects of their story that participants themselves were previously unaware of, generating personal insight. For example, one participant noted that she hadn’t realised how important a particular activity was to her self-care until she saw how central it became during the codesign process. This cocreation also meant that the final prototype was representative of both our perspectives. Participants viewed the cocreation as an enjoyable creative process, saying that they could never have envisioned what we had designed, but they still felt it was reflective of themselves.

> I think you made it really easy... when we first met... just being able to share that story, to share that and get it out there. …[A]ctually seeing it when… it was in front of me, I was like, ‘Geez.’ There’s things there that you say but you don’t necessarily process it or think about it. …[Y]ou’ve been able to pull things out of conversations and then come back… And it’s so good because you’ve just took it from my mind… (Lee)

Participants felt that the ongoing process of review and consent also gave them a reassuring amount of control over the final outcome. However, the open-ended nature of the methodology also meant that the project was, to quote one participant, ‘a step into the unknown’. While none of the participants commented on this aspect negatively, it is a potential consideration for designers in future applications.

## 4 – Discussion

### *4.1 – Dialogic process, support, and healing*

The methodology proved to be very effective for eliciting discussion with participants on deeply emotional and traumatic lived experiences. Both participants and myself were frequently moved to tears during the telling of their health stories, and it is very doubtful whether the same emotional depth would have been achieved during a group session.

Participant feedback from the final interview showed that they found the overall process supportive and enjoyable. This is reflective of the literature, which shows that health storytelling promotes a sense of wellbeing (M. J. Smith and Liehr 2014; Chuang et al. 2018). The *going visiting* (Despret 2016) approach I adopted for eliciting their health stories also allowed participants to direct the storytelling process, giving them control over what they wanted to disclose. Future work could expand on this by offering further support for participants *between* engagements as well as *during* – for example, by emailing links to external self-care resources.

Additionally, the dialogic process proved crucial for developing an understanding of each participant’s story, while also allowing sufficient room for me to respond to changes that emerged over the course of the work. For example, when I showed one participant an upbeat concept based around socialising during a codesign session, her response showed that I had failed to take a more nuanced understanding of her story. We ended up creating a completely different design using an alternative analogy of ‘light and shadow’, resulting in a drastically different prototype than I had planned (Figure 7).

FIGURE7

The dialogic approach allowed participants to not only correct or expand on my analysis, but also have the time to reflect between sessions. The level to which they engaged in this varied. Some participants preferred to simply sign off on my analysis, whereas two of the participants got into the habit of sending lengthy emails after each session with further thoughts and ideas. This reflection process could be formalised in future work by sending participants optional follow-up prompts after each engagement.

Because the research started under COVID-19 lockdown, all of the participant engagement needed to be done remotely. This allowed participation of people who might otherwise have been prohibited due to their health (e.g. because of exhaustion, limited mobility, etc.) or scheduling restrictions. The dialogic process also allowed a strong rapport to develop despite the physical distance. However, the design of the engagements was limited to what was possible to do with participants online within the constraints of both the engagement tools and their own technical ability. Future work could investigate this further through the use of mixed approaches which combine remote and in-person engagements.

### *4.2 – Addressing criticism of digital design*

The methodology addresses the earlier criticisms of digital design posed by Rosner (2018). Firstly, while best practice from healthcare does dictate a focus on individuals (e.g. as in the *person-centred approach*), the understanding of each person’s wider life context derived from their story incorporates their relationships and goals for sharing their stories within the digital designs (challenging *individualism*). Secondly, the emphasis on lived experience treats participants’ stories as a collection of situated viewpoints and acknowledges the designer’s role within the work (challenging *objectivism*). Thirdly, not attempting to generalise or flatten participants’ stories into a single narrative gives room for the research to explore uneven and differing experiences (challenging *universalism*). Finally, by ‘working with others where they are’ (Barcham 2021, 9), we leave the approach open-ended and unconstrained by any particular solution (challenging *solutionism*).

### *4.3 – Healing fabulations as design knowledge*

The fabulations are unusual for digital prototypes, in that they are highly personalised to each participant and preserve their individual story all the way through to the final design. A more usual approach in a prototyping process would be to develop a generalised narrative which combines the lived experiences of multiple participants (IDEO 2015) – for example, as with *personas* (Portigal 2008). Preserving the individual stories gives a richer viewpoint that captures their complexity, and the individual concerns and goals expressed by each participant. This can be characterised as a digital version of ‘truth to materials’ (Barassi and Copper 2015), in which the raw material (lived experience) is both visible *in* and dictates the form *of* the final artistic expression.

The speculative nature of these fabulations also illustrates one of the most powerful aspects of storytelling: its ability to not only inform us about the past, but to help articulate and advocate for a different future (Cronon 1992). After the project ended, one participant contacted me to let me know that she had shared the booklet containing her health story and images of her prototyped fabulation with her family, and that it had changed the way they supported her:

> Something kind of clicked with my mum and I've heard her speaking with people and explaining how my conditions affect me and why I take my medication instead of questioning it. That is a massive thing so thank you for giving me this opportunity. (Lee)

Speculative tools are commonly used in design work as a way of advocating for social change (Manzini 2015), and the feedback from the above participant demonstrates that the methodology proposed here may be effective for this purpose. Some similarities can be seen between our approach and Candy and Kornet's (2019) Ethnographic Experimental Futures (EXF). Both use looping workflows to generate speculative artefacts. However, their focus is primarily on future scenarios, rather than personal narratives. They also take the approach one step further in 'mounting' the artefacts to trigger and record responses from people other than the original interviewee. Future work on healing fabulations could incorporate an EXF-style 'mount' phase to investigate their value within a social justice context (for example, addressing issues of health inequality), as well as their impact on restorative practices within care relationships (e.g. Restorative Justice Council 2016).

In evaluating the usefulness of healing fabulations as tools for design knowledge, Manzini's (2015) definition of design-orienting scenarios – speculative artefacts meant to provoke conversation about future change – forms a useful guide. Firstly, the fabulations articulate a *vision* for the future through the digital representation. Secondly, the narrative of the participant's health story encapsulated in the fabulation demonstrates the *motivation* for the design and why it is meaningful. Finally, the fabulation provides a *strategy* for implementation by indicating what interactions and service journeys may be necessary to meet the participant's needs and goals.

Therefore, healing fabulations are both a prototype of a digital service and a representation of lived experience which can inform and inspire future design research. This makes them potentially valuable for use within multidisciplinary teams, where designers must work closely alongside other roles such as technical implementers.

### *4.4 – Metaphor and aesthetics in visual representations*

The feedback from participants showed that the visual metaphors used within their fabulations were important to them. The use of metaphors in the project was in part prompted by my own approach – for example, asking them to select objects which represented their stories. However, this continued to form a central focus of discussion throughout the work – even for the single participant who did *not* select any object to begin with. It was important to all the participants that their story was interpreted in a way that they felt was 'correct'.

In addition, participants described metaphor as being an important tool in broaching difficult or emotional topics. For example, one participant wanted to use the visual metaphor of a flower to represent his current level of hopefulness about his health and initiate conversations with friends on this subject. He preferred the idea of a flower over alternate suggestions because he felt that hope needs to be nurtured, showing that this specific metaphor was important to him. Findings from narrative medicine research show that metaphors and other explanatory constructs are a common part of health storytelling, and are often used by individuals as a way of conveying their experiences to others (Hunsaker Hawkins 1999; Kleinman 1988). *Spoons*, for instance, are commonly used by people with chronic health conditions as a metaphor for describing their daily energy levels as discrete units (Miserandino 2003).

Individuals can also become significantly distressed when the 'wrong' metaphors or constructs are applied – in other words, ones which do not match their experiences (Hunsaker Hawkins 1999). In group participatory methods, it would be more common to choose a single metaphor for use within the project, or to provide participants with a set selection (e.g. French and Raman 2021). The individual approach described here therefore offers a potential advantage for designers, in that the visual metaphors can be customised to match each participant.

While participants gave less feedback overall on the aesthetics of their design, the feedback still showed that this was important to them. For example, when a participant was shown an illustrative concept sketch and another using a more standard web layout, she said that she strongly preferred the illustrative style because she felt that it was more emotive and unique, and therefore more representative of herself and her story. As a designer, I also felt it important to take care over their designs and make things that were aesthetically pleasing to participants in order to show respect and consideration towards their experiences (Saito 2022).

Overall, understanding of aesthetics in design has been a neglected area of research (Folkmann 2013). Previous work on the aesthetics of healthcare shows that aesthetics embodying healing values can positively affect personal wellbeing (Butterfield and Martin 2014; Saito 2022), however such work has predominantly focused on the aesthetics of built care environments (e.g. Ståhlberg-Aalto 2019). The feedback from participants in this project suggest that healing aesthetics could be important within digital environments as well – a theme which could be explored further in future work.

### *4.5 – Replicability and future use*

Compared to other approaches, this methodology is somewhat labour-intensive and requires extended involvement with participants. In the case study, participant engagement lasted four months and could easily have been extended through further research cycles. This may make the approach unsuitable for projects with restricted time frames and/or budgets. However, the length of involvement and repeated engagements have significant benefits for researchers by allowing them to build an in-depth understanding of the participant's stories which could not be achieved through a one-off engagement (Pessoa et al. 2019). Because compassionate inquiry can be very demanding, the episodic format also protects researchers and participants by allowing space for healing, reflection, and self-care between sessions, which in turn adds to the ethical rigour of the research (Kumar and Cavallaro 2018).

The application of the methodology as described in the case study also requires researchers to have expertise in multiple areas. For example, they must have knowledge of digital design, training in undertaking compassionate design research, as well as an understanding of the healthcare context. For many researchers, this type of wide-ranging expertise would not be achievable. A similar effect could be achieved by a multidisciplinary team, although consideration would need to be given to balancing session participation so that participants were not overwhelmed by the number of researchers. In particular, the case study project would have benefitted from the inclusion of an expert on trauma and healing who could have further supported this aspect of the work.

Although this article has focused on the use of the methodology in healthcare, it would be suitable for any 'sensitive topic' (Hirsch 2020) which may be traumatic for participants. It is also not limited to a digital design context, but could be easily modified for any type of codesign. The nature of the approach gives researchers a particularly in-depth understanding of participant stories which informs the compassionate cocreation of design artefacts in a creative and emotionally supportive way. As such, the methodology when supported by someone with design expertise may also benefit researchers in other disciplines where a narrative understanding of lived experience is desirable – for example, the social sciences.

## 5 – Personal reflections

For myself as a researcher, undertaking this type of compassionate inquiry has been transformative. Health storytelling requires both participants and researchers to treat each other with the same level of consideration and intimacy as they would a close friend (Tillmann-Healy 2003). Listening to such a story means hearing about some of the most difficult times in that person's life. Its themes of hope and despair go straight to the heart of what it means to be human. While it can be emotionally difficult, the type of caring relationship which emerges from these interactions has a quality to it which can only be described as '*beautiful'* (Thompson 2015, 38).

> [W]hat is care? Is it an affection? A moral obligation? Work? A burden? A joy? Something we can learn or practice? Something we just do? Care means all these things… (Puig de la Bellacasa 2017, 1)

## 6 – Acknowledgements

The authors would like to thank the research participants for sharing their stories and making this work possible.

## 7 – Declaration of interest

This work was funded by Scotland's Digital Health & Care Innovation Centre.

The authors report there are no competing interests to declare.

## 8 – References

Barassi, Sebastiano, and James Copper. 2015. "Henry Moore and Stone: Methods and Materials." Henry Moore: Sculptural Process and Public Identity. 2015.

https://www.tate.org.uk/art/research-publications/henry-moore/sebastiano-barassi-and-james-copper-henry-moore-and-stone-methods-and-materials-r1151462.

Barcham, Manuhuia. 2021. “Towards a Radically Inclusive Design – Indigenous Story-Telling as Codesign Methodology.” *CoDesign* 00 (00): 1–13. https://doi.org/10.1080/15710882.2021.1982989.

Buse, Christina, and Julia Twigg. 2016. “Materialising Memories: Exploring the Stories of People with Dementia through Dress.” *Ageing and Society* 36 (6): 1115–35. https://doi.org/10.1017/S0144686X15000185.

Bustamante Duarte, Ana Maria, Mehrnaz Ataei, Auriol Degbelo, Nina Brendel, and Christian Kray. 2021. “Safe Spaces in Participatory Design with Young Forced Migrants.” *CoDesign* 17 (2): 188–210. https://doi.org/10.1080/15710882.2019.1654523.

Butterfield, A., and D. Martin. 2014. “The Silent Carers: Exploring the Role of Architecture and Gardens at the Maggie’s Cancer Care Centres.” *Psycho-Oncology* 23 (2007): 318–19. http://onlinelibrary.wiley.com/doi/10.1111/j.1099-1611.2014.3696/pdf%5Cnhttp://ovidsp.ovid.com/ovidweb.cgi?T=JS&PAGE=reference&D=emed16&NEWS=N&AN=71675582.

Candy, Stuart, and Kelly Kornet. 2019. “Turning Foresight inside out: An Introduction to Ethnographic Experiential Futures.” *Journal of Futures Studies* 23 (3): 3–22. https://doi.org/10.6531/JFS.201903_23(3).0002.

Charon, Rita. 2006. *Narrative Medicine: Honoring the Stories of Illness*. Oxford University Press.

Chuang, Hui Wan, Chi Wen Kao, Ming Der Lee, and Yue Cune Chang. 2018. “Effectiveness of Story-Centred Care Intervention Program in Older Persons Living in Long-Term Care Facilities: A Randomized, Longitudinal Study.” *PLoS ONE* 13 (3): 1–14. https://doi.org/10.1371/journal.pone.0194178.

Corbin, Juliet, and Anselm Strauss. 1985. “Managing Chronic Illness at Home: Three Lines of Work.” *Qualitative Sociology* 8 (3): 224–47. https://doi.org/10.1007/BF00989485.

Cronon, William. 1992. “A Place for Stories: Nature, History, and Narrative.” *The Journal of American History* 78 (4): 1347. https://doi.org/10.2307/2079346.

Cummings, Marissa, Jay Bradley, and Gemma Teal. 2022. “Patient Co-Design of Digital Health Storytelling Tools for Multimorbidity: A Phenomenological Study.” *Health Expectations*.

Dennis, Mary Kate, and Michael Minor. 2019. “Healing Through Storytelling: Indigenising Social Work with Stories.” *British Journal of Social Work* 49 (6): 1472–90. https://doi.org/10.1093/bjsw/bcz044.

Despret, Vinciane. 2016. *What Would Animals Say If We Asked the Right Questions?* Minneapolis, MN: University of Minnesota Press.

Dietkus, Rachael. 2022. “Trauma-Responsive Design Research: A New Model of Change.” New York: SDN New York. https://www.youtube.com/watch?v=5UYNdQP2b58.

Elliott, Denise E., Paula Bjelajac, Roger D. Fallot, Laurie S. Markoff, and Beth Glover Reed. 2005. “Trauma-Informed or Trauma-Denied: Principles and Implementation of Trauma-Informed Services for Women.” *Journal of Community Psychology* 33 (4): 461–77. https://doi.org/10.1002/jcop.20063.

Finlay, Linda. 2009. “Ambiguous Encounters: A Relational Approach to Phenomenological Research.” *Indo-Pacific Journal of Phenomenology* 9 (1): 1–17. https://doi.org/10.1080/20797222.2009.11433983.

———. 2014. “Embodying Research.” *Person-Centered and Experiential Psychotherapies* 13 (1): 4–18. https://doi.org/10.1080/14779757.2013.855133.

Folkmann, Mads Nygaard. 2013. *The Aesthetics of Imagination in Design*. Cambridge, MA: The MIT Press.

Frank, Arthur W. 2012. *Letting Stories Breathe: A Socio-Narratology*. Paperback. Chicago: University of Chicago.

———. 2013. *The Wounded Storyteller*. *The Wounded Storyteller*. 2nd ed. London: The University of Chicago Press. https://doi.org/10.7208/chicago/9780226260037.001.0001.

French, Tara, and Sneha Raman. 2021. “Engaging People with Lived Experience in Co-Design of Future Palliative Care Services.” *International Journal of Public Administration* 44 (9): 778–89. https://doi.org/10.1080/01900692.2021.1920612.

Hardy, Pip, and Tony Sumner. 2020. “About Patient Voices.” Patient Voices. 2020. http://www.patientvoices.org.uk/who-we-are/about-patient-voices.

Harrington, Christina N. 2020. “The Forgotten Margins: What Is Community-Based Participatory Health Design Telling Us?” *Interactions* 27 (3): 25–29. https://doi.org/10.1145/3386381.

Hirsch, Tad. 2020. “Practicing Without a License: Design Research as Psychotherapy.” *Conference on Human Factors in Computing Systems - Proceedings*, no. April. https://doi.org/10.1145/3313831.3376750.

Hunsaker Hawkins, Anne. 1999. *Reconstructing Illness: Studies in Pathography*. 2nd ed. Purdue University Press.

Hussain, Hera. 2021. “Trauma-Informed Design: Understanding Trauma and Healing.” Chayn. 2021. https://blog.chayn.co/trauma-informed-design-understanding-trauma-and-healing-f289d281495c.

IDEO. 2015. *The Field Guide to Human-Centred Design*. 1st ed.

Ingold, Tim. 2020. “Making Growing Thinking.” Glasgow: The Glasgow School of Art.

Jones, Peter H. 2013. *Design for Care*. New York: Rosenfeld Media.

Jupp, Eleanor. 2022. *Care, Crisis and Activism: The Politics of Everyday Life*. Bristol, UK: Policy Press.

Kleinman, Arthur. 1988. *The Illness Narratives: Suffering, Healing, and the Human Condition*. Basic Books, Perseus Books Group.

Kumar, Smita, and Liz Cavallaro. 2018. “Researcher Self-Care in Emotionally Demanding Research: A Proposed Conceptual Framework.” *Qualitative Health Research* 28 (4): 648–58. https://doi.org/10.1177/1049732317746377.

Liddy, Clare, Valerie Blazkho, and Karina Mill. 2014. “Challenges of Self-Management When Living with Multiple Chronic Conditions: Systematic Review of the Qualitative Literature.” *Canadian Family Physician* 60 (12): 1123–33.

Lieblich, Amia, Rivka Tuval-Mashiach, and Tamar Zilber. 2011. *Narrative Research*. Thousand Oaks, CA: SAGE Publications, Inc.

Manzini, Ezio. 2015. *Design, When Everybody Designs*. Cambridge, MA: The MIT Press.

Marcial, Laura. 2014. “Usability in Healthcare: A ‘Wicked’ Problem.” User Experience Magazine. 2014. https://uxpamagazine.org/usability-in-healthcare/.

Mattingly, Cheryl. 2009. *Healing Dramas and Clinical Plots: The Narrative Structure of Experience*. Digital ed. Cambridge: Cambridge University Press.

Meyer, Eric, and Sara Wachter-Boettcher. 2016. *Design for Real Life*. A Book Apart.

Meyer, Kylie, and Rosalind Willis. 2019. “Looking Back to Move Forward: The Value of Reflexive Journaling for Novice Researchers.” *Journal of Gerontological Social Work* 62 (5): 578–85. https://doi.org/10.1080/01634372.2018.1559906.

Miserandino, Christine. 2003. “The Spoon Theory.” But You Don’t Look Sick? 2003. https://doi.org/10.4324/9781315453217-19.

Mitchell, Wendy, and Annie Irvine. 2008. “I’m Okay, You’re Okay?: Reflections on the Well-Being and Ethical Requirements of Researchers and Research Participants in Conducting Qualitative Fieldwork Interviews.” *International Journal of Qualitative Methods* 7 (4): 31–44. https://doi.org/10.1177/160940690800700403.

Morrison, Gyles. 2019. “Bad Healthcare UX Is Killing People.” Medium. 2019. https://medium.com/@drgylesmorrison/bad-healthcare-ux-is-still-killing-people-be3270f281b3.

Murphy, John W, Berkeley A Franz, and Christian Schlaerth. 2018. “The Role of Reflection in Narrative Medicine.” *Journal of Medical Education and Curricular Development* 5: 238212051878530. https://doi.org/10.1177/2382120518785301.

Penn, Peggy. 2001. “Chronic Illness: Trauma, Language, and Writing: Breaking the Silence.” *Family Process* 40 (1): 33–52. https://doi.org/10.1111/j.1545-

5300.2001.4010100033.x.

Pessoa, Alex Sandro Gomes, Erin Harper, Isabela Samogim Santos, and Marina Carvalho da Silva Gracino. 2019. “Using Reflexive Interviewing to Foster Deep Understanding of Research Participants’ Perspectives.” *International Journal of Qualitative Methods* 18: 1–9. https://doi.org/10.1177/1609406918825026.

Portigal, Steve. 2008. “Persona Non Grata.” Montara, CA. https://portigal.com/wp-content/uploads/2008/01/Portigal-Consulting-White-Paper-Persona-Non-Grata.pdf.

Puig de la Bellacasa, María. 2017. *Matters of Care: Speculative Ethics in More Than Human Worlds*. Edited by Cary Wolfe. Minneapolis: University of Minnesota Press.

Quesenbery, Whitney, and Kevin Brooks. 2010. *Storytelling for User Experience: Crafting Stories for Better Design*. New York: Rosenfeld Media.

Realistic Medicine. 2020. “The Full Story.” Realistic Medicine. 2020. https://www.realisticmedicine.scot/the-full-story/.

Restorative Justice Council. 2016. “Restorative Practice in Other Areas.” Restorative Justice Council: Promoting Quality Restorative Practices for Everyone. 2016. https://restorativejustice.org.uk/restorative-practice-other-areas.

Rosner, Daniela K. 2018. *Critical Fabulations: Reworking the Methods and Margins of Design*. Boston, MA: The MIT Press.

Saito, Yuriko. 2022. *Aesthetics of Care: Practice in Everyday Life*. London: Bloomsbury Academic.

Sanders, Elizabeth B.-N., and Pieter Jan Stappers. 2008. “Co-Creation and the New Landscapes of Design.” *CoDesign* 4 (1): 5–18. https://doi.org/10.1080/15710880701875068.

Simonds, Vanessa W., and Suzanne Christopher. 2013. “Adapting Western Research Methods to Indigenous Ways of Knowing.” *American Journal of Public Health* 103 (12): 2185–92. https://doi.org/10.2105/AJPH.2012.301157.

Smith, Brett, and Andrew C. Sparkes. 2004. “Men, Sport, and Spinal Cord Injury: An Analysis of Metaphors and Narrative Types.” *Disability and Society* 19 (6): 613–26. https://doi.org/10.1080/0968759042000252533.

Smith, Mary Jane, and Patricia R. Liehr. 2014. “Story Theory.” In *Middle Range Theory for Nursing*, edited by Mary Jane Smith and Patricia R. Liehr, 3rd ed., 225–51. New York: Springer.

Ståhlberg-Aalto, Freja. 2019. *The Aesthetics and Architecture of Care Environments*. Espoo, Finland: Aalto ARTS Books. https://aaltodoc.aalto.fi/bitstream/handle/123456789/40965/isbn9789526087368.pdf.

Steen, Marc. 2011. “Tensions in Human-Centred Design.” *CoDesign* 7 (1): 45–60.

https://doi.org/10.1080/15710882.2011.563314.

Storytelling For Health 2. 2019. “Storytelling For Health 2.” The University of South Wales: The George Ewart Evans Centre for Storytelling. University of South Wales. 2019. https://storytelling.research.southwales.ac.uk/research/storyhealth2/.

Thompson, James. 2015. “Towards an Aesthetics of Care.” *Research in Drama Education* 20 (4): 430–41. https://doi.org/10.1080/13569783.2015.1068109.

Thorpe, Adam, and Lorraine Gamman. 2011. “Design with Society: Why Socially Responsive Design Is Good Enough.” *CoDesign* 7 (3–4): 217–30. https://doi.org/10.1080/15710882.2011.630477.

Tillmann-Healy, Lisa M. 2003. “Friendship as Method.” *Qualitative Inquiry* 9 (5): 729–49. https://doi.org/10.1177/1077800403254894.

Tronto, Joan. 1993. *Moral Boundaries: A Political Argument for an Ethic of Care*. New York: Routledge.

Trowbridge, Hayley. 2018. “Enhancing Person-Centred Care with Patient Stories.” People’s Voice Media. 2018. https://peoplesvoicemedia.co.uk/enhancing-person-centred-care-with-patient-stories/.

Tsing, Anna, Heather Swanson, Elaine Gan, and Nils Bubandt. 2017. *Arts of Living on a Damaged Planet*. Minneapolis: University of Minnesota Press.