

The Glass Witness

Visual and Tactile Engagements with Online Medical Crowdfunding

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Abstract

Donation-based crowdfunding platforms invite people to tell stories of unmet health needs in a hybrid form—using both words and images—but research to date has not addressed the role of visual practice in this setting, in any detail. In this Photo Essay I present an art installation responding to this gap and informed by empirical data from a three-year study of medical crowdfunding in Aotearoa New Zealand. Through a feminist new materialist lens, and connecting to scholarship on visibility and the gaze, I used the medium of stained glass to evoke and connect the experiences of both campaigners and audiences. I briefly discuss the design process, alongside reflections on the role of graphic medical imagery in an assemblage of witnessing; on disability, shock, and the economic function of voyeurism; on non-normative bodies and subjectification through the gaze; on biases in audience recognition; and on paradoxes of intimacy and distance through digital technology. I highlight that both the content and the context of images have a role in shaping the ‘response-ability’ of networked publics to the suffering of distant others; in the case of medical crowdfunding, with significant consequences for healthcare access.

Keywords

Crowdfunding, Compassion, Visual Ethnography, Social Media, Photography.

Introduction

Online crowdfunding platforms such as GoFundMe (internationally) or Givealittle (in Aotearoa New Zealand) invite people to tell stories of unmet health needs, using both words and images. Their audience is a fragmented online public among whom the campaigners aim to evoke the sort of moral emotions that will lead to donations. But compassion is an unstable emotion (Berlant 2004). A campaign's success or failure often relies on existing social capital, and the campaigner's ability to undertake media labour to create engaging campaign pages. Having a greater number of photos, and more compelling or attractive photos, has been shown to correlate with greater campaign success (Berliner and Kenworthy 2018; Snyder 2016; Pol, Snyder, and Anthony 2019). However, little scholarly attention has been given to the practices involved in the production and consumption of these images, or how they mediate campaigner-audience relations.

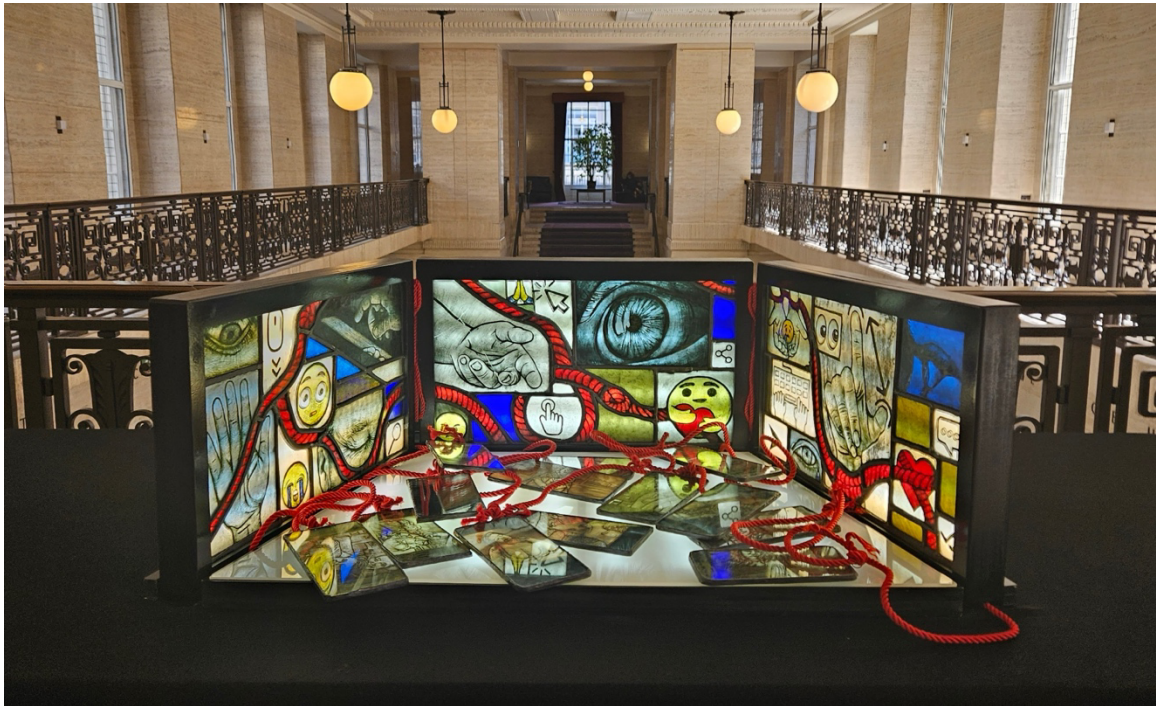


Figure 1: 'The Glass Witness', by the author. Hand-painted glass and lead panels, on a custom lightbox with painted wooden frame: 80cm x 50cm x 30cm. Approximately 60 hours work, completed November 2022.

Research and artwork

In 2022 I completed an art installation of stained glass which sought to respond to these gaps. It was informed by empirical data from my three-year study (2020–2022) of medical crowdfunding in Aotearoa New Zealand—a small, postcolonial, and highly neoliberalised nation, with an ostensibly good public healthcare system.

This study brought together case studies and interviews with campaigners, surveys of audiences, and content analysis of campaign pages. The installation intended to capture several interrelated aspects of crowdfunding, and explore these through a feminist new materialist lens; highlighting how responsibility and care might be embedded in visual practice, and in turn shaped by the ‘sensuous, aesthetic, and material conditions of the digital’ (Frosh 2019, 140).

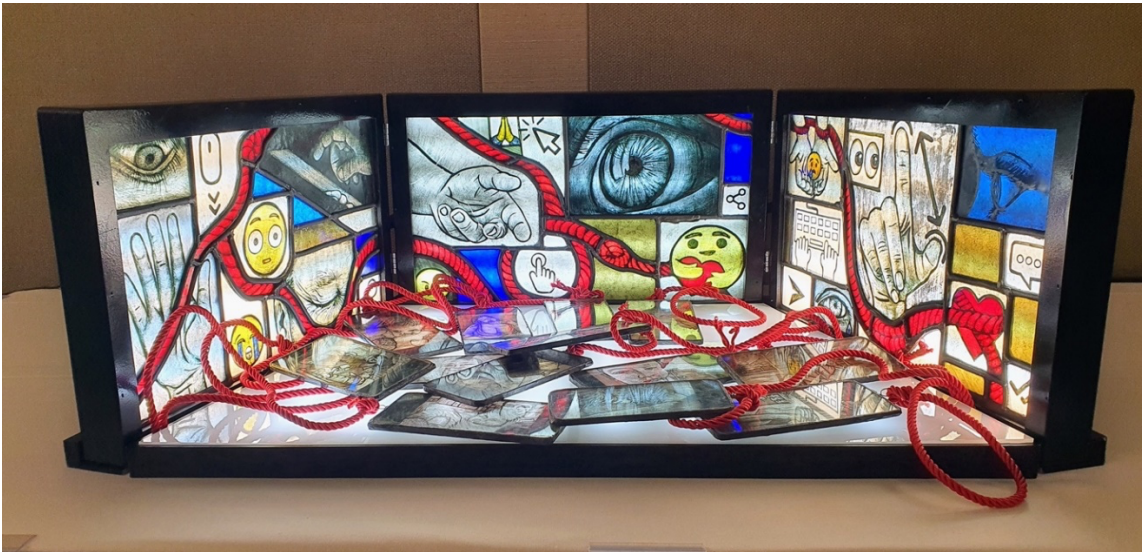


Figure 2: The installation is intended to be viewed by a person sitting at a table, so that the triptych evokes both computer monitors, and a panopticon.

The main panels of the triptych (see Figures 1 and 2) represent the networked publics who form the campaign audiences. Each of the three hand-painted panels (e.g., Figure 3) represent a cluster of affects—namely ‘Curiosity’, ‘Compassion’ and ‘Connection’—that was identified through an Nvivo-based thematic analysis of audience survey data. Each panel is also a composite image (Frosh 2019), highlighting indexical elements (such as emojis or icons) that form the graphic visual interface through which audiences respond via embodied actions of looking, tapping, clicking, scrolling, and zooming.



Figure 3: Close-up of panel three, 'Connection'.



Figure 4: Twelve individual pieces of hand-painted, coloured glass, each with a layer of smooth clear glass atop—plus an additional 13th piece of mirror—sit at the centre. While most of the original photos are in colour, glass painting is restricted to a black and brown palette.

The twelve freestanding pieces at the centre (see Figure 4) represent the visual practices of the campaigners. Each image was taken from an actual Givealittle page, as sampled in October 2022—all used with permission. Specific images were selected to convey some of the key visual tropes the content analysis identified, as discussed further below. The size, shape, weight, and tactility of these pieces was designed to evoke the haptic experience of smartphone use.



Figure 5: Close-up of setup, with red cords.

The connection between audiences and campaigners is represented by the red threads (see Figure 5): a visual throughline which also functions to connect the viewer to the installation, as they pick up the individual pieces and find themselves part of the assemblage. The goal was to interpellate viewers into processes of looking and touching, through glass, in a way that parallels the engagements of crowdfunding audiences, providing an alternative embodied and tactile access to the topic.

Baring bodies to the gaze: Reflections on vulnerability, voyeurism, and shock



Figure 6: Painting from a photo of an infant with a rare heart condition, pictured in the Neonatal Intensive Care Unit (NICU).

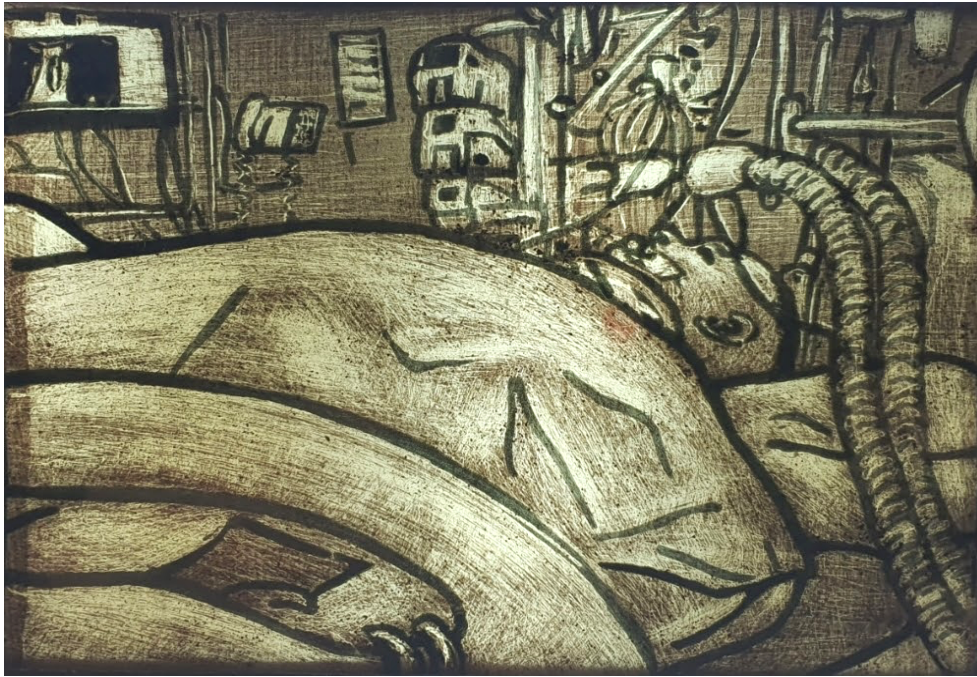


Figure 7: Painting from a photo of a man recovering in hospital from physical and neurological injuries, after a random public attack.

The use of graphic medical imagery (for example Figure 6 and 7) was common in the Givealittle campaigns I examined. In this marketised and competitive context, and amidst frequent audience suspicion around the veracity of campaigners' claims, visual references to vulnerability and pain follow a logic of both testimony and witnessing, where 'the body serves as a sort of collateral to justify the loan of our credence' (Peters 2008, 29). As such, these function as persuasive images. However, there is also an ambivalent quality to them: one audience respondent reported feeling 'uncomfortable' seeing people undergoing treatment, asleep, or in pain, preferring to avoid viewing images that 'portray someone in a vulnerable position and/or unaware that they are being photographed'.



Figure 8: Painting from a photo of a young man with a degenerative disease, who is a wheelchair user, seeking to access an unfunded drug.



Figure 9: Painting from a photo of a young teenage girl left with a severe facial deformity after surgery to remove a tumour, supported by an external metal brace.

There was also an ambivalence around viewing non-normative and/or disabled bodies (for example, Figures 8 and 9), when represented on Givealittle. Davis (2015) writes about disability as a 'rebellion of the visual', involving disruptions to normative assumptions about the body that can also generate disgust, fear, or shock. Some viewers clicked on the link for the campaign in Fig. 9, when it appeared in their social media feeds, specifically because of the 'confronting' image, noting that the girl's facial deformity 'with screws attached' made them feel 'shocked' as well as curious. This also echoes Susan Sontag's idea of photography as 'shock therapy', emphasising the satisfaction of being able to look at horrors, cruelties, or pain, without flinching . . . but also of the 'pleasure of flinching' (2003, 35). Indeed, the shock and novelty of this image may indeed have contributed to the campaign's success—raising over NZ\$280,000 from more than 2,400 different donors—in part through inviting voyeuristic attention that was transformed into economic value.



Figure 10: Painting from a photo of a teenaged boy with an aggressive form of cancer, whose family were fundraising for surgery overseas; pictured with a fluffy kitten.

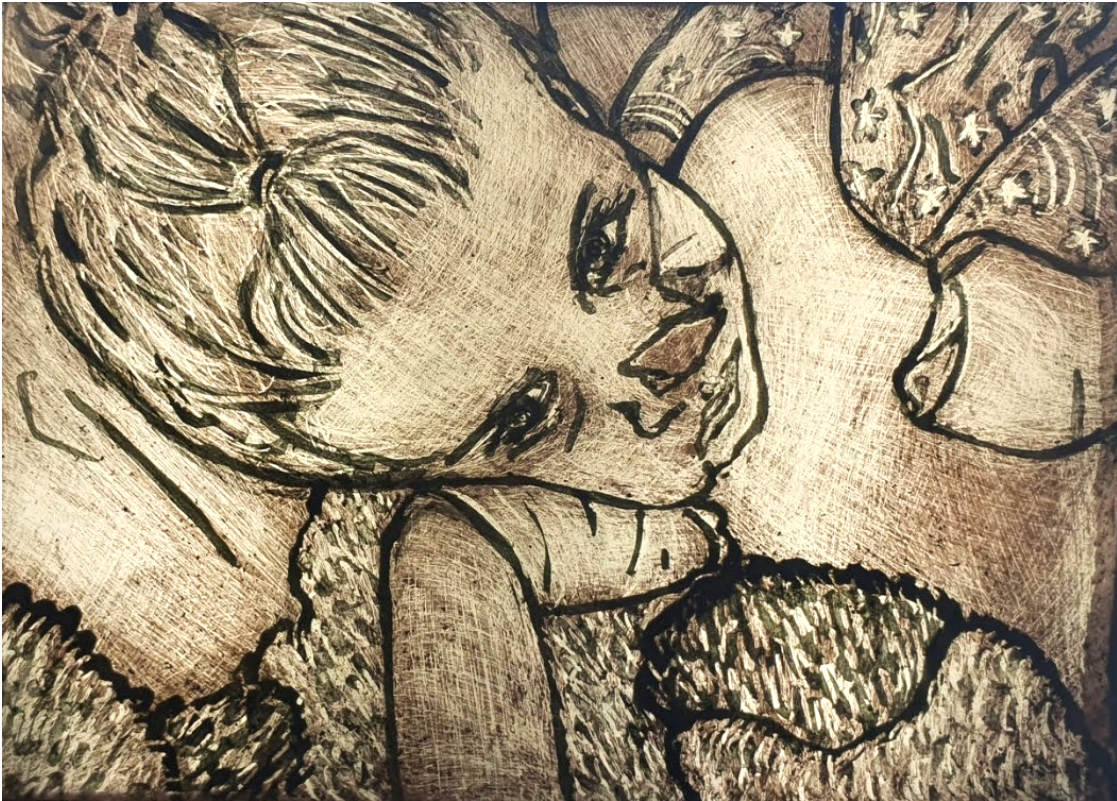


Figure 11: Painting from a photo of young girl with bandaged hands and face, wearing patterned pajamas and cuddling a large fluffy soft toy.

Shock, however, can become familiar, or wear off. Images we are exposed to frequently can come to incorporate a paradox of both shock and cliché (Sontag 2003, 18). There is certainly a high degree of repetition of certain visual tropes in medical crowdfunding: for example, babies connected to medical equipment (see Figure 6), or bald cancer patients (see Figure 10), the latter unsurprising given that 42% of all medical crowdfunding campaigns in New Zealand relate to cancer (Wardell 2020). While a sense of obligation to look can be part of the assemblage of witnessing (Peters 2008), a choice not to look, or a tiring of looking, is not necessarily callousness, but an instability of attention caused by a surfeit of images (Sontag 2003, 91). In my survey data, audiences reported feeling ‘flooded’ or ‘overwhelmed’ by ‘so many’ campaigns, leading to emotions of worry, heartbreak, uncertainty, or guilt. In this context, scenes of suffering can be an unwelcome demand. Indeed, some crowdfunding studies in the United States have shown that a more positive sentiment (Durand et al. 2018), or culturally specific values such as cheerfulness (Paulus and Roberts 2018), can be more successful than a sob story. This leads to my own questions about the effect of graphic medical images, or images with an otherwise negative tone (see also Figure 12), relative to positive

or humanising images (for example, Figures 10, 11, and 13), which were also common.

Non-normative bodies and online publics: Reflections on scrutiny, subjectification, and recognition



Figure 12: Painting of a woman seeking funds for bariatric weight-loss surgery. The original photo is also in black and white.



Figure 13: Painting from a mirror selfie that is the main image on a campaign for a woman seeking funds for breast reduction.

Looking is an exercise of power in many ways. The gaze can be part of subjectification; working to regulate, rationalise, and contain bodily difference (Davies 2005, 168). People with non-normative bodies—including cyborg bodies, fat bodies, and gender non-conforming bodies, as well as disabled ones—are caught in a bind, in that in order to access idealised states of health, they need to make their non-normative bodies visible to scrutiny from online publics (Wardell, Starling, and Withey-Rila 2024; Wardell and Withey-Rila 2024). While campaigns were often constructed collaboratively, the frequent use of selfies as campaign images on Givealittle (for example, Figures 9 and 13) was significant in showing the role crowdfunders could have in regulating themselves according to predominant (healthist, ableist) discourses. In this way selfies can act as technologies of the self.



Figure 14: Painting from the graduation photo of young man whose family were fundraising for him to receive an unfunded cancer treatment. He is wearing a traditional Māori korowai (cloak).

Black and brown bodies have also been constructed in visually specific ways through a white or colonial gaze (Knudsen et al. 2022). Healthcare inequalities in Aotearoa New Zealand already run persistently along the lines of ethnicity (Reid et al. 2022). This is further entrenched by crowdfunding; for instance with white-presenting funding recipients receiving more on average than those who present visibly as Pasifika on the same platform (Wardell 2020), and despite the same media labour and visual labour being undertaken (for example, Figure 14). This trend suggests that although audiences seem to recognise themselves in some stories and images—as also represented by one phone-sized piece of mirror included in the installation—which prompt empathetic imagination and propels donations, there are also limits, barriers, and biases in this process of looking, which remains entangled with wider socio-political logics of deservingness and recognition.

Conclusion: Looking and response-ability

Thinking through my research findings in the tactile medium of a glass art installation has sharpened my analytic attention to the context as well as content of images. This has included analysis of the visual tropes that predominate in this social field, and to the materiality of the smartphone and the screen. There is a paradox of intimacy and distance in engaging with images of other people's bared, vulnerable, and non-normative bodies, through devices cradled in hands, manipulated under fingertips, but remaining untouchable under glass. In this

setting, the eyes become an organ of touch (Hayward 2010; Wardell 2021), but a weighty and power-laden one. Overall, the artwork explores how several aspects of a visual and material assemblage might shape audiences' 'response-ability' to the suffering of distant others, acknowledging that in the case of medical crowdfunding, this mediates access to healthcare for thousands of people.

Authorship statement

This research project was designed and led by the author, as Primary Investigator. Data was gathered and analysed with support from research assistants and assistant research fellows. Responsibility for interpretations and representations of the findings in the artwork, and in this photo essay, lies with the author.

Ethics statement

All images from crowdfunding campaigns, from which artwork is derived, are used with permission from the campaign organisers. The research proceeded with approval from the University of Otago Research Ethics Committee.

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About the author

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