

DATA VISUALISATION AS A TOOL FOR PUBLIC ENGAGEMENT AND EMPATHY BUILDING

Carolina GILL, Kelly UMSTEAD, Sana BEHNAM ASL and Ranauk MAHTANI
College of Design, North Carolina State University, United States of America

ABSTRACT

Visualisations provide an accessible way to unveil new patterns or promote new perspectives on data. Data visualisations can also aid in highlighting the context and scope of social issues and is a compelling way to disseminate research findings to the general public. This paper presents an interactive exhibit displayed at the 2022 Accelerate Creativity and Innovation Festival, at the Smithsonian Institution's National Museum of American History. The exhibit utilised participatory and interactive visualisations, prompting visitors to share their experiences regarding trust and respect in maternity care. This case study showcases the potential impact of utilising participatory visualisation activities by a design research team to inform and actively involve museum visitors in exploring sensitive topics surrounding maternity care and postnatal care inequities. The use of these activities allowed for an inclusive experience, encouraging visitors to actively participate, reflect, and contribute to the conversation. Additionally, it allowed the team to disseminate and validate their findings.

Keywords: Participatory data visualisation, human centred design, design research, maternity care disparities

1 INTRODUCTION

In the field of public health, data visualisations are critical tools that aid in identifying disparities and implementation gaps, and support strategies for reaching population groups that are most in need of interventions [1]. Similarly, data visualisations in health care can assist in identifying patients based on their treatments and care needs. Data visualisations can offer health professionals the chance to recognise patterns of racial and ethnic inequalities, as well as the effects of structural racism, although their application in this context has been underutilised [2]. These types of visualisations rely on large data sets, visualisation software, and computing power. They are designed to find and illuminate truths. In design, data visualisations are often used for summarising and analysing data from research to make decisions about the design direction or to communicate insights to stakeholders in a clear and compelling way. Data visualisations can also be used by designers and artists to promote empathy by connecting stakeholders to the human experience. In this context, the intent is often to engage with the viewer's emotions, by eliciting responses and connecting viewers to the data on a deeper level [3]. The goal of these types of visualisations is not always objectivity. Their interpretations often incorporate personal experiences, individual perspectives, and the context of the viewer's experience [3,4].

Data visualisation may also be participatory, incorporating activities where people contribute data and actively partake in the generation of the data visualisation [4]. By encouraging individuals to contribute their own data to a shared visualisation, these activities create a sense of ownership and engagement for participants. These activities can be powerful tools for generating public awareness and promoting social discourse [5]. As a result, there may be unexpected uses, thought-provoking discussions on data, and unconventional dissemination of findings on data-related topics that hold significance for society.

In health care, participatory data visualisations can be particularly effective in promoting shared understanding among stakeholders, for instance between patients and health care providers. The contrasting perspectives of care experienced by patients and families across race and ethnic identities are not always evident to health care providers and administrators. This paper describes the use of visualisation tools around disparities in maternal care in the context of a museum exhibit. The intention of the activity was to engage the general public and students in discussing a sensitive topic and shedding light on inequities.

2 EXHIBIT DEVELOPMENT

Currently, the United States has significant differences in the incidence of adverse health outcomes related to pregnancy and childbirth based on race and ethnicity. This includes mortality rates due to pregnancy or delivery complications, as well as rates of negative health consequences resulting from unexpected pregnancy or childbirth outcome [6].

The authors of this paper are a team of designers working with health care experts at University of North Carolina at Chapel Hill and The Ohio State University on an Agency for Healthcare and Research Quality (AHRQ) funded grant to improve systems of perinatal care. The team is taking a human-centred approach to developing interventions by centring the needs of birthing parents. Birthing parents are included throughout the design process to create solutions that meet their needs and preferences. The research methods used in this project included shadowing, naturalistic video recording, interviews, focus groups and workshops.

The design team's project was selected to represent North Carolina State University at the 2022 Accelerate Creativity and Innovation Festival at the Smithsonian Institution in Washington DC. This festival was hosted at the National Museum of American History. During the three-day event, fifteen universities showcased thirty-eight interactive installations themed around place and environment; health, body and mind; and culture and the arts. The design team was tasked with creating an interactive display or exhibit that would allow the sharing of the project to the general public, including families, children, and students. This venue provided an opportunity to disseminate and validate research findings, share the human-centred design approach, and collect data. The team's goals for the exhibit were twofold: 1. to educate visitors about existing disparities in maternity care and research findings 2. engage visitors in sharing and collecting data about disparities regarding their postnatal experiences. In order to provide an overview of the project in maternity care to the general public, the team developed three tools to meet the first goal of educating visitors to the museum exhibit. First, the team wanted to provide an overview of the project and research methodologies along with some of the most impactful and relevant findings. To do this, the team designed a looping slideshow, presented on a large format video screen so visitors understand the context of the research quickly. The slides portrayed large scale artwork portraying birthing parents and direct quotes from birthing parents that share their feelings surrounding their experiences in maternity care (see Figure 1).

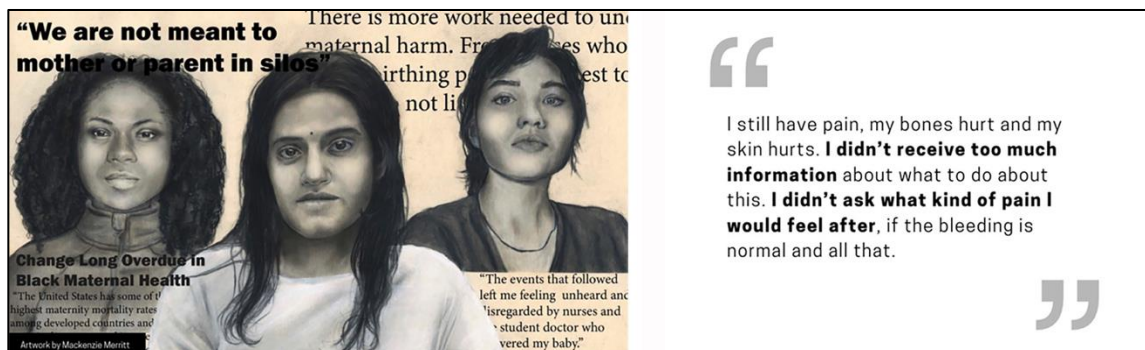


Figure 1. Slide show content

The second tool utilised quantitative data from maternal mortality and morbidity statistics reported from the Centres for Disease Control and Prevention (CDC) [7]. This data was presented as an interactive display, using Figma, on a touchscreen computer. The touchscreen display enabled specific interactions to address frequently asked questions around disparities in maternity care and communicate information in an interactive way. This was a user-driven experience, where visitors could explore questions and the associated answers at their own pace. The intent of this tool was to convey the magnitude of the problem in an accessible way.

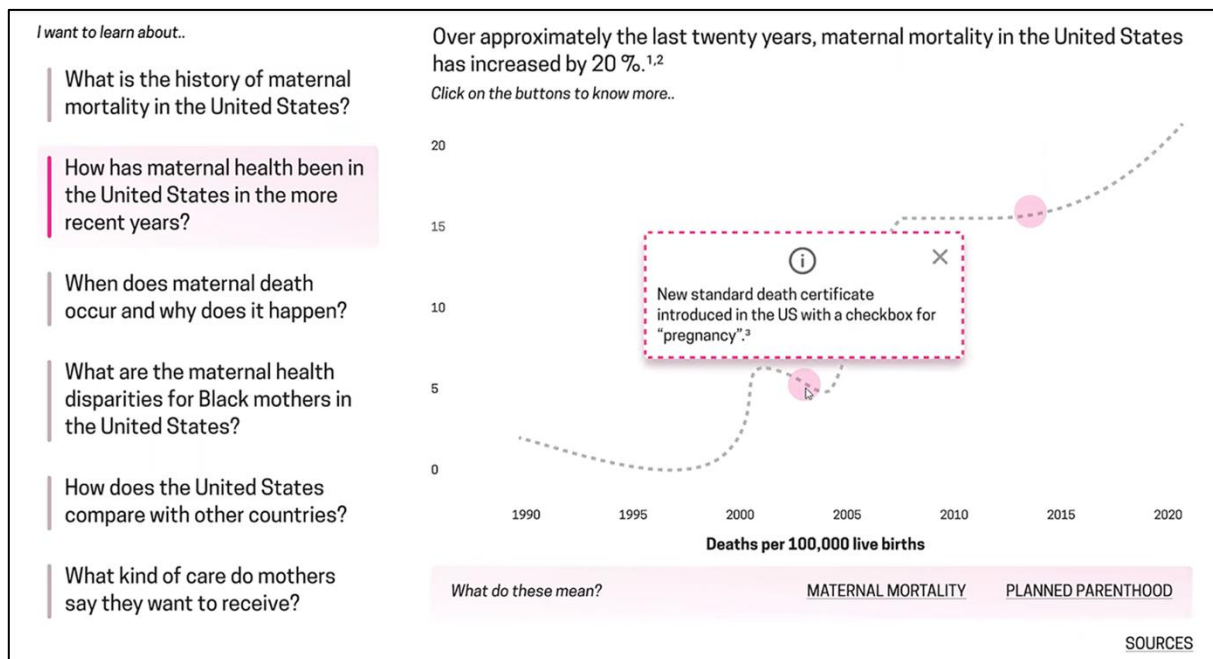


Figure 2. Interactive display

The third tool developed to educate and inform visitors was an animated video display that shared lived experiences of birthing parents and their families in the postnatal unit. Through these animations, the visitors would be able to hear and see examples of interactions between patients and health care team members, learn about those experiences and, in some cases, verify their own experiences. The goal with this portion of the exhibit was to use digital stories as a provocative artifact for discussion, inviting people to view, question, and reflect on the inequities of postpartum care [8].

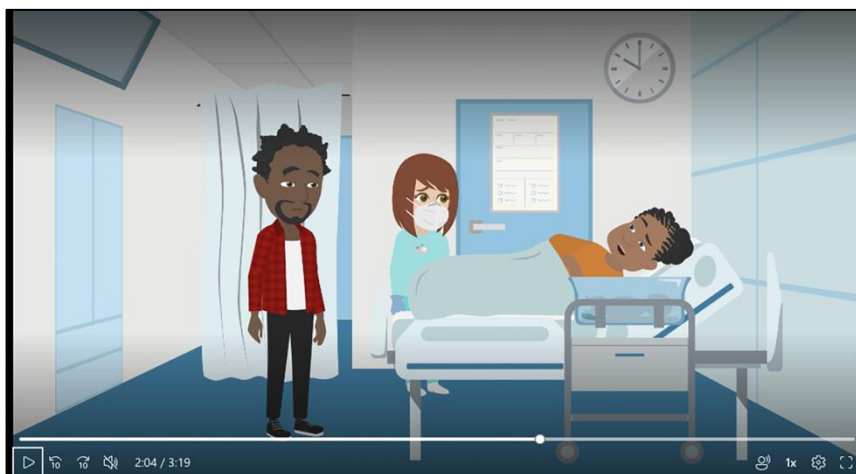


Figure 3. Screenshot of animated video display

2.1 Engaging participants in sharing

To accomplish the second goal of engaging participants and collecting data about disparities in postnatal experiences, the designers developed a participatory data visualisation display which allowed visitors to share their experiences in an unidentifiable way. The objective was to let visitors respond to questions about disparities silently or through dialogue with the design researchers. The board was intended to be the active component of the exhibit. It had to be user-friendly, straightforward, and easy to comprehend. It was important for the activity to be observable to individuals passing by and appealing to them. The visualisation board was meant to attract people into the exhibit and encourage them to interact with the animated videos and the interactive data display. The design team aimed to make the board tangible and physical to distinguish it from other technology-driven projects at the festival.

In searching references, one of the design researchers experienced an *East Meets West* Data Strings exhibit by Domestic Data Streamers in Hong Kong's Business of Design Week 2015 that reflected the qualities described. *East Meets West* was a tangible exhibit that transformed as participants provided responses, revealing communal trends around living and working based on where participants are from. Participants were prompted to respond to various questions by weaving their answers into the installation, creating a display of shared beliefs and statistics that allows them to juxtapose their responses with a wider context [9].

The design researchers wanted the exhibit to incorporate the ease of use and accessible qualities of the data string board in addition to allowing the participants to verbally share personal stories in relation to their answers. The design research team wanted to afford participants the ability to share as much or as little as they wanted while allowing them to see other participants' answers to the survey.



Figure 4. Participatory board questions to engage visitors

The questions selected for the survey on the board were based on research conducted by the authors on a related project in maternity care. These questions addressed issues about informational needs and emotional needs during the postnatal stay [10].

3 RESULTS

The exhibit was open to the public for three days from Friday, April 8 – Sunday, April 10, 2022, 10am to 5:30pm. During this time, two industrial design faculty and four research assistants staffed the exhibit in pairs during four-hour shifts. The museum reported approximately 11,000 visitors to the museum each day. The design research team conducted a group debriefing session at the conclusion of each day to record notes on the responses from exhibit participants.

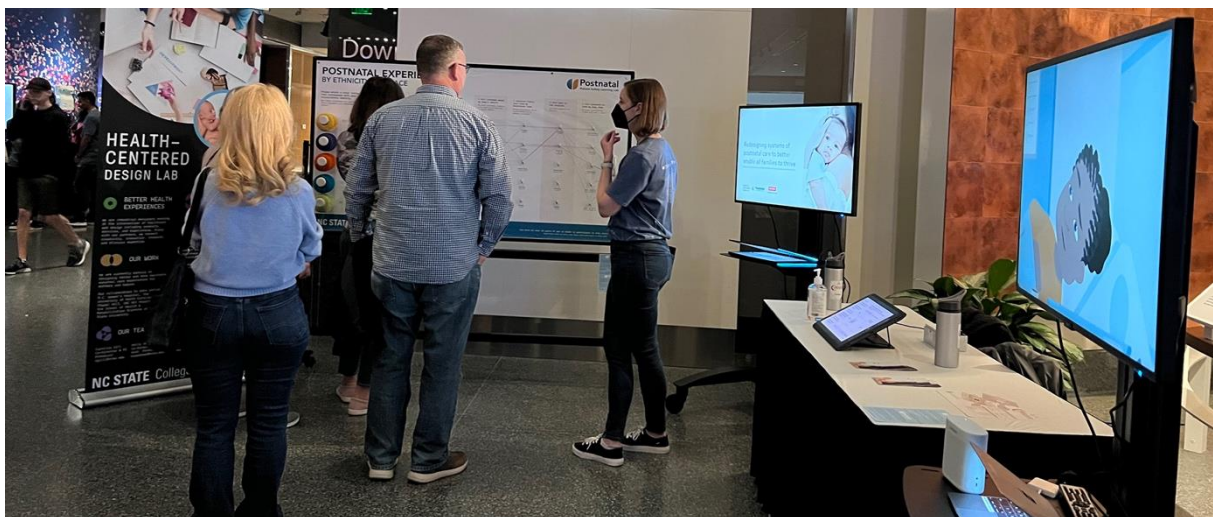
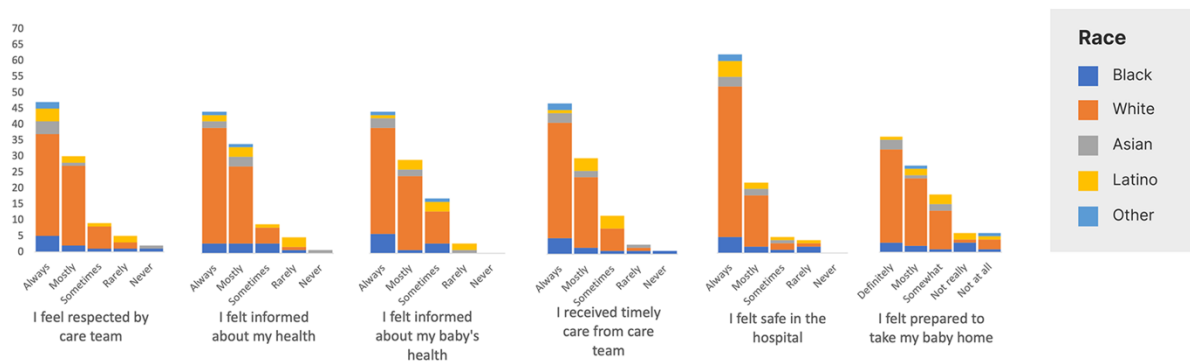


Figure 5. Exhibit in use

The results were a real-time data visualisation that displayed answers to questions about experiences in maternity care by race and ethnicity. Table 1 reports the summarised results of the survey questions by race and ethnicity. Ninety-three visitors contributed to the participatory data visualisation board. Sixty-six self-identified as White women, ten of them as Black women, nine of them as Latina, six as Asian and two as other. The results were not statistically significant, but there were trends in disparities. For example, to the question of feeling respected, three out of ten black women reported feeling respected sometimes, rarely, or never; three out of nine Latina women reported feeling respected sometimes or

rarely, one out of six Asian women reported never feeling respected, while only nine out of sixty-six white women reported similar feeling.

Table 1. Summarised Data of Participatory Board



3.1 Debriefing

The design research team compiled notes from each day the exhibit was on display. Distinct themes emerged from iterative thematic coding of visitor feedback and commentary. Comments primarily fell into one of two categories: 1) general feedback regarding the exhibit and awareness on the topic or 2) commentary on personal experiences around postnatal care. Table 2 describes select example commentary from each of the themes.

Table 2. Sample visitor commentary

General Feedback
<ul style="list-style-type: none"> ○ Visitors said the exhibit data seemed accessible and understandable to them. ○ Many visitors were unaware of the racial disparities in maternal outcomes. ○ Visitors would return to see how the data visualisation board had changed over time or bring a friend to participate. ○ Visitors stated they related to the videos that depicted postnatal care inequities.
Personal Experiences
<ul style="list-style-type: none"> ○ Many birthing parents shared they felt forced to consent to procedures or medications with very little explanation provided. ○ A Black birthing parent reported having a good experience with a Black OBGYN. ○ A Latina birthing parent shared she felt unable to speak up about her care because she didn't have insurance. She said she had medications pushed on her and she felt guilty for not preparing herself better. ○ A Black birthing parent shared that she had preeclampsia and felt she was not taken seriously. She shared she had to have her friend, who worked in the hospital call, on her behalf to be taken seriously. ○ Two European birthing parents reported having midwives provided as part of their standard maternity care.

4 DISCUSSIONS

Designers can make the invisible visible through the use of visualisations which generate, interpret, and communicate ideas. Moreso, participatory visualisations can inspire interactions among people, build empathy, and encourage public engagement. The intention of the museum exhibit was to educate and engage museum visitors around the topic of disparities in maternity care through interactive data visualisation tools. The design research team anticipated that visitors would preview the slides on the monitor, interact with the touch screen monitor to learn more about racial inequities and then perhaps participate in the data visualisation.

Black visitors commented that they were able to relate to the situations depicted by the animated videos, and they felt like they were accurate and generalisable experiences of disparities in maternity care. This was the first time the animations were shared with the general public and validated the premise that the videos are an appropriate tool for storytelling and empathy building.

Many visitors were eager to add their responses to the participatory visualisation board. The board emerged as a powerful tool to facilitate the telling of stories and personal experiences within maternity care. The design research team anticipated that visitors would fill out the board and then leave the exhibit or have a quick chat with the team. Instead, many of the visitors answering questions on the board told lengthy, in-depth stories of the care they received in the hospital. They were also interested in their answers as they compared to the answers of others and reflected on the contrasting experiences some others had at the hospital. The design researchers witnessed partners and children sometimes hearing these stories or perspectives for the first time. Although the initial intention of the board was to have a tangible, interactive aspect to the exhibit, the design researchers discovered a new application of this methodology to elicit qualitative data.

In conclusion, this study showcased the successful application of participatory visualisation activities by a design research team in raising awareness and promoting engagement among museum visitors on sensitive topics in maternity care and postnatal care inequities. These activities fostered an inclusive experience, encouraging active participation, reflection, and contributions from visitors. Furthermore, the exhibit provided an avenue for the team to disseminate and validate their findings.

The research project was reviewed and approved by the Biomedical institutional review board of University of North Carolina at Chapel Hill (No. 19-1900). This project is supported by grant number R18HS027260 from the Agency for Healthcare Research and Quality. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Agency for Healthcare Research and Quality.

REFERENCES

- [1] Narayan K. A. and Nayak M. S. D. P. Need for Interactive Data Visualisation in Public Health Practice: Examples from India. *Int J Prev Med.* 2021;12:16. doi:10.4103/ijpvm.IJPVM_171_20
- [2] Migita D., Cooper A., Barry D., Bettinger B., Tieder A. and Sharek P. J. Equity Dashboards: Data Visualisations for Assessing Inequities in a Hospital Setting. *Paediatrics.* 2023;151(3):e2022058848. doi:10.1542/peds.2022-058848
- [3] Kennedy H. and Engebretsen M. 1. Introduction : The relationships between graphs, charts, maps and meanings, feelings, engagements. In : ; 2020:19-32. doi:10.1515/9789048543137-005
- [4] Morais L., Andrade N. and Sousa D. Exploring How Visualisation Design and Situatedness Evoke Compassion in the Wild. *Computer Graphics Forum.* 2022;41(3):441-452. doi:10.1111/cgf.14553
- [5] Valkanova N., Jorda S., Tomitsch M. and Vande Moere A. "Reveal-it! the impact of a social visualisation projection on public awareness and discourse." In *Proceedings of the SIGCHI conference on human factors in computing systems*, pp. 3461-3470. 2013.
- [6] Petersen E. E. Racial/Ethnic Disparities in Pregnancy-Related Deaths — United States, 2007–2016. *MMWR Morb Mortal Wkly Rep.* 2019;68. doi:10.15585/mmwr.mm6835a3
- [7] Prevent pregnancy-related deaths. Centres for Disease Control and Prevention. Published May 14, 2019. Accessed Jan 16, 2023. <https://www.cdc.gov/vitalsigns/maternal-deaths/index.html>
- [8] Behnam Asl S., Gill C., Umstead K., Mahtani R. and Tully K. A Collaborative Approach to Digital Storytelling in Healthcare Settings. In: *DS 117: Proceedings of the 24th International Conference on Engineering and Product Design Education (E&PDE 2022), London South Bank University in London, UK. 8th - 9th September 2022.* ; 2022. doi:10.35199/EPDE.2022.107
- [9] Kent C. Domestic Data Streamers fighting indifference using data and art Available: <https://www.clotmag.com/interviews/domestic-data-streamers-fighting-indifference-using-data-and-art>. Published January 11, 2022. Accessed Jan 16, 2023.
- [10] Tully K. P., Gibson A. N., Pearsall M. S., Umstead K., Gill C. and Stuebe A. M. Screening and Referral for Social Determinants of Health: Maternity Patient and Health Care Team Perspectives. *Health Equity.* 2022;6(1):887-897. doi:10.1089/heq.2022.0020