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“Don’t be afraid to tell your story. Your voice is important, and your story is unique.”

---Meredith Lavitt

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The Authors

The co-authors of this White Paper were co-creators and co-researchers on their photovoice project “Two Mom’s & a Researcher.”

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Jesse Van Leeuwen

Jesse Van Leeuwen is a “Two Moms & A Researcher” co-creator, writer, mother activist, and the campaign manager for The Moms We Love Club — a group that campaigns for financial resources for women enduring long-term hardship. Mrs. Van Leeuwen’s daughter, Nora, was diagnosed with a rare form of epilepsy —Aicardi Syndrome— when she was 3 months old. Since then, Mrs. Van Leeuwen has been writing about her family’s journey with chronic illness and medical complexities at noraeverafter.com. She strives to ensure her family, and other families like hers, receive the care and support they need and deserve. You can follow her work here: noraeverafter.com.

Executive Summary

This White Paper outlines how a researcher and two mothers of children with medical complexities created a successful virtual photovoice project that became a safe virtual space where “medical mothers” could share their experiences and strategies. The project was born out of a need for medical mothers to navigate the daily challenges they face as primary caregivers and advocates for their children. The White Paper describes their photovoice project process from start to finish, from developing a logo and online identity, to recruitment, engaging with sensitive topics, creating a successful virtual photovoice exhibit, and engaging a virtual audience. The paper concludes with a checklist of lessons learned, to inform decision-making by other virtual photovoice projects and teams. The co-creators’ process of building trust and mutual respect among the core team, with the participating mothers, and with the medical and social services community in San Diego and beyond, is certain to inspire empathetic approaches to photovoice decision-making by future virtual projects that use photovoice to explore sensitive topics.

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Cultivating Engagement in a Virtual Photovoice Project on a Sensitive Topic

Written by: Melanie Sonsteng-Person, MSW and Jesse Van Leeuwen

The “Two Moms & A Researcher” Origin Story

Our project, “What I Would Do to Take Away Your Pain,” was born out of a need identified by Jesse, mother to Nora, a child with medical complexities. Knowing she needed something more from the systems in her San Diego community in order to meet the health, education, and social-care needs of her daughter and family, Jesse reached out to her friend Melanie, a researcher at UCLA, to find out what resources and current research, or literature, were available to her and families like hers. In particular, she wanted to identify resources that would help her navigate the daily challenges she faces as Nora’s primary caregiver and advocate. Together, Jesse and Melanie quickly realized that both the research and medical communities had done little to learn about the voices, or needs, of mothers whose children have a chronic illness and medical complexity. To fill this void, Jesse suggested they create a research project centered on the voices of mothers who have children with medical complexities. From these conversations between friends, a photo-voice project was born.

During the initial planning phase, Jesse brought in another project co-creator, her local San Diego friend Darlene Abrams (Dar), who also has a child with medical complexities and a passion for building social awareness. While Melanie applied for Institutional Research Board approval from UCLA to conduct the project, Jesse and Dar got to work planning,

from determining weekly session topics, to recruitment, to options for the photo exhibit at the end of the study. Their planning sessions took place over the video phone app Marco Polo. In fact, although they maintain a thriving friendship to this day, Melanie and Dar have never met in person. By utilizing a video app, the core team was able to communicate daily and build a strong rapport as they bounced ideas off each other and connected on a personal level, even at a distance. The initial planning conversations, along with the bond they established between co-creators, was paramount to setting a welcoming, participatory tone for the project.

To make the project more accessible to mothers with children who have complex medical needs, and to reduce the barrier of travel time between San Diego and LA, Jesse, Melanie, and Dar decided that the project’s weekly meetings would take place virtually, even before COVID-19 “shelter- in-place” parameters were established.

In this paper, we briefly outline how we created a successful virtual photovoice project, first by discussing recruitment, then the ways we engaged with sensitive topics, and finally our strategies for creating a successful virtual exhibit and engaging a virtual audience. We conclude with a list of lessons learned, in the hopes that they will inform virtual photovoice decision- making by other projects and teams.

Project Recruitment & Establishing Trust

Based on Jesse and Dar's backgrounds and their social media presence, we decided to frame the project around the "brand" "Two Moms & A Researcher." Initially built out of excitement for the project, this brand marketing approach was crucial for participant recruitment, for establishing ourselves and our project in the San Diego healthcare community, and later for engaging an audience for the virtual event. In order to create a successful brand, we took several steps, including:

- Creating a logo, email signatures, and letterhead. Any project communication that went out had these components.



- Creating an active social media presence by developing a [website](#) and [Instagram page](#), and engaging individuals on Facebook. Our activities focused on sharing our personal stories, passions, experience, and photographs of our faces, or graphics that represented our brand and, by extension, our project. We purposefully used the Internet to build an audience for our project and reach potential co-researchers in such a way that they could quickly orient potential participants to the project and help them to feel comfortable with us.

Jesse and Dar also used Instagram Live sessions to connect with the San Diego community about the project and support the recruitment process. During their Instagram Live sessions, Jesse and Dar talked about the project, answered audience questions, and reminded people to sign up to be a part of it. They engaged with a social media audience by asking their followers to reshare the "Two Moms & A Researcher" Instagram account or the flyer on their own social media platforms.

giving mothers of children with
medical complexities a strong voice

Two Moms & A Researcher



If a mother expressed interest, she was directed to a survey link where she could provide her contact information. Melanie then reached out to each interested mother to set up a phone call to discuss the project and gauge her interest. During these initial phone calls, mothers were exploring whether this was the right project for them, and at the same time, Melanie was attempting to determine whether they were a good fit for the project.

During the conversation, Melanie explained photovoice, how the project was created (by Jesse and Dar), the weekly discussion topics, the photo-taking and sharing process, and the exhibit that would take place. In these first conversations, Melanie sought to set each mother at ease, while also providing as much information as they needed to make an informed decision about whether or not to commit to participating fully.

Melanie also gave the mothers time to talk to their families about the commitment before asking them to decide. Asking someone to be a part of a photovoice project is asking them to not only give up their time, but also, to give part of themselves and their families to this project. Photovoice is something that a potential participant should consider seriously before deciding if it is right for them.

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Melanie answered follow-up questions and provided reassurance that all moms would be in similar situations and have some understanding of what they are going through and their need to be flexible. Once a mom decided she wanted to participate, Melanie consented her into the project. Together, Jesse, Melanie, and Dar recruited six participants, based on their initial conversations and their level of enjoyment talking about and sharing their experiences.

Keeping the project to six participants ensured that each mom would have plenty of time to share and discuss the session topic each week in a virtual setting.

Engagement with Sensitive Topics

Building trust and engaging with sensitive topics was an essential goal for the project. Here are a few essentials to keep in mind.

First, recruitment and “brand building” created a foundation for trust. During recruitment, Dar and Jesse showed vulnerability during their Instagram LIVE conversations. They continued to share their experiences and feelings in an authentic, open way publicly during the recruitment process. This approach likely pulled in other moms who were excited about joining these conversations and sharing their own perspectives and insight.

This authentic, sharing-focused recruitment approach set the tone for a supportive group atmosphere throughout the project, though that was not the intention of the recruitment conversations when they started.

Next, the initial phone calls with Melanie built trust and helped mothers feel comfortable with the university co-researcher. During these calls, Melanie found it essential to share a part of her story and her introduction to the medical world through Jesse’s daughter Nora.

Melanie showed her own vulnerability by explaining how it took her time to learn how to be a supportive friend, and how she wished there was a project like this to help her understand what her friend might be experiencing and what she might need.

She also listened to the mothers about the support they had or didn’t have among family and friends, and talked about how and what they would like to communicate with them.

Finally, the first session was essential for setting the tone for the group. During the first session, the co-researchers established group norms and rules. The group talked about what they wanted the discussions to look like, how they wanted to be responded to when a sensitive topic was brought up, and what project support outside of the group meetings would look like.

Each group member introduced themselves, and included their introduction into the world of medical motherhood. Many of the participants were interacting with the same group of providers, caregivers, and institutions in the San Diego area. Early on the group decided that it should be a “closed group,” meaning, the only story or experience that could be discussed or shared outside of the project group was one’s own story. In other words, “If it’s not your story, then don’t share it.”

While co-researchers reflected an array of both positive and negative experiences within their shared healthcare systems, the group wanted to avoid creating fear or distrust in medical institutions or in the providers serving project participant families. Setting boundaries around confidentiality and group discussions and responses forged a foundation that allowed the group to continue to build trust and rapport throughout the project.

Additionally, beginning each weekly session with a more “generic” and perhaps less emotionally laden topic first, allowed the group to get to know one another better. As we built trust, set the tone, and moved into deeper topics, we saw the group engage in an authentic and relatable way each week.

"Trust means taking the risk to try something new or different, even though it may seem scary at first."

We were also conscious of the adult learning needs of the participants. A considerable effort was spent on creating a “syllabus,” or outline, that showed a breakdown of what would be taking place in the meeting each week. Thus, before each session began, everyone knew the topic and what the structure of the group would look like.

In addition, group members had an influence on the project topics. Starting at the end of week 1, we talked as a group about the topic for next week and the pictures we might take. As the weeks progressed, it became easier and easier for participating mothers to share their pictures and talk about them. Each mother interpreted the topic in her own unique way and was vulnerable with who they are and what they have experienced. Because of this vulnerability, the mothers were able to engage with each of the pictures in a meaningful way and talk about what it meant to them and what stood out the most for them about the topic and discussion.

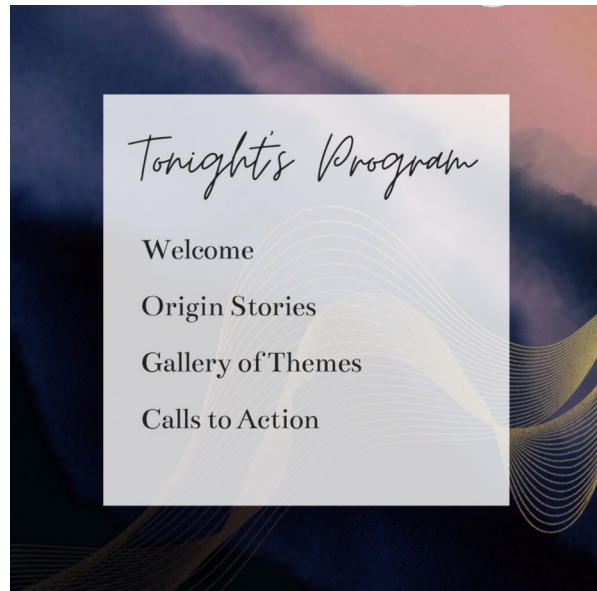
Virtual Audience Engagement

While initially the end product was supposed to be a photo exhibit at the local Children’s hospital, our final product evolved into a virtual exhibit. Due to COVID-19 and the virtual nature of the project, there were several things we had to consider when changing from an in-person to a virtual exhibit: platform, audience engagement, and how to present the topics and pictures in a compelling way.

First, the three project leads attended trainings and webinars on how to create virtual events. We ultimately presented several options for our event to the group of moms. It was decided that a Zoom webinar would be best, as it allowed us to keep the momentum of our project, control audience participation, and record the session, while supporting the highest number of audience members.

Second, as a group, we had to think through how we could engage our audience in a meaningful way during the webinar. Since we could not have our audience members walk around and engage with each other, photos,

and mothers in person, we had to consider how we could present the same information in a compelling (virtual) way. As a group, we consulted with Dar’s father-in-law, Glenn Abrams, a producer, who suggested the use of PowerPoint to present our content, and asked the group to think of the PowerPoint as less of a lecture and more of a short and impactful film. Second, our group created a program for the “film,” as such:



When it came to engaging with sensitive content with an audience, Melanie was intentional in communicating with participating mothers about the unique nature of a “virtual” event. Throughout the process of determining the content to be shared publicly, the mothers were reminded that due to the virtual nature of the event, there was a lack of “control” over the content. Sharing the content virtually meant that their personal stories, experiences, and photos, were leaving their hands. However, Melanie was able to refer back to preestablished group norms and remind the mothers that they could, at any point, pull any personal photo or content they were not comfortable sharing publicly, even if they wanted to do this just minutes before the event. Throughout the project, these reminders from Melanie appeared to contribute to and enhance the strong sense of trust and support built within the group.

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Jesse actually opted to pull a personal photo the night before the event and was met with support and understanding from her co-researchers.

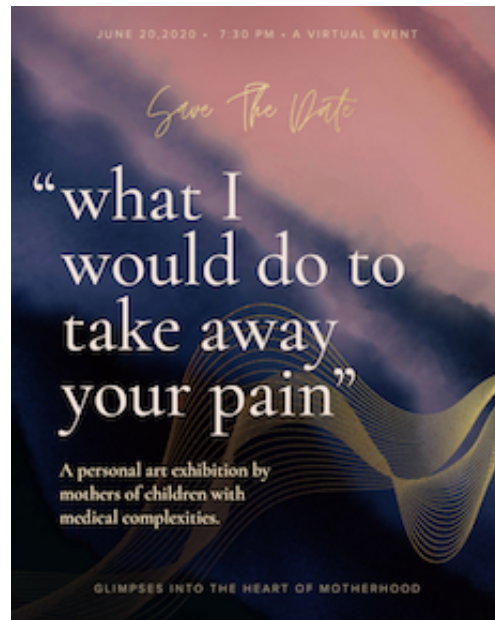
As a group, we chose to pre-record each mother's "origin story," or the personal account of how each woman came into the role of medical mother, for the event. We knew that these origin stories would be deeply personal and hard-to-share narratives that would elicit strong emotions from the speaker and fellow participants/co-researchers. We wanted to preserve the emotional space around each narrative, for our group and also for the viewer, while maintaining our ability to stay present and move forward with the presentation that we had worked so hard to create. We rehearsed the virtual exhibit three times to make sure that everyone was sufficiently prepared. Glenn, our production consultant, created a script for the virtual exhibit, donated his time to offer public speaking tips to our mothers, and ran the PowerPoint during rehearsal and the live event.

Jesse believes the trust cultivated within the group as a whole made for a successful and comfortable live Q&A during the event. The group trusted Melanie's ability to field and discuss sensitive questions and topics, all while having a deep respect, understanding, and appreciation for each other's perspectives and experiences — something that was evident very early in the group process, but manifested clearly at the virtual event.

As a group, we made a guest list of the individuals and organizations we wanted to be present at the virtual event. Location was not an impediment to participation. We opted to invite all members of the San Diego community of medical mothers, and any organizations and systems that overlapped with our group of mothers. A clear and aesthetically noteworthy invitation was created by Dar's husband, in tandem with an Eventbrite page to facilitate RSVPs and communication with guests. This is where the hard work of establishing a trusted "brand" early on in the project—with a logo, and across social media—benefited the project as a

whole. Potential guests were able to learn about our project and its research aims, and learn something about the exhibition prior to the event.

Because the project and our group of mothers have extensive rapport and relationships within the San Diego community, several organizations offered to promote the event via their personal email accounts, social media accounts, or by word of mouth. to families with children with medical complexities. Organizations included: California Children's Services (CCS), SD Live Well Collaborative, Make-A-Wish, Rady Children's Hospital, and other local healthcare organizations, or therapy centers, serving children with medical complexities and their families. Mothers shared invitations within their networks, and 80% of attendees of the live event reported receiving a personal invitation from one of the mothers.



Finally, as a group, we decided it was essential to build momentum leading into the event, to start engaging with our audience in whatever ways we could, and ensure that registered attendees actually logged in to the live event. We did this by creating a "drip marketing campaign," where we sent out weekly reminder emails, or what we called, "Weekly Event Briefings," to the registered audience that included one mother's written narrative of her personal "origin story" per week.

This project in virtual form was successful for many reasons. Still, at its core, its success could be traced back to trust and mutual respect between its original co-creators, Jesse, Dar, and Melanie, and their ability to translate “Two Moms & A Researcher,” into a trusted brand within the San Diego and wider communities. But ultimately, our project and the virtual event was and remains simply an extension, or an invitation, to the safe and beautiful space created by a group of encouraging, kind, passionate, and empathetic medical mothers.

And, from our perspective, creating and cultivating this space together was our most tremendous success and joy.

What is Photovoice?

Photovoice is a participatory visual research method first employed and codified by Caroline C. Wang and Mary Ann Burris in 1992 as a way to bring daily life experiences of village women in Yunnan Province, China, into decision-making for regional development.

Photovoice puts cameras in the hands of people with valuable lived experience so they can explore and share their perspectives on health, family, community, and their futures.

For the past 25 years, projects have been carried out with youth, persons living with chronic health conditions, persons who have physical, emotional, developmental, or cognitive disabilities, homeless, pregnant teens, veterans, and many others.

A straightforward method fostering patient, family, and community dialog, photovoice is an innovative way to reflect, talk, learn, share, create awareness, and plant seeds for change.

Founded in 2019 PhotovoiceWorldwide’s mission is to help individuals and organizations worldwide use photovoice safely, ethically, and successfully, and to create a global community for photovoice peer-to-peer support and continuing education.



For more information, visit our website at www.photovoiceworldwide.com

Best Practices for a Successful Photovoice Project in a Virtual Setting on a Sensitive Topic

1. Identify a topic that has the potential to be meaningful for photovoice project participants and inform and educate the community.
2. Take time to build rapport and trust among the core facilitators/ co-researchers.
3. Establish a "brand identity" from the start.
4. Spend time helping participants understand the project purpose and process, and allow them to make an informed decision about participating. Use the initial conversation to gauge the potential participant's "fit" with the project and the group.
5. Keep the project group small to allow enough time for full participation by all in every project session.
6. As co-researchers, be willing to be vulnerable to potential participants, each other, and the community.
7. Create group norms early on and stick with them.
8. Keep project conversations private to the group, to avoid creating stigma, antagonism, or discomfort among providers, the healthcare system, or other social systems available to participants.
9. Encourage rich photo conversations by starting with more generic topics.
10. Create instructional transparency, share ownership, and reduce anxiety by engaging participants in determining session topics and sharing outlines and plans at the start of each session.
11. Draw on available resources among family and friends. Get training if needed to create virtual exhibits and other outreach products.
12. Revise and confirm photo submissions throughout the project. Allow any participant to withdraw their photo at any time.
13. For the virtual presentation, consider pre-recording participant presentations, to help ensure that sensitive, emotional experiences are successfully presented.
14. Engage with stakeholders early and often through social media and personal contact.
15. Create excitement for the virtual exhibit through planned "mini-activities" during the weeks beforehand.