



"What I want you to know" - adult women's stories of cleft lip and/or palate

produced June 2024



PROJECT IN PROGRESS FOR PARTIAL FULFILLMENT OF A DOCTORATE IN CLINICAL PSYCHOLOGY, BY INSIDER-RESEARCHER, DANIELLE MCWILLIAMS

CONTACT: d.mcwilliams835@canterbury.ac.uk

AN OVERVIEW

This project employs a narrative, photovoice methodology to explore adult women's stories of cleft lip and/or palate.



Photovoice is a form of data collection, whereby participants are asked to take photographs to represent their narrative. This method was used in direct response to findings in cleft and craniofacial research that people are often left feeling unheard, disempowered and that many professionals and others around them do not 'truly get it'. With long histories and current experiences of invasive treatment and often lasting physical/psychological impacts, the notion that cleft is entirely a childhood condition is outdated. By deliberately keeping prompts sparse and encouraging the women participating to 'come as they are', participants have complete ownership about what they chose to share and how they wanted their stories told.

Narrative interviewing describes a method which utilises humans' native storytelling ability. With no set agenda other than "tell me your story", participants were not limited to a satisfaction questionnaire, an account of their treatment experiences or subscribing to an 'angle' (e.g. difficulties or 'resilience'). Narrative work allows for, and requires, the listener to have a role, and rejects the idea of researcher neutrality, as it simply is not possible; everyone has a story. Stories are co-constructed as they unfold, using the images to guide and enrich the conversation.



Through the women themselves producing images that tell their unique story of an adult born with a cleft, untold stories are **constructed**.

Through a narrative interview with the lead researcher, who is also a woman born with a cleft, stories are **shared** and enriched.

Through utilising an academic and professional platform to write a thesis, produce manuscripts, create training material and raise awareness, stories are **heard**.

ABOUT THE RESEARCHER

My name is Danielle McWilliams. I am a trainee Clinical Psychologist with experience in craniofacial research. I am also a woman born with a bilateral complete cleft lip and palate.

This project is my thesis for my DClin qualification at Canterbury Christ Church University (UK). I also have an MSc from Kings College London and an MA and BA from The University of Cambridge.

I am also a reviewer for the Cleft Palate-Craniofacial Journal, and have spent four years working in craniofacial research. You can read my other publications by scanning the QR code below.



Danielle McWilliams,
Insider Researcher

My work tells an important part of my story, one which I am proud of. I am also proud of the fact that I have done this alongside navigating and making sense of my **own** story. I have had approximately 28 operations, been treated in four different cleft teams and have my own story of what it is to be a woman with a visible difference in today's world.

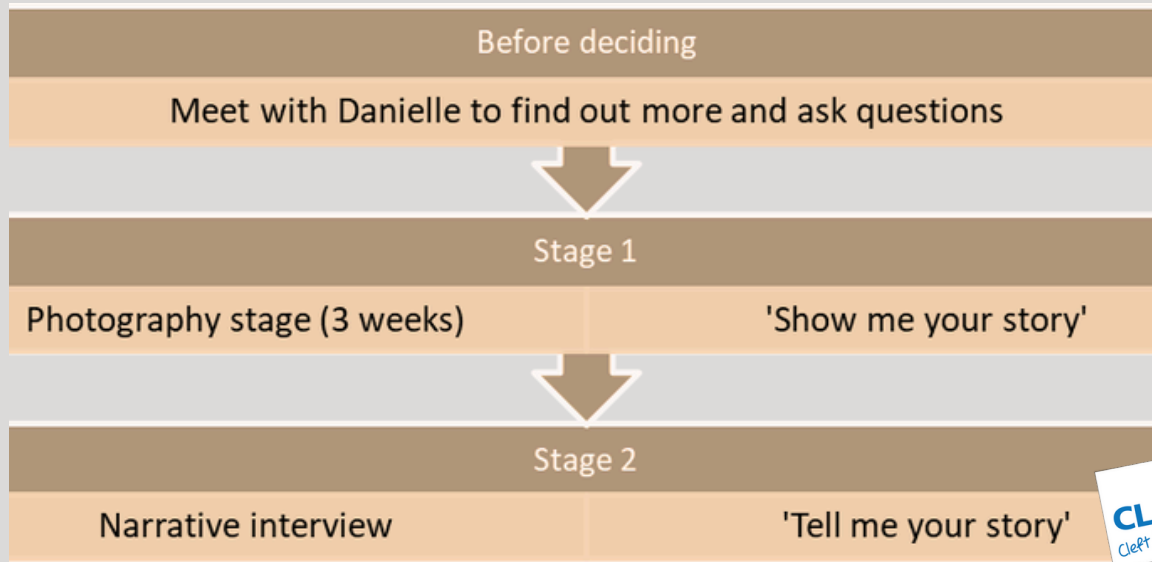


I am a strong believer in the importance of lived experience within clinical and research teams. I have learned **how** and **when** to use my lived experience in a way that enriches my work, and the work of teams I have had the pleasure of working within.

The rest of this booklet tells you about my project. Please know that I have laughed and cried with these women, and have often found great strength, alongside pain, in their stories. It has been an absolute honour to hear, bear witness to and be trusted to tell them.

WHO TOOK PART AND HOW?

The data collection is nearing completion, with only a few interviews left to go as of end of June 2024.



Participants were recruited via social media and with support from CLAPA and Face Equality International.



Every prospective participant met with me via MS Teams to find out more, and were provided with an information sheet and consent form. Interviews were recorded and transcribed verbatim.

To date, 14 women have participated in the project, 9 in the UK and 5 in the US. At the time of interview, the women were aged between 22-72, with an average age of 44 years.

Type of cleft	#
Unilateral cleft lip and palate	5
Bilateral cleft lip and palate	6
Cleft palate only	2
Bilateral cleft lip only	1

Participants took photos on their smartphones, and were free to photograph anything. All images including faces or identifiable information were used for the interview stage but will not be published to ensure confidentiality.

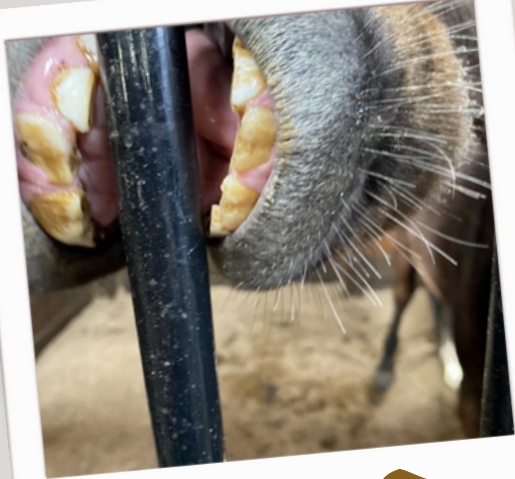
Jennifer is an **Expert by Experience** consulting on the project. She is a teacher living in New York (USA) and founded the Women's Cleft Coterie, a highly successful Facebook network connecting cleft-affected women across the world. Jennifer was instrumental in helping to design the protocol for the project, recruitment in the US and will continue to have input as we progress with analysis and dissemination.



This project is supervised by Academic Tutor and Clinical Psychologist Dr. Alan Hebben-Wadey

A SNAPSHOT OF THE DATA

This is a very preliminary insight into some of the images and stories that have been constructed throughout the project.



This is a young horse at my barn...doing a silly thing with his teeth on the bar. It reminded me of having the photos taken when I was younger, where the surgeon or the orthodontist would ask me to put these plastic pieces in my mouth and pull back my lips so they could take photos. They never showed anything...but what was missing and damage and what needed to be put together. To this day I'm extremely camera shy and I put that directly back to having those what I call the ugly pictures taken. It would have been really nice after all the ugly pictures just to hear "OK smile. Let's take a nice picture." - *Georgia, 55*

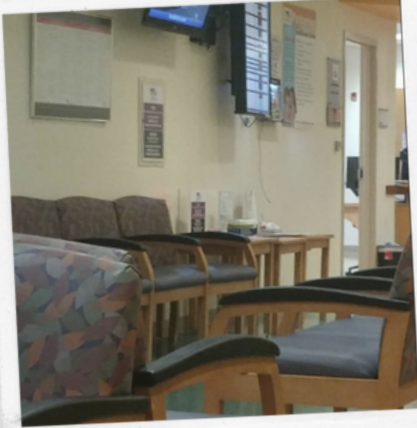
You hear people lamenting that they can't find a partner and "I just want someone who's different." Well, I am someone who's different so I know that they're not always telling the truth on that. They want a very curated kind of different. It was hard and there were times that I would be set up and I could see the shock or the disappointment or maybe it was disgust, you know, when the the man showed up. - *Anna, 55*



I'm a big butterfly lover...to me it does mean metamorphosis and change and growth. It has to do with my growth and change, and to me my self-love and acceptance...I know that my beauty is unique and that butterflies are resilient. Change, which I've done so many, many, many times: I'm not afraid of change. When I was in my 20s, I used to walk down the street with my head down 'cause I didn't want people look at me. Now it's like "oh, I don't care. I'm gonna look you right in the eye" and here we are. I'm 72, 73 next month." - *Terri, 72*

Piercings...there's more of an identity aspect to this. Is it that I want to reinforce the 'unique and different' idea? Is it that I want control, bearing in mind that a lot of the cleft surgery and dentistry is in your face, inside your very personal space? I think I wanted control over what I looked like and who went in my headspace. So, it represents way more than how many earrings I've got in my ear - does that make sense? - *Leah, 54*

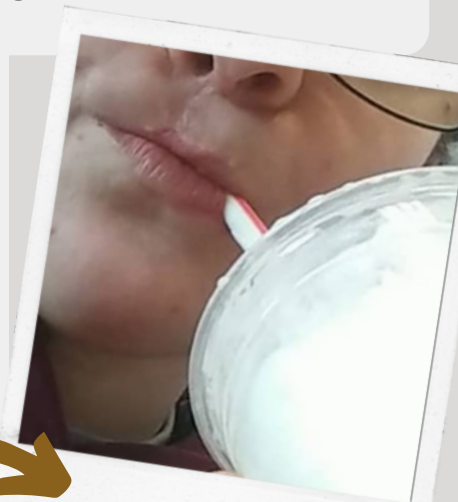




Having so many surgeries and painful medical situations surrounding my cleft has almost definitely given me medical post traumatic stress disorder. Medical waiting rooms stress me out, like the smell of the alcohol wipes they use to prep your IV stresses me out. All of those traumatic childhood things don't just go away when you become an adult, they follow you. Recently, I had to get put to sleep for like a very minimally invasive procedure like very low risk and I told the anesthesiologists that I was gonna need anxiety medication. He told me "you don't need that. It's a very easy procedure. Nothing's gonna go wrong" -

they're trying to be helpful but they don't understand the degree of like embedded reactions that I have to medical situations.

I had jaw surgery....not only could I now drink out of a straw, but it was a milkshake! One of my uncles commented "oh, you don't need to have surgery. You're beautiful the way you are" for which I appreciate the sentiment, but it just was one of those moments that highlighted to me that other people don't realise that even into adulthood, surgeries are sometimes really important for your quality of life. Like it's not just an aesthetic thing, it's being able to drink a milkshake!



I've run into a lot of people trying to be nice and tell me that no, you don't look noticeably different. You're beautiful. Which...is a problematic way of going about it. I know they're trying to be helpful, but in saying that you're saying "to look noticeably different would mean you're not beautiful. But don't worry, I couldn't even tell anything was different about you." I can tell that I have cleft lip and palate and I know that other people can too. And I don't think that that makes me not beautiful. - *Harriet, 23*



I have always been and am always very careful about how I present myself. I think I compensate a little bit for the fact that I feel that my face is unusual or unattractive by making sure that I always look nice and it is a huge part of who I am...otherwise I would be worried that people would assume that I was not clever and not in control. I'm well aware because I'm a teacher that that people do make assumptions. Beauty bias is a really real thing. I think people make assumptions about unattractive children: that they're less intelligent.

I think that I worry that I put myself in that category and I give people a leg up by by looking the part and then they're more likely to overlook my face. - *Charlotte, 43*

There are over 700 pages of stories just like these.

RESPONSES SO FAR

Preliminary responses to the project, both from the women who took part, other adults with cleft and those without, are summarised here.



Mini-exhibition
Toynbee Hall, London
CLAPA Adults Conference

OTHER ADULTS WITH CLEFT

"Is it sadness? Is it catharsis? I've come so far in my life and yet never heard another person say that they have felt the way I have felt until now."

"I love the visual element to this. It's so powerful."

"YES! This is how I feel."

"Even in 2024, people's judgement and making assumptions are the worst things we (as cleft women) face. Well articulated."

ADULTS WITHOUT CLEFT

"The stories that are told are undeniable. Any woman can relate to feeling scrutinised, feeling different, and even feeling dissatisfied. These images/stories unlocked something in me: seeing the true vulnerability and rawness coming through in what I reckon could only be achieved by a conversation between two people who truly see each other."

"Very different way of producing and reporting research, I hope to see this go far!"

"Through the lens of women's experiences, the images and stories were able to bring attention to discrimination and pain faced by some people with cleft lip and palate today, and I felt acutely aware and personally upset by how unfair that is."

THE VOICES OF PARTICIPANTS

"I've loved it. I don't really ever see myself through that lens and this has brought it together. It was so lovely to talk to someone who makes it feel normal and isn't uncomfortable with me mentioning anything."

"It helped me to draw out the expansiveness of what each picture and experience meant, and to see the depth and complexity of my experiences."

"I wouldn't have opened up to this like this to somebody who did not have cleft herself. And I don't think I would have opened up to a man with cleft. It's going to be a really big thing, there's lots of opportunity here."

All in all, a most validating experience. Danielle is an active and engaged listener, reflecting back and clarifying with genuine understanding but with no assumptions at all. Genuinely a very skilled practitioner and interviewer.

It has helped me take several steps along the path to understand myself, which I very much value.

I feel that I trusted Danielle fully to portray an accurate and detailed account of the conversation.

Often, researchers are seeking to understand the thoughts and feelings of a population group which they have some connection with, but aren't part of.
Discussing cleft with someone affected by it, hits very differently.

LOOKING AHEAD - COULD YOU BE INVOLVED?

These stories now need to be heard more widely.

By April 2025, the data will have been analysed in full and a DClin thesis will have been produced.

Ideas for the future

Publishing manuscripts

Conference exhibits/talks

Public exhibitions

Staff training events

Media coverage

Community awareness events

Online gallery space

Celebration events for participants

I am also keen to explore the potential therapeutic benefit of inviting cleft-affected adults to share their stories in this way, which could inform psychological support for adults.

Opportunities for support

I am looking to the whole global cleft community, and those with any connection or desire to connect to it to support and share this project in the hopes of securing future resourcing, platforms for sharing, funding and interest.

If you have any questions, feedback, opportunities or ideas in mind, please get in contact.

d.mcwilliams835@canterbury.ac.uk

For ongoing updates, follow the project's X/Twitter account



@WomenAndCleft

www.x.com/WomenAndCleft



Thank you for your interest and I look forward to hearing from you.