



Essays

A cleft in time

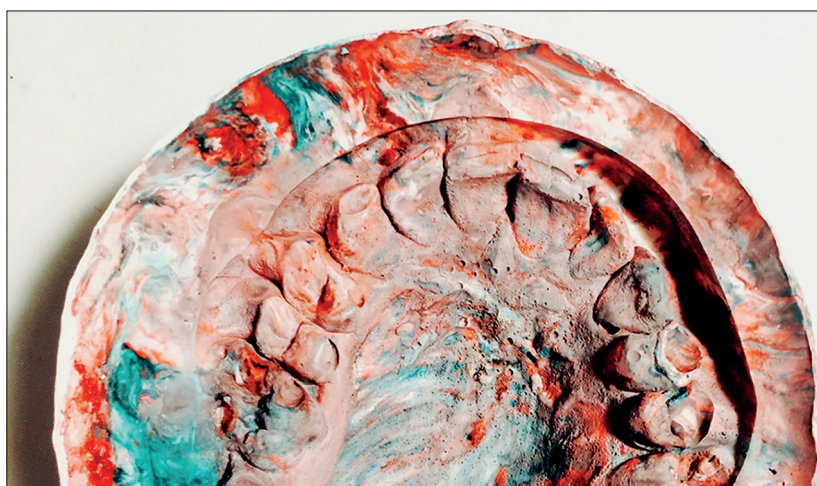
Sitting together in a circle on the floor of the National Portrait Gallery (London, UK), the group is sharing stories as the rain and busy traffic rumbles outside. “Well, after my second bone graft failed, sometimes I used to make milk come up through my cleft palate and out my nose to surprise people”, one of the girls giggles. “Oh, that was also my party trick!” chips in her friend. The rest, all of whom were soon to start high school (aged 10–11 years), nod along with approving grins. The group of young people has spent the afternoon exploring portrait paintings and making new friends as part of an outreach day with the Cleft Lip and Palate Association (CLAPA).

As an artist leading a programme of events in collaboration with the charity, I sit down with them to reflect together on their thoughts about the art they’ve seen. With the portrait as the starting point, they readily exchange stories together about growing up with cleft lip and palate. They explain to me that it’s difficult for others at school to completely understand when there’s such widespread misconception, especially when many aspects are hidden from what you can see visually. To grow up with a diverse, multidisciplinary health-care team planning treatments for you from your first childhood memories until adulthood can seem unfathomable to outsiders. Missing school for frequent appointments when he is not ill, one boy explains with a sigh, is something his classmates are jealous of, and they frustratingly continue to query why he gets more time off school. The truth is, he says, he would like them to already know what a cleft palate entails without him needing to tell them, so that they would appreciate that he’s had several uncomfortable surgical operations with recovery taking up his summer

holidays. He reflects on the dreaded frequent visits to specialist dentists, speech and language therapy for his lisp that he’s been bullied for, and appointments with a clinical psychologist to review his mental state. At 10 years old, he tries to explain to his peers, but given what he’s experienced, how could they fully understand?

The weird, wonderful, confidence-boosting, frustrating, tearful, and laugh-out-loud funny moments that the group talked about, carved through a childhood of growing up intertwined with the health-care system, are often hidden for children with a cleft. They reach far beyond the frequently assumed public opinion that cleft predominantly involves a faded scar on the lip. As an artist who is qualified in both medicine and dentistry, I endeavour to use artistic workshops for young people with a cleft to foster interconnectedness and storytelling, with self-representation and the portrait at the project’s core. This interdisciplinary arts project was in collaboration with the South West Cleft Service, Science Gallery London, and the charities Above & Beyond and CLAPA, and it sought creative outlets to offer an alternative discourse of facial difference, led by young participants constructing their own emotional understandings.

Artistic explorations of facial difference require thoughtful and open communication, the creation of safe spaces, and an appreciation of the intersection of the ethics and aesthetics involved in discovering a personal identity. For young people shaping their sense of self, creative exploration in this project was a way to connect to others and build relationships, helping others to understand them and to perceive experiences through their eyes. This was brought to the forefront as a different group of young people stood in the middle of The Island art gallery in Bristol, UK, gazing in eager anticipation as melted wax started to solidify in a cool sheen of alien blobs over a model nose. One of the teenage girls with a cleft who had been through several facial surgeries had dribbled hot wax all over the deftly crafted wax facial model that she had sculpted that afternoon. Earlier in the session, this group (aged 15–17 years), under the care of the South West Cleft Service, had been guided in anatomical musculature of the face by sculpting faces in wax upon a plaster skull base by artist Eleanor Crook. In this part of the session, though, we were experimentally abstracting the face and distorting conventions of what a face should look like, by embedding jewellery, shells, hair, coloured inks, and curious wax shapes into quirky new designs. Alongside consultant cleft psychologist Dr Julia Cadogan, we spent the afternoon opening dialogues, with the arts activities being the stimulus sparking conversation. One older participant

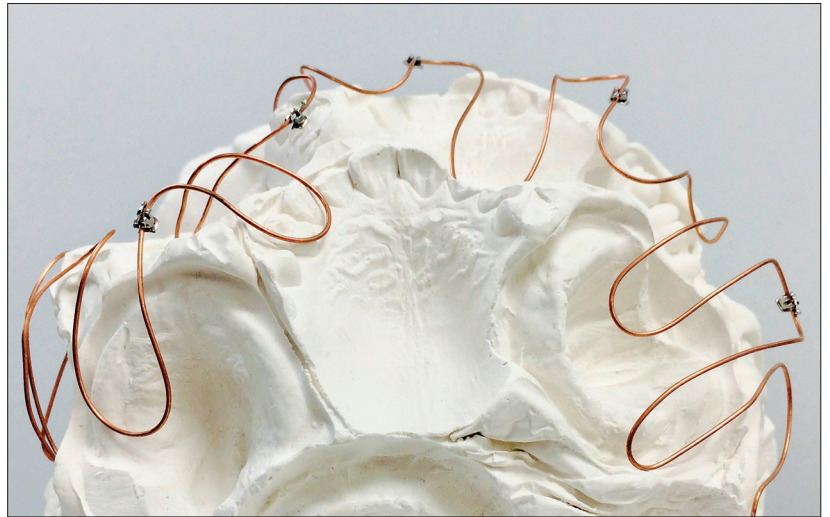


Mouth and hard palate impression casted in coloured plaster by a workshop participant

had joined the group—a retired woman who grew up in a different era with a cleft. As we pushed the wax with our fingers into the curious faces peering up at us, she shared her stories with the teenagers of how cleft care was different for her as a girl. Experiences of stigma with facial difference resonated across the generational divide for the young participants listening interestedly, and we felt connected in the group, with the arts activity having drawn together those who wouldn't normally cross paths to share experiences and reconnect after many years.

A few weeks later, I sit in a classroom with 30 pupils in year 9 (aged 14–15 years) from a South London school who have come to King's College London for an outreach art workshop. I think back to the narratives shared by those with a cleft and how they invited me into their journey. As part of the public engagement work, these young people are learning about the hidden aspects of cleft palate for the first time. I'm joined by a young person's worker from CLAPA, and we share stories and video clips of young people with a cleft explaining questions and experiences that they felt their peers should know about: what is the hard palate and why does it have such an impact when it forms differently? A unique rippled imprint, like that on our fingertips, the hard palate is hidden from view on the roof of our mouths and can be revealed with our tongues. The group uses dental materials to cast their hard palates and newly realise them in coloured plaster, with the weightiness of the abstract objects sitting in the palm and inviting the fingertips to trace over the rugae. The individuals in the group compare their cast with a friend's, which readily shows the surprising and strange normal variations in our mouths and bodies. The young people taking part are encouraged to take away their abstract plaster cast housing their oral impression to show their friends and family. In doing so, participants are encouraged to share what they have learned, to educate others about cleft. The participants themselves were also collaborators, with their hard palate silicone impressions then re-used as part of an art installation exhibited for public display and education at Guy's Hospital (London, UK), which included sound recordings from young people with a cleft discussing their experiences.

By placing storytelling at its heart, the arts project used creative enquiry to allow young participants to construct their own understanding in spaces that encourage



Part of the audio installation and sculptures exhibited in Guy's Hospital (London, UK)

interconnection and reflection. The humanities are increasingly being recognised for their value in person-centred care, and by learning from their narratives, the impact upon me personally as a clinician and artist was palpable. Navigating clinical experiences through the arts has deepened my relationship with patient groups such as these young people with a cleft, through their openness and kindness. It has helped me to reflect on lived experiences, foster shared understanding, and build meaningful relationships with diverse groups, alongside considering how the creative arts within medicine and caregiving provide a language to articulate challenges of the human experience that can be intangible, transient, and emotive. This ability of the arts to invite audiences to experience elements of life that are hidden or cannot easily be grasped, lends itself to helping health professionals and the public understand nuances of patient experience and ethics, particularly through storytelling. As a long-term influence on my clinical career, the arts and particularly the portrait are a fundamental method to explore interconnectedness in my practice and research, with pieces of art forming visual reflections of relationships along the way.

Simon Hall

India's adolescents: taking charge of the future

In the heart of Mumbai, India, there is a small pond in front of a school where children play, skipping rocks and dipping their feet in the water. This oasis serves as a respite where young people can converse freely about anything on their minds, away from the attentive ears of parents, guardians, or school teachers. By the pond,

we meet each other—Dr Priya Shankar, a pediatrician and co-founder of a non-governmental organisation, Adolescent Health Champions (AHC), that trains youth as peer educators, and Neha Bhat, a 15-year-old school student and AHC peer educator, who will soon teach her classmates about adolescent health.



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