

Chapter 14. Under the microscope

Susannah Hall¹, Sofie Layton, Giovanni Biglino²& Anna Ledgard³

¹*GOSH Arts, Great Ormond Street Hospital for Children NHS Foundation Trust*

²*Bristol Heart Institute, School of Clinical Sciences, University of Bristol*

³*Artsadmin Associate Producer*

susie.hall@gosh.nhs.uk

Abstract

Under the Microscope is an arts research project conceived and led by artist Sofie Layton in partnership with GOSH Arts and the NIHR Biomedical Research Centre at Great Ormond Street Hospital for Children NHS Foundation Trust and University College London.

Over 12 months Sofie explored how children and families interpret medical information and understand disease. Working with clinicians, researchers, patients and their families to understand the issues she developed artwork in response to these conversations, and created imagery and representations of disease, as well as the experience of treatment.

The project culminated in a series of installations exhibited at the hospital and the Institute of Child Health. Artworks included 3D medical heart prints, interpretive heart sculptures, soundscapes, embroidered and embossed hearts made by Sofie and participants, and a sensory installation, which explored the visual landscape and intricacies of the immune system, and the experiential reality of a young patient undergoing gene therapy. Audiences were invited to 'scrub up' and enter an interactive isolation tent with an accompanying soundtrack.

Patients and hospital staff were invited to attend the exhibition and discuss the issues raised. The exhibits were also open to the public on bookable tours guided by young people from our Young Persons Advisory Group. Feedback was gathered from all participants and the public were also given the opportunity to comment. There was a highly positive response from both patients and clinicians, and the general public.

Keywords: art, PPI, imagery, narrative, children's hospital, 3D printing.

Description of Experience

The project ran over 12 months and was broken down into the following phases;

1. Interviews / discussion with clinicians, researchers and biomedical engineers at GOSH and ICH as part of the research phase
2. Workshops with patients and families at Great Ormond Street Hospital on Bear (Cardiac), Fox (Bone Marrow and Stem Cell transplant) and Robin (Immune and Isolation) wards
3. Workshops with a specific group of Young People with Congenital Heart Disease (CHD) exploring the notion of uniqueness
4. Public Exhibitions



Figure 1. Young people with Congenital Heart Disease taking part in a creative body mapping exercise (Stephen King, 2015)

The three public exhibition outcomes were as follows;

Unique, Main Entrance, Great Ormond Street Hospital Exhibition documenting artist - led participatory workshops involving young people living with cardiac conditions and congenital heart disease and related artworks. Including group work made by participants with the artist, and work by the artist.



Figure 2. Collaborative art piece made by artist and project participants using embossing techniques and quotes from patients and families (Stephen King, 2015)

Making the Invisible Visible, Gallery, Institute of Child Health
A series of multi-disciplinary artworks about the heart including textile panels, 3D medical heart prints, and sculptures that translate some medical aspects of cardiology. Created in conversation with the cardiovascular imaging team, clinicians, parents and patients on Bear Cardiac Ward and young adults attending transition clinics and their parents.



Figure 3. 3D printed heart models on display as part of exhibition *Making the Invisible Visible* (Stephen King, 2015)

In Isolation, Friends' Roof Garden, Great Ormond Street Hospital
A sensory installation, which explored the visual landscape and intricacies of the immune system, and the experiential reality of a young patient undergoing gene therapy. Participants were asked to 'scrub up' (i.e. put on hospital gloves, apron and mask) before entering a replicated isolation tent, and sit on a hospital bed whilst listening to a specially edited sound track of patient testimony and gathered sounds.



Figure 4. Participants listening to sound track inside sensory installation *In Isolation* (Stephen King, 2015)

Reponses from participants were gathered throughout the project and in specific interviews led by evaluator Anna Ledgard at the end of the project.

During the workshop process young people commented that the creative process had helped them visualise their heart in a particular form, and gave powerful metaphors.

My heart is a Rubick's cube, a puzzle, a patch work that cannot be fixed! Patient

My heart is a soldier; it's been through the wars, I am really proud of it. Patient

Participants also articulated how taking part in the project had been a useful and cathartic experience.

I am no different from everyone else and everyone's heart is different including those considered 'normal'. Without the 3D printing and

Sofie taking it upon herself to have an MRI scan, I would never have known that there is no such thing as a 'perfect' heart. Patient

It is wonderful seeing our opinions and reflections brought to life in amazing art work. I am very pleased with the outcome, and proud to have been involved. Patient

Staff involved in the project also commented on how the artistic process allowed patients to express complicated feelings about their conditions;

Young people who have struggled to articulate their feelings about their heart for years have been able to express it in other ways Clinical Nurse Specialist

Giving insight through art to invisible processes and structures is very important for learning, patient experience and patient outcomes. Artistic imagery can be very powerful and more memorable to the non-scientist than scientific images and this stimulates interest and awareness. The work helps to make science more tangible and something to be embraced rather than feared for the non-scientist, conveying that science is not just for scientists but is for all of us. Health Psychologist

Results

The project brought together an artist with a strong vision and practice, and an established hospital arts programme. Working in partnership and over a longer time period than usually viable, enabled the artist to really embed herself into the life of the hospital and take time to make relationships and explore avenues of interest. Longer term artist-in-residence interventions can allow sensitive topics to be explored and deeper outcomes to develop (Caulfield, 2014).

The workshops, particularly the focused sessions with young people with CHD, allowed patients to explore the uniqueness of their condition in depth,

and work in a supportive environment with a multidisciplinary team (Layton et al, 2016).

The project also allowed the arts team to develop a strand of work that broadened their reach from specific delivery of creative activities to patients and their families, to a wider audience of clinicians, researchers and the general public. This public facing work, whilst not altering the programme's core purpose of arts activities for children at their specific hospital, allowed GOSH Arts to raise its profile and develop practice (Ledgard, 2016).

Embedding the work within the existing arts programme also meant the artist was properly supported, and could build upon the existing relationships and positive reputation of the arts programme within the hospital to make initial approaches to staff and patients. Arts in health projects can involve many diverse partners who can be difficult to bring together (Raw et al, 2012) without the support of an established figure in the hospital. It also meant all procedures and logistics regarding hospital guidelines such as infection control, safeguarding etc would be adhered to. The uniqueness of the setting and particular guidelines can be difficult and confusing for an artist to navigate on their own (Noble, 2012). The programme also offered the artist additional opportunities to engage with patients and staff, and to share practice with other artists from all art forms working in the programme.

The project reached a much greater number of participants than originally expected. Over 200 direct participants, approximately 1400 exhibition attendees, plus additional numbers viewing online and engaging through social media and twitter. Of particular interest was the number of clinicians and researchers reached who might not normally engage with the GOSH

Arts programme. Staff contact with the exhibition had some profound effects, with many staff commenting that they hadn't considered the patient perspective in this way before.

The installation reminds staff that there is a person behind that heart, scan or medical image and staff should consider the whole person and how that person feels about their heart
Clinical Nurse Specialist.

The location of the exhibition *Making the Invisible Visible*, in the gallery corridor which links Great Ormond Street Hospital and Institute of Child Health, was particularly significant both symbolically and in giving the work profile and status with staff at both institutions.

In the final evaluation report, Ledgard (2016) explored the findings and wider implications of the project;

'Under the Microscope met and, in some instances, exceeded its original objectives, producing high quality beautiful artworks, and was considered a model of good practice by all involved: clinicians, researchers, nursing staff, psychologists, patients and general audiences alike.'

The aesthetic and 'beauty' of the final artworks, despite, or because of, their sensitive subject matter, was appreciated by many participants, and figured highly in narrative analysis of audience responses. Written feedback was gathered from 128 respondents through a 'Comments Book' situated in the exhibition and 'postcards' that could be filled in and returned.

One of, if not THE most beautiful exhibition I have ever seen. The imaginations of artists, scientists, clinicians and patients in one place is mind-blowing. Visitor

This has been the most beautiful display so far. Visitor

The pictures are complex, bold and beautiful and in some ways they mirror the complexity and beauty of the subject matter. I found the use of the 3D printed hearts, the printed screen, the metal tables as well as the pictures all complementary which gave a really holistic feeling to the installation. Visitor

The 'beauty' or quality of the artwork also gave it credibility with visitors, and this could lead to deeper engagement with the subject matter.

Because it is so beautiful, I took the time to stay and read the information. Visitor

Discussion

For the arts programme in the hospital the project offered an opportunity to embed an artist over a longer period of time, and therefore explore issues that are complex or sensitive. The regular programme does not often directly address illness and disease in this way due to constraints of time and context, but working with an artist who gained the confidence of clinicians and support staff such as nurses and physiologists meant GOSH Arts felt confident in the integrity of the process and quality of the final outcome. The buy-in and proper support of staff is key to the success of this type of work (Charnock, 2006).

This can then lead to deep and effective collaboration between 'artists' and 'scientists/ 'clinicians', as Biomedical Engineer Dr Biglino comments in Ledgard, 2016;

Working with an artist provides the scientist with a new avenue of research, paved in the artist's vision. [...] When working together, the artist is not just an outlet for a scientific concept, embellishing it or simplifying it in order to make it more accessible. Her work is complementary, adding form, colour, texture, and above all narrative to a concept, which is often abstract or technical. (Biglino in Ledgard, 2016)

This project has led to further collaboration and an on-going relationship between the artist, the biomedical engineer and GOSH Arts, which has resulted in funding from The Wellcome Trust for a three year project specifically focusing on medical and poetic representations of the heart, please see <http://www.insidetheheart.org/> for further information on this project which will lead to a public exhibition and tour in 2018 in Newcastle, Bristol and London, UK. *The Heart of the Matter* hopes to explore and expand upon the narratives and positive outcomes outlined in the *Under the Microscope* project in this paper.

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