UNDER THE MICROSCOPE

EVALUATION REPORT

Spring 2016

Under the Microscope was an arts research project conceived and led by artist Sofie Layton, created in partnership with GO Create! (Great Ormond Street Hospital arts programme) and the National Institute for Health Research Biomedical Research Centre (BRC) at Great Ormond Street Hospital & University College London. The project was co-funded by the Wellcome Trust, the Biomedical Research Centre, Great Ormond Street Hospital Charity, and the Blavatnik Family Foundation. Sound by Jules Maxwell. Photography by Stephen King.

The artist thanks the patients and their parents for their input into the project and their generosity in sharing their stories.

Evaluation Report written by Anna Ledgard

1. SUMMARY & VISION

Under the Microscope (April 2015 – May 2016) is an arts research project with a strong interdisciplinary component, conceived and led by artist Sofie Layton. The work explored how paediatric patients and their families interpret medical information and understand disease, and culminated with the creation of installations (*Unique, Making the Invisible Visible* and *In Isolation*) situated around Great Ormond Street Hospital (GOSH) and the Gallery linking the hospital with the Institute of Child Health (ICH). The work was conceived and created in partnership with clinicians, researchers, and GOSH patients and families.

This report intends to offer an insight into a complex, multi-layered project led by an artist who was exploring the role of art in mediating communication between patients, biomedical professionals and wider publics. Responses to the project from participating parents, patients and biomedics were unanimously positive. Audience responses to the public art installations were united in their surprise and delight at the power of the art to present the voice of the patient alongside the biomedical reality of rare diseases. The artwork explored the reality of Severe Combined Immune Deficiency Syndrome (SCIDS) and congenital heart disease (CHD). The project demonstrated that a collaboration between the arts and medicine can work very effectively as part of the normal workings of a research institute and hospital, prompting fruitful reflection for all parties involved.

Fig. 1 – close-up of batik tent fabric showing a virus drawn by the parent of a patient with leukaemia, as part of the *In Isolation* installation within *Under the Microscope*.

A number of key factors are responsible for the project' s successes: the experience and high level skills of the artist in relational as well as artistic practice; her embedded relationship within the hospital, with GOSH, the BRC and the ICH supporting at the highest level and giving her access to patients, nursing staff and clinicians; the interdisciplinary nature of the project, across biomedical science, arts and psychology; and a close professional collaboration with a biomedical engineer (Dr Giovanni Biglino, Centre for Cardiovascular Imaging, GOSH).

Under the Microscope was a research and development project delivered through an artistic interface and it offers valuable insights which are relevant for potential future collaborations. Particular achievements were the high quality of engagement and empowerment of young patients. The

experience provided young people with access to a community of peers and a 'safe' way of exploring and articulating attitudes towards their illness which they were able to see as unique and special to them. The interdisciplinary approach provided young people and families with a means to communicate about potentially sensitive conditions through art and metaphor. This also revealed young peoples' awareness of their condition not so easily expressed in the context of the formal consultation or even the family conversation.

The project generated awareness of complex and invisible health conditions and the application of new technologies such as 3D printing or gene therapy to a wider audience. Importantly the project has focused attention on the way researchers and clinicians communicate and has certainly helped staff to hear from patients what it means to them to have a particular health condition, thus humanising the science and offering a model for patient and public involvement/engagement (PPI/E) which could involve patients more actively in research into their own conditions. The non-hierarchical approach characterised by the arts process facilitated the sharing of experience across clinical and patient worlds.

An autobiographical arts workshop exploring the notion of uniqueness with young people with CHD was a key part of engaging professional staff in the artistic process and building their confidence in the capacity of the arts to engage patients deeply with both the science and the inner landscape of their condition. The workshop process has been explored in an academic paper co-authored by the project team (currently under revision in the *Journal of Applied Arts and Health*).

Fig.2 – The project involved working with patients on the wards (left), creating embossed hearts; and a close-up from one of the artworks, *Heart Narratives*, displayed in the final exhibition (right).

For the artist, the project represents a shift in her practice from principally presenting the patient/parent experience to engaging as much with medics and researchers as with patients. This has enabled her to make a new body of work comprising powerful multi-layered artistic interpretations, merging patient experience and biomedical information.

The project was overseen and facilitated by GO Create! GOSH arts programme. The Head of GO Create!, Susie Hall, reported that the project model, involving the artist in close dialogue with scientific and medical practitioners over 10 months, offered new and useful insights into the

particular requirements and resourcing of this *embedded* model of arts collaboration.

Under the Microscope has resulted in learning at a number of levels within the hospital and the fact that key partners are committed to generating future public engagement and arts collaborations is a clear indicator of its value to all. This learning and supporting evidence are explored in more detail in the bulk of this report.

2. BACKGROUND

Bedside Manners (http://sofielayton.co.uk/installations.34.html) was a previous piece of work created by Sofie Layton in an NHS hospital setting, funded by Guy's and St Thomas' Charity and the British Kidney Patient Association. This residency at Evelina Children's Hospital focused on the parents of sick children, their role within in the care of their child within a medical setting, the dis-empowerment of the carer, and the subsequent lack of personal identity in that setting. Layton was interested in empowering parents through a creative arts practice, creating works at the bedside and collecting the stories of parents' experiences. The culmination of this was a multimedia installation (including a soundscape) positioned in the hospital, incorporating artworks created by patients' parents. Whilst the piece was very well received, the artist felt that the scientific and medical voice was missing from it. It is in the light of this observation that she embarked on *Under the Microscope*, exploring medical language and striving to incorporate more scientific and medical

elements into the artwork that would result from the residency at Great Ormond Street Hospital for Children.

Under the Microscope indeed provided an artistic framework in which to explore CHD and rare diseases from four different perspectives: lab-based researcher, clinical practitioner, patients and patients' families. The project encouraged exchange between these groups, with the artist positioning herself at the centre of this dynamic, aiming to voice the distinct experiences of individuals. Such a setting allowed her to explore how to generate a richer and more *embedded* artistic research process within a medical setting, particularly a specialist clinical centre with state-of-the-art research facilities.

3. PROJECT OBJECTIVES

These are based on the original Wellcome Trust application (2015):

- To develop an artist' s residency as a Research & Development project to connect children and families with the world of the biomedical researcher;
- To explore how families interpret medical information and understand disease;
- By furthering patient knowledge of scientific processes, to empower children and families and de-mystify hospital care;

- To enable biomedical researchers to understand the experiences of children with rare diseases and see how their work directly impacts on patients and families;
- To provide a creative framework and artistic vocabulary to narrow the gap between lab-based research, clinical practice and patient experience;
- To create a sound and sculptural installation in response to the work with families and biomedics.

4. ARTISTIC APPROACH

Layton' s 25 years' experience of participatory arts practice, her work within NHS contexts (since 2012), and her sensitive approach were critical to the success of the project. Indeed, as Sheila Preston asserts, those working in applied arts 'have a responsibility towards ensuring that the representations that are made are produced through a climate of sensitivity, dialogue, respect and willingness for reciprocity' (Preston 2009: 65).

A key principle of this approach is that the participatory process and the end artistic elements are of equal quality and require distinct skills and expertise. Layton is able to 'hold' a space for the involvement of diverse groups and individuals, maintaining alertness to their emotional comfort whilst introducing them to new ways of thinking about their circumstances through artistic expression. Layton has developed a confidence and articulacy about her approach and was able to adapt her message appropriately for different audiences (i.e. parents, young people, medics, researchers). Her willingness to engage at a deep level, to explore and

learn about the medical and scientific processes (well exemplified in the fact that she had an MRI scan herself to fully appreciate the process, in relation to CHD patients for whom MRI scans are part of their clinical assessment) communicated to patients her personal commitment and non-hierarchical approach to the work. Her interest in asking the same questions of parents as of scientists and academics meant that she was able to present both perspectives in the finished work.

> *'Medical and artistic approaches may sometimes seem worlds apart, but I' ve found an equivalence –as an artist– in the materialization of processes like MRI scans and 3D printing and in the embroidering and embossing the minutiae of cellular structures.'* (Sofie Layton)

As artist in residence at GOSH, Layton interviewed staff and clinicians and facilitated participatory workshops involving young people with CHD. In response, she created a series of multi-disciplinary art works about the heart (*Unique* and *Making the Invisible Visible)*, in conversation with the cardiovascular imaging team, clinicians, parents and patients of Bear Cardiac Ward, and young adults attending transition clinic and their parents. *Unique,* situated in the GOSH main entrance, documented artist-led workshops with young people looking at congenital heart disorders. *Making the Invisible Visible*, installed in the Gallery linking ICH and GOSH, included a series of multi-disciplinary artworks about the heart, 3D medical heart prints displayed in bell jars with voile printed screens, and sculptures translating some medical aspects of cardiology. The installation also included a series of five large textile panels entitled *Landscape of Heart Disease* alongside embossed heart images made with parents, a text work

Heart Narratives and a soundscape which included a mother talking about her son's heart transplant and MRI sounds.

During the residency Layton also spent time meeting patients with rare diseases and learning about the work of rare disease specialists including those involved in genome science, regenerative medicine, gene therapy and innovative surgical techniques. These meetings resulted in a sensory installation, *In Isolation,* located in the glass atrium entrance to the GOSH Friends' garden. It was an immersive installation, where the audience had to scrub up and wear gloves and protective clothing prior to entering the tent. The tent fabric represented a visual landscape inspired by the cellular structures of the immune system created in silk and over-printed with the viruses and bacteria that attack it, housed inside a clear plastic outer layer. A soundscape presenting the reality of a young patient undergoing gene therapy was played and the audience could sit on a hospital bed within the tent, immersing themselves in the created environment.

In her explorations into the nature of 2D/3D imagery, Layton used the stereolithography (.stl) files of modelled hearts created from MRI scans to generate the artworks which were re-worked in different ways, exploring the heart visually in a topographical format and using a computer generated mesh of the heart surface as part of the iconography of the work. These became 2D imagery realised as screen prints onto a shot silk echoing the difference in colour that she had observed between the oxygenated and de-oxygenated blood, particularly reminiscent of seeing blood in the chambers of ventricular assist devices (e.g. Berlin Heart®) on the cardiac ward. These works also explored the landscape and language of the heart and the medical conversations around it, according to themes

of Anatomy, Conditions, Medication, and Techniques & Devices, which are part of the patient and parents' world.

Fig. 3 – Close-up of silk screen printed panel on medications
as part of the journey of a patient with congenital heart disease.

As part of Layton's exploration of the 3D printed heart for the workshops she explored scale and materials. This was manifested in a series of hearts taken from a healthy heart of a 10 year old child in different clear and white resins. Miniature bronze and silver-plated hearts allowed people to explore notions of the preciousness of the organ and the metaphorical weight of the heart.

Following a body maps workshop with a group of young people with CHD, Layton worked with the same group in a follow-up workshop to explore their poetic heart. This was achieved in similar way using the individual's

heart form, printed on paper as a 2D representation. The participants traced around their own heart outline, as they had done in the previous body maps workshop, and were asked to find a metaphor or image for their hearts. Powerful imagery emerged through the process. One young man said: *'My heart is a Rubick's cube, a puzzle, a patch work that cannot be fixed!'* A young woman said: *'My heart is a soldier, it's been through the wars, I am really proud of it*.'

Layton is well aware of her responsibilities in working with very sick patients and families in NHS contexts. Projects of this nature require time both for the artist to develop relationships and to be immersed in science as well as patient experience. This is an ethical responsibility recognised as critical to the success of *Under the Microscope* by health psychologist and senior research fellow Dr Jo Wray (GOSH):

> '*[SL] demonstrated that there are no short cuts or substitute for spending time if the final result is to do justice to the patients, their families and the professionals'.*

GOSH staff noted the professionalism of Layton's introduction which was clear and consistent, establishing her experience, her open-ended artistic process, offering her skills and explaining that her aim was to understand better the experiences of families in hospital. Parents looking after children in hospital have many demands on their time and emotions and so the way the artist first approaches the family is critical in building commitment and engagement. If not well-managed the artist could become yet another demand. Layton understands this and so she usually started on the wards as an observer, sometimes engaged in an embossing, sewing or

embroidery task, waiting until parents approached her to find out what she was working on.

> *'She never imposed on anyone, and that made her more intriguing, the way she went about it was brilliant, so in the end we'd more come to her. If she'd come with a form and asked me to sign up I'd have said no, no time, not in the mood.'* (parent on Bear Ward).

5. INTER-DISCIPLINARY COLLABORATION

In preparation for her residency Layton interviewed: Prof David Goldblatt (vaccinology and immunology); Prof Maria Bitner-Glindzicz (genomics); Prof Bobby Gaspar (gene therapy); Prof Paolo di Coppi (stem cell treatment); Prof Andrew Taylor (cardiology); Dr Giovanni Biglino (cardiovascular imaging), Dr Kimberley Gilmour (immunology); Prof Michael Ashford (pathology); Dr Erin Walker (Joint Lead for Patient and Public Involvement and Engagement in Research); Lindsay-Kay Leaver (adolescent nurse specialist); Dr Jo Wray (health psychologist); Miguel Calero (gene therapy PhD student); Katie Snell (research nurse).

Layton was genuinely curious about the biomedical science behind patients' conditions. Regular contact with Dr Biglino and access to his colleagues' academic expertise enabled her to mediate the communication of science with parents, e.g. a parent enquired about what cardiomyopathy looked like and Layton had access to information within the research community.

Fig. 4 – Interdisciplinary collaboration involved exploring cardiovascular anatomy with 3D printing technology, and models resulting from the process were displayed by the artist under bell jars within the cardiac-themed installation.

Layton' s partnership with Dr Biglino was at the heart of the project and was characterised by a shared recognition of the important mutual learning that could come from their different disciplines, and Dr Biglino' s particular interest in exploring patient engagement in his research. The involvement of psychologist Dr Wray and clinical nurse specialist Lindsay-Kay Leaver in the work with CHD patients resulted in a valuable holistic discourse around patient uniqueness.

Part of the multidisciplinary process involved an appreciation of medical imaging and MRI in particular. Layton describes the revelation for her of looking at MRI scans of hearts and then seeing them modeled in 3D, and later 3D printed, realising the possibility of 'making the invisible visible'

and bringing complex science 'alive'. From this she saw that she could devise a way of adapting an autobiographical arts workshop, using body maps methodology and self-portrait activities to explore the uniqueness of young people with CHD. Dr Biglino's research interest in considering whether 3D visualisation could be more effective than 2D visualisation for understanding the anatomy of CHD blended well in the process and he contributed directly to developing the workshop together with Layton. The principle behind the workshop is that the arts process could offer a creative channel to explore beyond the clinical, measurable and scientific features of the heart to the feelings associated with heart conditions. The workshop and its findings are explored in a paper (Layton et al. *Journal of Applied Arts and Health*, under revision).

Quoting the conclusion of the paper:

> *'A workshop was successfully run by a multidisciplinary team led by an artist, demonstrating that an immersive artistic workshop can be conducive to generating imagery through which young people with CHD can express the uniqueness of their condition. Findings also highlighted an overall immediacy, comfort and familiarity with 3D forms vs. 2D drawings. Participants engaged well with a body maps exercise, which gave them the opportunity to explore their individuality within a group of young people who share similar, but different, medical conditions and life experience, incorporating elements of their medical history. An interestingly contrasted array of feedback was collected when discussing 3D heart replicas of different sizes and materials, reflecting individual preferences and emotional response diversity'.*

Dr Biglino took part in the artistic workshops himself and described the collaboration between researcher and artist as 'bi-directional' involving him in co-planning with Layton workshops, presentations and events of different types for families and patients in different settings. When running the workshops, Dr Biglino offered a biomedical perspective on how the heart works whilst Layton's workshop enabled patients to explore what their heart meant to them and how having CHD affected their lives. Dr Biglino gave generously of his time and saw the collaboration as complementary to his research on 3D printing and its application, exploring intuitive qualities of the 3D model and its potential in building patient understanding of their condition. He is now planning further study into 3D printing to evaluate the possibilities of translating the technology into clinical practice.

Since the project Dr Biglino has involved patients in designing surveys and can see the potential to involve them much more closely in research into their own conditions.

> *'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.'* (G. Biglino)

Dr Biglino's satisfaction partly echoes the findings of Stephen Webster's

research into arts collaborations in hospitals:

> *'The scientists involved in such projects invariably express their satisfaction at the manner in which collaboration with an artist has given them an audience that differs vastly from the normal specialist arena of laboratory and scientific conference.'* (Webster 2006: 77)

In addition to this, he valued the truly essential input of the artist into the collaborative process and the delicate, respectful and yet powerful way in which she managed to bring the human element into the exploration of medical conditions.

6. MANAGEMENT, FINANCING & DELIVERY

The project was managed by the GOSH arts programme GO Create! The invitation to collaborate with BRC and GOSH had originally come from Professor David Goldblatt, who had seen Layton's earlier work *Bedside Manners* at Evelina Children's Hospital. A small grant from BRC and Professor Goldblatt's support from the outset meant that the project was supported at the highest level within the hospital and enabled Layton to have unusual levels of access to researchers, clinicians, nurses and patients. Wellcome Trust funding offered additional endorsement of the project's status and quality of approach.

Layton approached this residency as an open-ended artistic and scientific enquiry conducted in close collaboration with patients and staff. Because this approach was not the norm for GO Create! there were some initial

reservations that the GO Create! team were not resourced to manage the demands of such an immersive approach. Any concerns were allayed as it became apparent that Layton was very skilled at communication and building trust in relationship-making at all levels and would take on the production aspects of the installation. GO Create! managed the overall budget, administration, liaison and communications within GOSH (with clinicians, the Young People Advisory Group (YPAG) , and PPI/E staff), setting up the installation within the working hospital, the opening event, and the online booking system for accompanied tours of the final installation.

Under the Microscope has offered important insights into the practical realities of managing and facilitating an embedded arts approach to patient and public engagement and communication of biomedical themes. Such insights may be useful as GO Create! plans its approach to artist involvement and communication of biomedical themes within the new Zayed Centre for Rare Diseases (due to open 2018).

Projects of this nature require flexibility and responsiveness to sensitive needs and a duty of care for patients and families that are not easy to predict when costing projects in advance. This project' s success is due to the fact that the artist and GO Create! staff contributed well over the anticipated number of days to ensure a well-supported experience for patients.

Fig. 5 – Visitor experiencing the isolation tent. In order to make the installation as immersive as possible, the artist conceived that visitors would scrub up, wearing a plastic apron, gloves and a mask, re-creating the protocol of entering an isolation space, and heightening their awareness of the patient experience and the reality of being in isolation.

7. EVALUATION METHODOLOGY

Evidence was gathered through analysis of: grant application and project set-up information; feedback questionnaires completed by workshop attendees; phone, live or email interviews with principle project lead and main contributors (i.e. artist, biomedical researcher, psychologist, clinical nurse specialist), 3 parents and 2 patients; detailed mid- and end-project interviews with artist, researcher and GO Create! Head, and end of project evaluation meeting with project lead staff. Audience responses were

gathered from 128 visitors to the installation. They have been analysed for recurring themes and insights (Figure 10). Reference was also made to the draft of the *Journal of Applied Arts and Health* paper (Layton et al., under revision)

8. INVOLVEMENT FIGURES

Workshops, meetings & presentations	Indivs.	Target
Artist meetings with different hospital staff (gene therapy, cardiology & cardiovascular imaging, stem cell treatment, genomics, immunology, pathology, symptom care, psychology)	12	10
PPI/E staff meetings	5	3
YPAG (Young People Advisory Group) participation Nov 2014 Introduction workshop June 2015 Embossing Workshop Feb 2016 Participation in tours and opening event	 10 12 8	15
Ward and hospital based workshops: May – June 2015 Thursday workshops Gene Therapy Ward May – November 2015 weekly workshops on Cardiac Ward July 2015 CHD Uniqueness Workshop, Coram Fields Poetic Hearts follow-up session with GB Poetic Heart follow-up session 24 October BRC Open Day Uniqueness Workshop Embossing Heart Workshop Presentation to Clinical Psychologists and play therapists Nov 2015 Parents Workshop	 4 24 7 1 4 40 15 40 6 5	40 families + 30 staff

July–October attendance at individual clinical consultations or waiting room encounters with patients and parents May 2016 Research Awareness Week Workshop	10 20	
Total	**223**	**98**
Installation Audiences		
Attendees at Installation Opening event:	80	250
Installation public tours	27	
Installation private tours:	25	
Making the invisible visible viewers 10/2–23/5/16: (*estimated based on 20 people per day viewing the installation over 73 days, out of an average 595 people using the corridor every day)	1,460	
Online viewings, Twitter & media (estimated)	2,500	500
GRAND TOTAL	**4,315**	**846**

9. PATIENT & PARENT EXPERIENCE AND ENGAGEMENT

9.1. Patients

The project gave young patients a mechanism to explain their conditions to others and to undertake activities independently. It provided social interaction with peers who had similar experiences and a meaningful way of exploring the ups and downs of their experiences in a non-clinical environment.

Young patients appreciated having access through the project to bio-medical research and other medical professionals involved in their conditions:

'It also made me realise how many people were involved behind the scenes as I only have the chance to meet the doctors.' (patient)

The interaction with staff in the personal and non-clinical environment of the arts workshop offered a non-threatening, non-hierarchical space to share experience. The arts process gave patients time, space, permission and support to consider their feelings about their hearts and to convey these to clinicians in a non-confrontational way:

'Patients and parents often feel unequal to staff; [...] doing something non-clinical gives them shared neutral ground. [...] patients often struggle to convey their thoughts to clinicians in a clinic consultation.' (clinical nurse specialist).

The high quality artistic outcomes endorsed the significance of the young peoples' contribution. Patients reflected that the artist had understood them and was able to convey their own and their families' feelings through the installation:

'*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).

The workshops exploring uniqueness had particular value for teenagers who can struggle with their identity as a 'heart patient' whilst wishing to explore their wider identify. '*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). The workshop and the

discussions both informed patients and helped them to recognise themselves as individuals with 'difference' rather than 'abnormality':

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

Fig. 6 – Body maps workshop with young people with congenital heart disease. In the picture, Dr Jo Wray, Sofie Layton and Dr Giovanni Biglino are discussing the young people's artwork in a group reflection.

Psychologist Dr Wray describes what art can bring to the patient experience:

> *'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.'

Amongst the participatory activities that she undertook, Layton offered heart embossing workshops to young people waiting to see their consultant. In their responses young people mentioned reducing boredom (*'it makes the experience of waiting in a waiting room more interesting'*), improved experience of waiting, and speeding up of time as particular benefits (*'it makes the time go quick'*).

9.2. Parents

Parents valued the relationship with an artist who, at one level could be seen to relieve the emotionally draining experience of looking after a child and provided relief from the tedium of the routine of each day. She was perceived also as someone outside the medical sphere who provided the companionship of sewing, making or just chatting and was a distraction or temporary respite.

'I loved the escapism of art. Sofie introduced me to new art skills and I never imagined I would have the bonus of actually practising art whilst stuck in isolation for months whilst my son had his second bone marrow transplant' (parent).

Parents appreciated the fact that Sofie provided activities specifically designed for the parent when attention in a children' s hospital is understandably usually more focused on their children.

> *'It' s very difficult being in isolation for such a long time, and on top of that you have the never-ending worry for your child. You' re so immersed in the medical world of treatment and symptoms – questioning life and death. You feel trapped physically and mentally. The art project enabled me to break out of the routine – escapism, being creative again.'* (parent).

Like their children parents felt 'safe' with the opportunity the arts process gave for them to share their personal experiences and thoughts with other parents. Once parents saw the translation of their experience into the installations parents began to talk about the art works differently using words like *'enlightening' , 'unique' , 'journey'* reflecting the way that immersive artistic practice can value experience or look at the familiar through different lenses.

> *'My son has double relapse leukemia, and looking at microscopic images of the cells that keep trying to kill him was emotive. They should look unpleasant and sinister but they have an extraordinary beauty. I like that paradox, and the puzzle of how an artist could represent that contrast'* (parent).

Fig. 7 – A visitor at the exhibition looking at the *Heart Narratives* piece, which incorporates the voice of a number of parents who have worked with the artist.

One mother, who powerfully described her son's transplant in the soundscape, reflected on this experience as '*feeling like a celebration*', of completing a journey, which in her case had resulted in a successful heart transplant. Art in this instance was providing a ritualising space at the end of a very tough experience.

An additional benefit expressed by one family of a teenage patient was the fact that the artistic process provided a vehicle for parents and child to communicate about her condition:

> '*it has been a real joy and also opened our eyes to our own daughter's feelings regarding her condition*' (parent).

One of the project objectives was to provide a creative framework and artistic vocabulary to narrow the gap between lab-based research, clinical

practice and patient experience. Layton saw herself as an intermediary between parent and medics, so that when a parent asked to know what cardiomyopathy looked like, Layton was able to find out and then interpret this knowledge through art in a way that was more immediate than a straightforward medical description. Dr Biglino suggests that the art works and relationship with Layton provided participants with a wider vocabulary to discuss the science of illness, embracing shape, size, technology and emotion all at the same time.

10. STAFF ENGAGEMENT

Staff responses suggest that the artworks offered a vehicle to reflect on the humanisation of science and personalisation of the patient. Staff talk of a new awareness of the power of the artistic process in enabling patients to voice their experiences, and thus for staff to understand the impact on patients and families, and the particular issues for young people in hospital. Seeing patients in a new way reflecting their individuality can encourage staff reflection on their existing perceptions of patient narratives.

> *'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 GOSH clinical psychologist team invited Layton to give a presentation after which they discussed the effectiveness of the arts process in enabling young people to explore their feelings, acknowledging that for some

young people this may have been the first time they have explored their feelings about their heart condition.

A personal conversation with a consultant cardiologist revealed the difficulty of truly assessing patients' awareness of their condition, particularly at the time of transitioning to the adult centre. He then appreciated that the artistic methodology allowed a young man to immediately express medical concepts, particularly using the colour purple in his body map (medically standing for cyanosis) and including imagery of spinach (medically representing vitamin-K rich food that cannot be eaten by the patient due to warfarin medication). In this specific case, the cardiologist recognised the immediacy of the arts practice through which the patient expressed medical concepts.

Dr Biglino suggests that this kind of collaboration can be illuminating for researchers, particularly in the way they approach the engagement of patients in their research. Professor David Goldblatt echoed this sentiment in his introductory speech during the *Under the Microscope* opening event.

In designing and creating the installations Layton had two priorities: to make high quality artistic pieces which honored the contributions of patients and families; and to locate her work within a working hospital in spaces which could support and complement her aesthetic ideas. In hospitals this can be difficult and sensitivity must be shown towards the users of the spaces, particularly with work which represents family experience in difficult circumstances. One exhibit was open to families and patients in the hospital main entrance and was deliberately chosen to reflect the project to a more public audience. The other two exhibits were

situated in spaces used largely by medical professionals. For *In Isolation* the contrast of the light and airy glass atrium with the isolation and solitude of the installation enhanced its impact. The gallery space, instead, is a corridor with high footfall of staff and researchers (595 per day), which has housed exhibitions before. Regular users passing through the corridor commented on the particularly high quality of this installation and its impact on wellbeing.

'This has been the most beautiful display so far.'

'It has transformed an inert passageway into an art gallery.'

'*Walking past this everyday lifts my spirits.'*

Fig. 8 – The gallery space where *Making the Invisible Visible* was displayed.

However, a hospital is not a public exhibition space and enabling visitors to visit the exhibition stretched the resources and staffing of GO Create!.

Because the corridor could not be permanently staffed it was not possible to gather statistics of how many corridor users stopped to look at the exhibition and for how long. One respondent suggested that *'because it is so beautiful, I took the time to stay and read the information'* (response book). Anecdotally this seems to have been a view shared by others making regular use of the corridor.

11. PUBLIC ENGAGEMENT

11.1. Opening Event

An opening event took place on 3 March bringing together parents, patients, researchers, clinical staff and invited arts in health professionals. A question & answer session facilitated by Layton and Dr Biglino produced a rich discussion prompted by the arts installations, which provided a mediating context in which the perspective of patient, parent, clinician, nurse and visitor could be aired in a neutral, non-clinical environment. The importance of the context and the value of the work were voiced by Susie Hall – Head of GO Create!

> *'It was very special having these people in the room together listening to each other's experiences in a way that isn't usually possible.'* (Susie Hall).

Fig. 9 – Sofie Layton holding a Q&A session with Giovanni Biglino during the opening event of *Under the Microscope*.

11.2. BRC Open Day (in conjunction with Bloomsbury Festival)

As part of the BRC Open Day (24th October 2015), which targeted families and the general public, Layton, Dr Biglino and one of the patients who were involved in the workshops prepared and delivered a seminar discussing the process of an arts-and-science project developed in a clinical setting. They then opened the discussion to the audience, and one element that emerged in the discussion is that the arts engagement had provided a 'leveller' as it is rare for such a range of those involved in the care of patients to be gathered in discussion together.

11.3. Visitor Responses

The public installation provided an opportunity to present complex and invisible health conditions to wider audiences of hospital staff and users and invited members of the public. Responses were gathered from 128

visitors to the installations either on a postcard or by filling in the comments book. In the analysis of these responses a number of themes recur (see chart/responses in full in Appendix 1). Responders reflect a deep appreciation of the high quality of the artworks ('beauty' or 'beautiful' were the most common recurring words). There were also frequent references to the emotions and the way that the installation moved people to greater understanding of the experience of the patient as well as informing them about new techniques such as 3D printing. I include below a small number of responses.

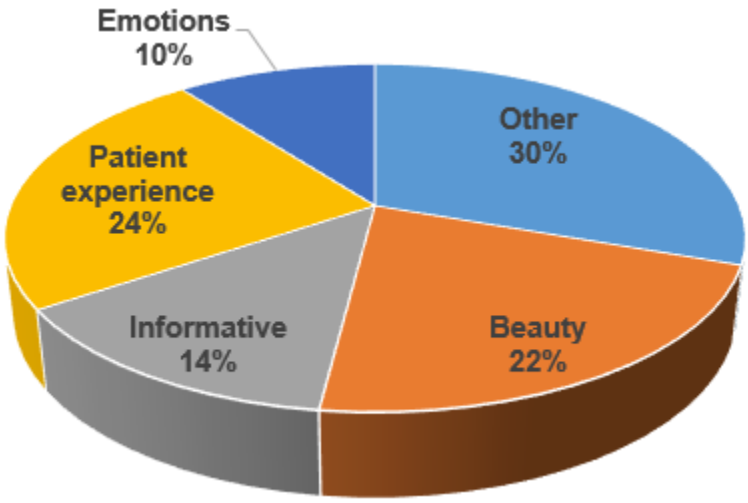

Fig. 10 – Thematic analysis of visitors' responses.

Understanding Patient Experience

'[The tent] really captures the isolation, loneliness and fear/panic of being stuck on a ward. I've been trying to write about that for about a year and I haven't come close.'

'The isolation tent is a wonderfully claustrophobic experience. As someone who has spent 6 weeks in hospital, you really captured the claustrophobia and the 'craziness.'

'It gave a depth of understanding of the experience for parents and children that I cannot imagine achieving in other ways.'

'Gives a human view on the experience of disease.'

'So clever to have made an experiential space that' s beautiful and seductive and given you time to listen to the stories and understand something of how it feels to live with a life-limiting illness.'

'Helped me understand a little better what it would be like to have a condition that keeps you in hospital, and the confusion that comes with having something wrong with you that you can' t see. I guess you understood it through the art.'

'What touches my heart is to listen to personal stories, as these are real/life. Making something beautiful or artwork out of those hard experiences is challenging but valuable.'

Affecting the Emotions

'Intense and very moving. Love bringing the humane to a seemingly clinical–only environment. Fascinating.'

'It was an amazing experience. As a person having no knowledge or adequate information about heart conditions, I felt the agony, the limitation, the sorrow. But at the same time I felt the hope, the optimism, and dreams.'

'I found the tent very emotional, quite overwhelming experience, emphasising solitude. But the positioning outside/sunshine was very effective.'

Informative

'Under the Microscope providing an original, insightful, colourful, emotive and captivating insight into the complexities of the heart and the different experiences that children at GOSH go through.'

'What I have learnt was the authenticity of the whole experience. How research has changed the lives of people for the better and I think this form of art especially with Sofie has been the best way to explore medicine.'

'It has been a truly inspiring and moving exhibition – a fascinating insight into such an essential organ.'

Audiences expressed considerable interest in the 3D printing and repeatedly expressed surprise at the size of the human heart, including medical students.

'*I did not know my heart is that big pump!'*

'I did not know the human heart was so big!'

Beauty

'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.'

'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.'

12. ADDITIONAL OUTCOMES

12.1. A catalyst for future projects and collaborations

The Heart of the Matter is an interdisciplinary project designed to engage a wide audience and foster better understanding of heart anatomy and heart narratives. It stems from the conversations that took place during Layton' s residency at Great Ormond Street, particularly during her time working with the cardiovascular imaging team. Indeed, the proposed project would also include Dr Giovanni Biglino, Dr Jo Wray and Prof Andrew Taylor, all contacted by Layton for *Under the Microscope* and involved in the conversation during Layton' s residency. *The Heart of the Matter* is an ambitious public engagement project that will involve collaboration between three cardiovascular centres of excellence (GOSH, Bristol Heart Institute, Newcastle Freeman) and will culminate in a touring exhibition with extensive public engagement in Bristol, Newcastle and London. The chief aim of *The Heart of the Matter* is to engage a wide audience on key concepts of heart anatomy and heart narratives, through multimedia artworks inspired by patients' stories blended with anatomical 3D heart models, thus creating a strong dialogue between the

heart and the science. The project is shortlisted for a Wellcome Trust Society Award (decision expected May 2016).

Under the Microscope has also 'scratched the surface' on other fascinating aspects related to cardiovascular physiology as seen through patients' lived experiences, and how patients and families respond to these. The idea of sound and heart rhythm as well as the visualisation of blood flow lend themselves to future exciting collaborations, that Layton and Biglino will facilitate involving a wider team of collaborators. Concepts of heart rhythm (ectopic beats, arrhythmia, tachycardia) will be explored through music workshops, while concepts of blood flow streamlines visualisation gathered with advanced MRI tools will be explored with animations. These ideas relate to the overarching scope of *The Heart of the Matter* but are stand-alone research projects. Layton, Biglino and their collaborators are currently evaluating the submission of an EPSRC Impact Acceleration Account Public Engagement Award (aimed to the technology aspects of sound and MRI visualisation) and an Arts Council Award (to fund music workshops and collaborative work with animators).

Fig. 11 – 3D heart models as part of the installation of *Under the Microscope*; interdisciplinary discussions around heart anatomy were in part a catalyst for conceiving future collaborations.

In discussion with Professor David Goldblatt (BRC) Layton is also exploring how the learning around gene therapy and genomics could be taken forward by exploring how an arts process could specifically support families involved in research. The *In Isolation* tent may be remounted as part of BRC' s open day in October 2016 with YPAG members acting as explainers to the public. Other venues for the piece are also being considered.

12.2. Additional engagement activities

Due to their success, the installations in the Gallery were exhibited for an additional 6 weeks and Layton was commissioned to run a workshop on arts methods for 20 GOSH staff as part of 'Research Awareness Week' May 2016.

12.3. *Under the Microscope* in the media

The piece has been reviewed in the Independent.
http://www.independent.co.uk/voices/campaigns/give-to-gosh/the-pioneering-art-display-helping-families-come-to-terms-with-heart-disease-at-gosh-a6866101.html

12.4. Academic output

- Peer-reviewed publication on workshop methodology: Layton, Wray, Leaver, Koniordou, Schievano, Taylor and Biglino, "Exploring the uniqueness of congenital heart disease: an interdisciplinary conversation", *Journal of Applied Arts and Health* (under revision)
- *Under the Microscope* is mentioned in G. Biglino "3D printing cardiovascular anatomy: a single-centre experience" in "3D printing" (Ed. InTech, in press). In this book chapter Dr Biglino highlights how the artistic approach can enrich the exploration of cardiovascular anatomy.
- G. Biglino, "A little Danish mermaid and other stories (of rare disease)", *Medical humanities* (submitted)
- July 2016 – *COMET* conference (Communication Medicine & Ethics), Aalborg, Denmark. Presentation by Sofie Layton on Narratives of Illness.
- September 2016 – V International Health Humanities Conference, Seville Spain. Presentation by Sofie Layton on *Under the Microscope*.
- November 2016 – Elements of *Under the Microscope* installation

have been selected to be installed especially for the *Feel it Festival* organised by the University of Bristol, an exploration of pain and breath through performance and art (collaboration between the Elizabeth Blackwell Institute for Health Research, the Life of Breath project and the Public Engagement office of the University of Bristol, made possible through support of the Wellcome Trust).

- *Under the Microscope* was profiled in Anna Ledgard' s key-note talk at Wellcome Trust Public Engagement Art of Health and Creative Research Conference in Mumbai, in February 2016.

- Sofie Layton gave a presentation at Wellcome Trust Public Engagement event April 2016 in London, on the subject of "Ethical issues in engagement practice" ; the talk included reflections from her recent residency at Great Ormond Street Hospital and the creation of *Under the Microscope.*

- Dr. Biglino was invited to discuss *Under the Microscope* as an example of interdisciplinary collaborative research at Going Public 2016 - Academic Practice Symposium (April 2016), run by the University of Bristol. He also presented his experience of collaborating with Sofie Layton to a group of engineers at an event organised by the Royal Academy of Engineering (April 2016).

13. FINANCE FIGURES

INCOME	
Wellcome Trust	£29,925
Blavatnik Family Foundation	£4,000
BRC	£5,000
GO Create! original contribution	£4,000
TOTAL	£42,925
ADDITIONAL INCOME	
GO Create! additional contribution for installation, documentation, and production	£3,500
GRAND TOTAL INCOME	**£46,425**
EXPENDITURE	
Fees	£26,627
Production, materials, hire	£16,122
Transport	£746
Evaluation	£2,500
Miscellaneous	£430
TOTAL EXPENDITURE	**£46,425**

14. ISSUES & LEARNING

14.1. Patient participation

Although several patients participated in workshops or in 1:1 activities at the bedside, the maximum number of participants per workshop was relatively small (maximum 7 people). However, this enabled them to get to know each other, to be comfortable in expressing themselves, and have a

meaningful engagement with the art process. If a goal in future is to reach larger patient numbers and organise larger workshops, careful thought needs to be given to how to achieve this without compromising the quality of engagement and taking into account the specificity of the group (e.g. patients' needs).

Fig. 12 – Patients passing around heart models during a workshop with the artist.

14.2. Project management in embedded arts residencies

Deep collaboration and responsive arts practice require time and resourcing from managers within hospital contexts and freelance staff. Success depends on allowing time for sensitive relationship development and for the artist's immersion in science as well as patient experience. This has implications for contracting and employment of freelance artists and others, and the allocation of arts in health staffing resources in

hospital contexts. In this instance GO Create! contributed £2,500 more than their original agreed contribution and artist, evaluator and GO Create! staff all exceeded their allocated hours.

14.3. Patient awareness of scientific process

Two of the patient participants made direct reference to improved awareness of scientific processes as a result of their involvement and that participation has helped them to voice their understanding of their condition. This would suggest that a well-planned arts process could play a useful role in engaging and giving patients a voice in research into their own conditions.

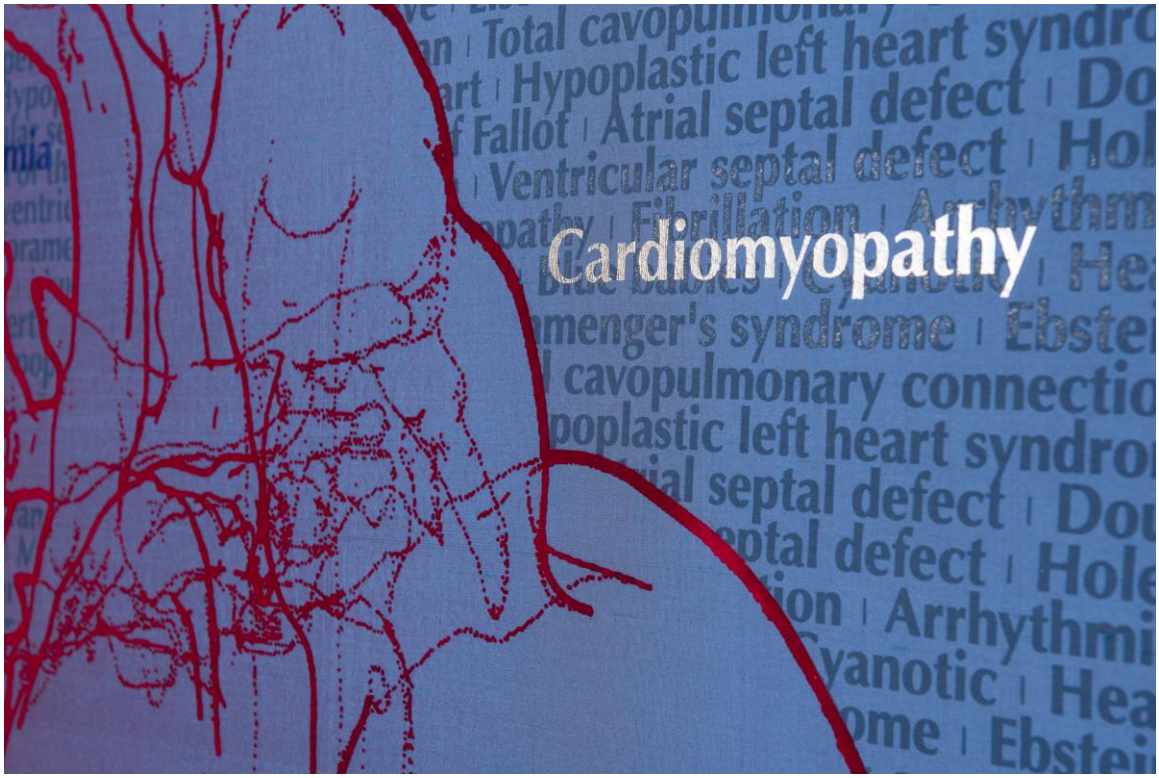

Fig.13 – Language and narrative are central to *Under the Microscope* (detail from one of the silk screen print panels that represent the landscape of heart disease).

14.4. The ethics of handling sensitive information

Reflection at the end of *Under the Microscope* highlighted the sensitivity of the narratives that are being input into the artistic process, thus stressing the responsibility of the artist to obtain permission to use their voice and equally the responsibility of translating this voice in an appropriate manner. The team reflected that obtaining such a permission is not a standardised process (as, for example, the process of consenting patients into a research project). Layton and her collaborators thought this was an important reflection in view of future work and the ethics of engaging patients and families. The artist felt she should act as custodian of the work and she should disseminate it appropriately, as part of her responsibility. This also raises an interesting reflection around the shared ownership of artwork that is created through a participatory process.

14.5. Further dissemination

The project has had success in disseminating its findings in arts and health settings. Whilst exceeding the target audience for the installation, the artist will now seek to increase the visibility of the piece by incorporating the works created through this research into future arts installations with wider public audience targets, for example the *Feel it Festival* at the University of Bristol in November 2016 (Layton' s participation already confirmed).

14.6. Research potential

The project presents evidence, gathered through qualitative reflections and personal conversations with key protagonists, of benefits to patients,

staff and families of arts participation. However, there is a need for additional research to further explore the particular qualities that the arts bring to patient and public understanding that other methodologies do not, particularly where they relate to patient well-being, staff communication and a wider understanding of science in the longer term.

15. CONCLUSION

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.

A highly skilled and informed artist brought a creative framework and artistic vocabulary, which involved children and families in discussing the biomedical science behind their particular conditions, suggesting that the arts in this instance offered an empowering mediating space between health professional and patient. Medical practitioners commented about the potential for the arts process to provide insight into how families and patients understand medical conditions. The project evidences the value of the well-planned interdisciplinary conversation between artists and biomedics, in agreement with Jan Cohen-Cruz' s view that for 'public, inclusive art to benefit our shared civic life, we need opportunities that create intersections between engaged artists and people from other disciplines and communities working towards the same goals' (2010: 196–97).

The project involved strong partnership with several artists as well as close interdisciplinary collaboration with researchers and clinicians. Such an interdisciplinary arts approach was successfully used to explore sensitive themes around medical language and rare diseases. The resulting artwork effectively brought together the different languages that it set out to explore in its aim, including 3D medical imagery, 2D anatomical representations, exploration of microscopic and macroscopic shapes, as well as technical jargon blended with emotional patients and parents' narratives. Recognising the importance of the *narrative* in the healthcare encounter (Garden 2015), the artist skilfully and tactfully included this element in both installations, to which end soundscapes played an essential role in reiterating the patient and the medical voices within the landscape of the isolation tent and of the cardiovascular-themed environment.

16. ACKNOWLEDGEMENTS

Under the Microscope was made by Sofie Layton in collaboration with Stephen King, Jules Maxwell, Nicola Griffiths, Tom Layton, Simon Dormon/Oblique Furniture, Royal College of Art Reprographics Department, and PrintAll studios.

The artist thanks the patients and their parents for their input into the project and their generosity in sharing their stories.

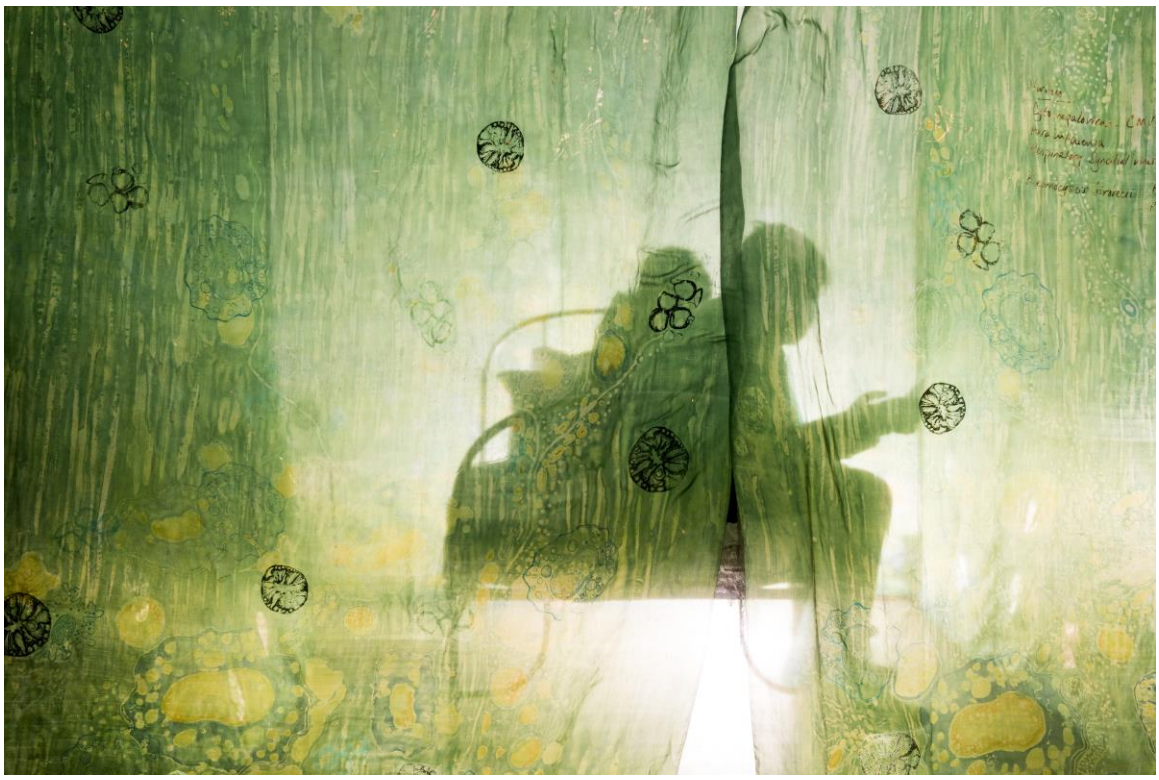

Fig. 14 – The isolation tent: an immersive experience for the viewer.

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