FACINGOUT



Evaluation Report

Lucy Burscough

June 2019

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1 1 Project Summary











"I'm a pretty positive person. Being part of the project has been another positive experience I would never had had if it wasn't for the cancer. I've met some lovely people and been part of a special project. The impact of those 'positive chemicals' in our bodies can never be underestimated in my quest to hang on to life."

Graeme Heward, Facing Out Portrait Subject. Written Feedback

Facing Out has been a two-year long 'arts for health' project with multiple engagement strands culminating in an exhibition at The Whitworth Art Gallery, Manchester which opened in February 2019. It was devised and delivered by 'arts for health' focused portrait artist, Lucy Burscough, in collaboration with several partners, not least of whom are its six portraiture subjects. The sitters all have experience of facial cancer, five from the position of patient, one as a reconstructive plastic surgeon. The project was funded by Arts Council England with support from The National Lottery.

As someone whose art practice focuses on the human face, Burscough is interested in what happens when an individual experiences cancer and surgery that alters their appearance. If the face changes, how does that affect one's sense of self? Her subjects speak of being acutely aware of the gaze of others, in the street or at their work, and they recognise that people's eyes can naturally be drawn to people whose faces are unusual. Becoming the subject of a portrait under these circumstances is an empowering act of defiance, and welcoming people to look at one's face, scars and all, is an invitation to acknowledge a shared humanity and triumph over this indiscriminate illness. Burscough's portraits seek to address the cultural invisibility of people with facial disfigurementⁱ in the canon of art history, which is played out in our public museum collections and on our gallery walls. In the Facing Out collection the sitter defiantly returns the gaze, promoting acceptance of diversity of appearance, and encouraging viewers to consider their appearance-related stereotypes.

This report will recognise the extent to which society dismisses and discriminates against people whose faces look unusual and suggest that raising awareness of these issues is of benefit to wider society. It will also seek to understand whether a project such as this can be helpful to the wellbeing of those who take part as portraiture subjects. In order to do this, it will explore the psychosocial impacts of head and neck cancers that result in visible

¹ Changing Faces, the UK's national charity for people with visible differences, acknowledges that, "It's important to note that not everyone likes the word 'disfigurement', preferring instead 'visible difference', 'unusual appearance' or 'look different'... 'Disfigurement' is a term that is used in a legal context as it is enshrined in law in the Equality Act 2010, which gives legal protection to people with 'severe disfigurements'."

After careful consideration during the planning and delivery of the Facing Out project, the artist/author, in conversation with participants, concluded that the word 'disfigurement' it is an honest if brutal word, and one that is understood to describe what has happened to a face following a facial cancer, an acquired facial change, as opposed to describing a congenital facial difference, where it is perhaps more problematic. During Facing Out, it has never been used to define a person as 'disfigured'. The artist and participants have used the terms 'unusual appearance', 'altered appearance', 'facial scarring' and 'disfigurement' to describe facial change following surgery throughout the project with no objections being flagged. For that reason, those terms will continue to be employed here.

scarring and/or functional loss. It will determine which types of interventions research identifies as effective ways to mitigate the psychological impact of experiencing head and neck cancers and suggest that these are the very elements at the heart of Facing Out.

In her previous work, Burscough has recognised the benefits to health and wellbeing that art can provide¹. As a result, Facing Out has included a bold outreach and engagement programme with 'arts for health' at its core. Perhaps most significant is the production of the art itself. The project builds on Burscough's model of 'painting as performance', where the artist creates paintings in public spaces with the intention of inspiring conversation and creating an atmosphere that is beneficial to people who are experiencing stress due to illness. The production of the artworks took place at Maggie's Manchester, a cancer support centre in the grounds of Europe's largest cancer hospital, The Christie. Maggie's ethos was the perfect fit for a project such as this, embracing art and architecture as tools for promoting wellbeing: 'built for healing on a human scale... [the centres have] given rise to a new genre – the architecture of hope. '.²

Engagement with the wider public has taken place locally and internationally, through the delivery of more than a hundred hours of practical workshops, presentations, discussions and performance events aimed at promoting arts as a means to bolster good health and to raise awareness of the challenges faced by people who have experienced facial cancers or have a visible difference. Participants have included students of all ages, workshop attendees who have spent their previous hours receiving cancer treatment, families bonding over working together and groups of international gallery professionals moved and inspired by the focus on health. This report will seek to prove that 'arts for health', when it is woven through every strand of an ambitious project such as Facing Out, can have a profoundly positive effect upon the individuals and communities that it touches.

2 The Impact of Facial Cancers

2.1 Head and Neck Cancers

Head and neck cancer is the eighth most common cancer in the UK, and accounts for approximately 3% of all new cases of cancer. There are around 12,000 new cases annually. There is a gender difference: in the UK, in men it is the fourth most common cancer, while in women it is the thirteenth most common.

Head and neck cancers include cancers of the mouth and the throat, as well as some rarer cancers. These include cancer of the sinuses, the salivary glands, or the nose or middle ear. Mouth cancer can develop on the lip, tongue, or anywhere inside the mouth. The most common places are the side of the tongue or floor of the mouth.³

As the Head and Neck Cancer Foundation states – "Treatment for head and neck cancers is still largely based on invasive surgery. What makes head and neck cancers different are the facial scars and life-changing impact surgery can have on the vital functions of breathing, swallowing and speech. Current standard surgical procedures also impact the senses of sight, hearing, taste and smell."

Facing Out also worked with people who had experienced skin cancer which occurred on their faces. The generic term 'skin cancer' can refer to non-melanoma⁵ or melanoma types. Melanoma is the fifth most common cancer in the UK with 13,500 new cases of melanoma are diagnosed each year. More than a quarter of skin cancer cases are diagnosed in people under 50, which is unusually early compared to most other types of cancer.⁶

2.2 The Role of the Face

People who experience facial cancers find themselves confronted by a complex and arduous crisis which may call upon levels of resilience that many are unlikely to have needed before. A cancer that occurs on the face or within the head or neck, has a particular set of challenges that are bound up with the social, cultural and functional significance of that area of the body.

2.2.1 The Functionality of The Face

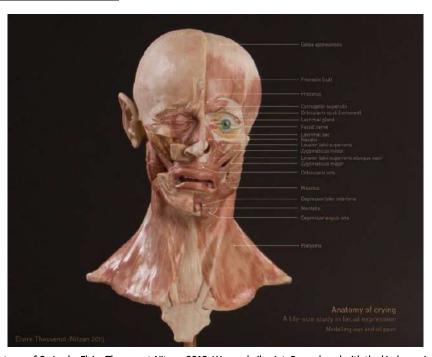


Figure 1 The Anatomy of Crying by Elvire Thouvenot-Nitzan, 2015. Wax and oil paint. Reproduced with the kind permission of the artist

The functional aspects of the head and neck are, of course, manifold. Leaving aside the fundamental role of the brain itself, the head contains many of the components with which we interact and communicate with the world. The physical elements required to see, hear, eat, taste, smell, swallow and speak all are all contained within a relatively small area of the body and so, when cancer attacks here, the potential consequences faced by all those confronted by a cancer diagnosis (threat to life, painful and distressing treatment, disrupted lifestyle, financial/employment implications etc.) are added to greatly.⁷

2.2.2 The Face and Identity

The face-the index of a feeling mind.

George Crabbe, Tales of the Hall (1819)

The face occupies a unique place in our understanding and experience of our physicality and sense of self. It is primarily how we are recognised by others⁸ and remembered in the mind's eye.⁹ Through its complexity of musculature, the face offers us innumerable subtleties of expression and micro-expression conveying emotion, mood and thoughts, allowing complex interactions to be exchanged without a word being spoken. Each element of the face serves to express our feelings and communicate them to others, whether via a doubtful eyebrow, a disgusted nose, a flirtatious glance or a sympathetic turn of the mouth, each element can be read and understood instantaneously without the need for conscious thought. The traits that make up our personalities, identified by psychologists as the 'Big Five'¹⁰ (openness to experience, conscientiousness, extraversion, agreeableness, and neuroticism), are conveyed primarily to the world through our faces.

Faces not only share our personalities, but also give clues to our place in the world. Facial similarities can identify us as belonging, not only to an ethnic group or region, but to our families. The blending together of a couple's looks in the faces of the next generation can be a cause of great delight and allow echoes of the features of departed family members to be inherited and loved again. These associations frame the complex interrelationship between face and social identity.

It is the common wonder of all men, how among so many millions of faces there should be none alike.

Sir Thomas Browne, Religio Medici (1642), Part II, Section II.

Our understanding of the extent to which we equate the face with 'identity' became very apparent at the beginning of this century when commentators such as the medical anthropologist Linda Hogle addressed the ethical complexities of the first facial transplantations saying, 'you're really transplanting more than the tissue itself [with face transplants]. You're bringing someone's identity and overlaying it on the recipient's body' 11 12 13 Other academics, such as Facing Out collaborator medical anthropologist Dr Anne-Marie Martindale, question the extent to which identities are embodied in the face, rejecting 'claims that identities are facially based, and that they can be restored to (passive) recipients via medical interventions or transplanted between persons' 14. It is, however, undeniable that the face plays a significant role in our construction of a sense of self.

2.2.3 <u>Disfigurement and Discrimination</u>

It is an uncomfortable fact that facial appearance, as it is interpreted as attractive or unattractive, can play a disproportionate role in how we are valued in society with attractiveness impacting success in careers¹⁵ as well as everyday exchanges. Facial symmetry has widely been found to be rated highly for attractiveness¹⁷, as have 'evenly coloured pliant skin, clear eyes and shiny hair... as well as signs of being disease-free' factors are thought to be bound up in the evolutionary imperative to find a mate with 'good genes' Unfortunately, the flip side of this understanding is that people who are not symmetrical or seen to be sending out

signals of good health have greater barriers to succeeding at work and to being valued more widely in society. In 2017, Changing Faces, the UK's national charity for people with visible difference published Facial Disfigurement in the UK, a damning report which found that 67% of people attach fewer positive attributes and characteristics to people with a disfigurement, far higher than discrimination based on ethnicity or gender. The report also included data gathered from people who live with a visible disfigurement, of whom four fifths had experienced unpleasant comments from a stranger and half felt that how they looked had hindered their career in some way.²¹ These findings reflect a body of academic papers with similar findings including Ranik and Borah's research which found that strangers who are shown photographs of people with facial differences such as scars are more likely to judge them as 'dishonest, unsuitable for employment, unintelligent, and unattractive.'²²

2.2.4 Culture and Disfigurement

"Deception. Disgrace. Evil as plain as the scar on his face."

— "Not One of Us," The Lion King II: Simba's Pride

It is right to question whether these assumptions and prejudices are not wholly born from our physiological need to meet a healthy mate and have healthy children. Dr. Martindale, in her thesis 'A life lived: experiencing an acquired facial 'disfigurement' and identity shift',²³ includes a chapter that examines examples of facial disfigurement as it appears in popular culture and acknowledges that, although there have always been critical challenges to this premise²⁴, it is often the case that goodness is equated with beauty and ugliness or disfigurement is used to denote an evil or corrupt nature. She cites instances from as long ago as ancient Greece, noting that Homer equated evil with ugliness in the Iliad and citing Synnott who quotes Plato's assertation that 'beauty is good and the good beautiful, souls should not be wasted and destroyed by ugliness and evil'²⁵.

Martindale finds examples of this trope in cultural sources as far afield as the Bible, the plays of Shakespeare, the Victorian novels of Austin, Stevenson and Wilde, right the way through to the villains of James Bond books and movies. Examples in fine art are equally as prevalent, from the grotesque art of Bosch²⁶, Bruegel²⁷ and Grunewald²⁸ to the painterly disfigurations of Francis Bacon²⁹. Perhaps the one of the most overt examples is Hogarth's The Rake's Progress³⁰ which illustrates not only a descent in morals and social standing, but also a descent into a world peopled by the disfigured.ⁱⁱ

Unfortunately, these lazy and damaging tropes continue to be called upon to this day. They have become so hackneyed that online movie-fan sites have a term to describe the disfigurement that denotes villainy: 'The Red Right Hand'.³¹ It is interesting to note that these sites also host discussions of the differences between 'Good Guy/Bad Guy scars' where the difference between heroic and villainous scars are defined by their placement, texture and shape and size³². Despite Changing Faces' British Film Institute-supported campaign, *I Am Not Your Villain*, which urges the film industry to 'stop using scars, marks or burns as a shorthand for villainy'³³, it is disappointing to note that 2019's likely top-grossing film, Avengers-Endgame, features Marvel's ultra-villain Thanos, whose face is heavily marked with scarification. That is not to suggest that some notable steps forward haven't been made of late. We have seen the emergence of well-rounded and nuanced heroic characters with very noticeable disfigurements (quite different to the usual heroic scars) such as Tyrian Lannister, Beric Dondarrion and The Hound in The Game of Thrones and the fundamentally heroic, if morally ambiguous, Deadpool.

There are a growing number of people with facial differences who are gaining celebrity in a media landscape in which they were once invisible. People such as Falklands veteran Simon Weston, BBC tv's Strictly Come Dancing contestant Katie Piper, and presenter and campaigner Adam Pearson are well known in the UK. More and more people with unusual appearances are finding a platform to share their lived experiences through social media. Nikki Lilly, a young girl with a disfigurement due to arteriovenous malformation (AVM), has become a YouTube star with half a million followers. She has made numerous tv appearances and her own programme sharing her story with other young people on CBBC. The book 'Wonder' by R.J Palacio and its subsequent film, which tells the story of a young boy with a facial difference negotiating his start at a new school, has been a hugely successful. These positive narratives will hopefully serve to inform and influence people to be more aware of discrimination due to disfigurement, question cliched media portrayals and recognise and confront prejudices in the workplace. As the Disfigurement in The UK Report concludes,

[The Report] speaks to a nation that has to change. Not to any particular sector or agency or company, but to the wider society where it remains at least tolerated and at worst accepted that people who look different should be treated unfairly or unequally...An unequal society negatively affects everyone and if we do not succeed, people who have a disfigurement are prevented from reaching their full potential and will have a reduced quality of life as a result. The time for change is now.

[&]quot;Hogarth's works including The Rake's Progress, displayed as part of *Prints of Darkness: Goya and Hogarth in a Time of European Turmoil* on show at The Whitworth in 2018-19 have been employed as part of Facing Out's engagement programme, see 3.3.3.1

2.3 The Psychosocial Impacts of Head and Neck Cancers

The psycho-social impact of head and neck cancers can be massive and devastating. The visible nature of the disease and subsequent treatment/reconstruction, the threat to or loss of sensory functionality, the fear of discrimination and loss of social anonymity can all play a significant role, adding to the to the psychological strain experienced by people who are diagnosed with other forms of cancer.³⁴ Such factors led Koester and Bergsma to describe head and neck cancer as more emotionally traumatic than any other type of cancer.³⁵ Substantial psychological distress can occur manifesting as depression³⁶, social avoidance³⁷, anxiety³⁸, body-image disturbance³⁹ and suicide. The result of such strains is starkly apparent in the research carried out by Osazuwa and Peters who conclude that people who have experienced head and neck cancers are twice as likely to commit suicide as other cancer patients. ⁴⁰ Appropriate psychosocial support is rarely available. Facing Out collaborative partner Prof. Diana Harcourt (see 3.3.1.3.1.2), writing with Nicola Rumsey, her colleague at The Centre for Appearance Research in Bristol, acknowledges that 'despite a consensus that disfigurement is associated with psychological distress, relevant support and interventions are not routinely available and most existing psychosocial care is reactive rather than preventive. '41

2.3.1 Patient-Centred Qualitative Research and Assessing the Impact of Facing-Out on Its Portraiture Subjects

Facing Out asked the question, 'Can sitting for a portrait be beneficial to people who have experienced facial cancers and reconstructive surgery?' Acquired changes in appearance due to facial cancers and the psychological impact of living with an unusual or scarred face were of particular interest to the artist in her role as a portrait painter. It was necessary therefore to look at a very specific research area which addressed these issues.

Qualitative research relating to body image specific to head and neck cancers with a patient-centred focus has been found to be somewhat lacking. In their review of the research literature, Ellis et al. ⁴² conclude that 'Managing body image concerns remains a key component of HNC [head and neck cancer] survivorship care....many patients with HNC are affected by BID [body image disfunction] and there are substantial negative functional and psychosocial associations. Currently, no evidence-based treatment options exist for patients with HNC with BID.'

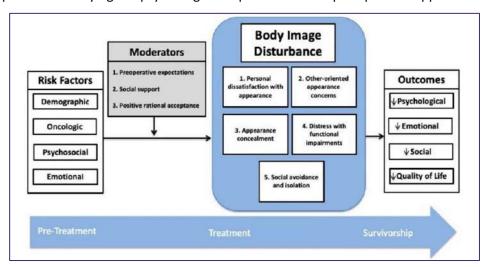
Ellis and al., have undertaken and very recently (April 2019) published a subsequent study, *Body Image Disturbance* in Surgically Treated Head and Neck Cancer Patients: A Patient-Centered Approach⁴³ seeking to provide 'an in-depth, patient-centred description of body image concerns in HNC survivors to improve patient-centred approaches to conceptualize, measure, prevent, and treat BID in HNC patients.'. This study contains a beautifully succinct and accessible 'conceptual model of body image disturbance in head and neck cancer patients demonstrating risk factors, key domains, experiential modifiers, and negative outcomes' (see

Figure 2). The model is informed by that of Rhoten et al⁴⁴ with the addition of new qualitative findings about key themes and experiential modifiers of HNC-related BID. These additions were developed by the researchers employing insights acquired using patient-centred methods, specifically, the data analysis of interviews with a sample group of patients with a lived experience of head and neck cancers.

It is these 'experiential modifiers', key factors which were found to influence how the subject perceive the severity of body image disturbance, that are of the greatest interest when assessing the impact that the Facing Out project has had on its portraiture subjects. It is particularly interesting to note that 'social support' and 'positive rational acceptance' are highlighted as capable of modifying the psychological impact. The attempt to provide opportunities

for the Facing Out subjects to benefit from social support provided by the artist, by fellow portraiture subjects with a similar shared experienced and by the wider public were a fundamental aim of this project.

Figure 2 Ellis et al.'s 'Conceptual model of body image disturbance in head and neck cancer patients demonstrating risk factors, key domains, experiential modifiers, and negative outcomes.'



Moderators

- 1. Preoperative expectations
- 2. Social support
- 3. Positive rational acceptance .. aided by involvement in an artistic intervention???

Figure 3 A proposed addition to Ellis et al's model

'Positive rational acceptance' is defined by Ellis et al. as being the implementation of 'strategies to emphasize acceptance of one's body image and positive thinking about appearance to minimize the severity of BID.' Facing Out, at its heart, was a conceived as an 'arts for health' project. It had many strands that engaged with various groups and the general public with the intention of benefiting those who participated. The core aim, however, was to be beneficial to those individuals who sat as portraiture subjects and at the heart of that was the intention of helping the subjects come to an acceptance of their newly altered appearances. Couched in these terms, Facing Out's interaction with its portraiture subjects could be defined as an 'experiential moderator' or 'psychological intervention'. Christine Callaghan, a medical social worker and researcher, sets out the 'Tasks of Recovery and Intervention' describes the final two stages in recovery thus:

Reframe the experience. Through this task, the patient learns to redefine aspects of the injury in terms that are acceptable, realistic, and positive. Patients acknowledge the loss(es) but find hope and mastery in new-found strengths and skills⁴⁶.

Integrate the experience. This final task involves the integration or psychological "metabolism" of the injury into the overall fabric of the patient's life. He finds meaning, perspective, and significance through the experience that correlates with other life events and values.⁴⁷ It essentially becomes part of self and is integrated into the complexity and humanity of each individual.

2.3.1.1 A Note on Evaluation of the Impact of Facing Out as a 'Psychological Intervention' and 'Experiential Moderator'

It was Facing Out's intention to help and support its subjects to both 'reframe' and 'integrate the experience' of their cancer experience and disfigurement. The use of art, and particularly portraiture, to encourage acceptance of an altered appearance and perhaps lessen the psychological impact, is a novel approach and as such requires an appropriate level of documentation and evaluation. Evaluation of this element was primarily carried out via interviews with participants which included formal recorded interviews, filmed interviews and informal conversations noted by the artist after the fact. These anecdotal elements were generally recorded because they were of particular significance and were not expressed via other, more traditionally gathered means. Some participants with limited functionality of speech felt that they could communicate more effectively in the written word, and so provided written statements. A written feedback via a questionnaire was also completed at the end of the project. The evaluation of this element of the project can be found at 3.2.3. iii

It must be noted that the artist, who is not a trained psychologist, art therapist or social worker, acknowledges the shortcomings in her knowledge base but has approached the researching and evaluation of these elements with as much rigour as possible without the support and resources of an academic institution. Academic papers where possible have been accessed via direct communication with the authors, openly published papers or via 'pay per paper' online portals. This has limited access to some extent.

The artist also recognises that the scope of the research into to the psychological impact undertaken is limited and that this project could have provided richer findings had academic research partners with an interest in psychological impact of head and neck cancers had been involved in evaluation of the project from the outset. This is regretful and is an element that the artist intends to rectify when embarking on similar projects in the future.

3 Production Phase

3.1 A Residency at Maggie's Manchester

The production phase took place for the most part at Maggie's Manchester⁴⁸, a cancer support centre in the grounds of Europe's largest cancer treatment centre, The Christie Hospital.

One of the aims of this residency was to offer a 'painting as performance where conversation is key' model of engagement, as developed by the artist during previous hospital-based projects. ⁴⁹ This model sees the artist creating portraits with a strong bio-medical narrative in public spaces where people who may be affected by illness are present. The intent is to inspire positive and thoughtful conversation with passers-by, offering them a distraction from their own worries around illness and treatment, providing them with an interesting and restful interlude as they watch the artist at work and share with them the subjects' stories.

In the early planning stages of the project, it was envisaged that the paintings would be produced in the waiting areas of head and neck cancer clinics in Manchester Royal Infirmary and at The Christie Hospital. Previous projects had been delivered in similar settings. However, the artist did have misgivings about sharing the stories of portraiture subjects who had perhaps been through very difficult cancer journeys in a space where people may be receiving an initial diagnosis or an upsetting prognosis. Although the model had worked very successfully in clinical settings before, this project was at risk of impacting badly on the very people it was designed to help. As planning continued, Burscough was introduced to Maggie's Manchester and recognised that this setting might be a much better fit for this project. The Centre Head, Sinéad Collins, immediately saw a shared ethos in the belief that 'conversation is key'. She reframed the artist's concerns positively: the centre's raison d'être was to offer support, not least psychological and emotional support, and that happens most easily when people talk openly and honestly about their experiences.⁵⁰ For every person who has a visible scar from their cancer treatment, there are many more who have scars that are hidden beneath clothing and who may be struggling to come to terms with their changed body. Allowing the stories of the portrait subjects to start difficult conversations in a safe space such as this, with councillors, psychologists and cancer support specialists on hand, could be something of great benefit, facilitating opportunities to tackle the vital stages of psychological recovery, 'reframing' and 'integrating the experience' (as outlined above 2.3.1).51

"Facing Out is important work...The paintings have started so many conversations, and that's what we're all about"

Sinéad Collins, Centre Head, Maggie's Manchester

Throughout the project, Sinéad was unflinching in her conviction that the portraits should never shy away from telling the authentic stories of the sitters, acknowledging their lived experiences, no matter how appalling the circumstances or unsightly the image, because to do so would be a kind of betrayal of a life lived. Sinead's deep understanding of the disease and its impacts, drawn from years working as a cancer nurse meant that having her support for and belief in the project was all the more significant and heartening.

3.1.1 Maggie's Centres

Maggie's is a charity that is wholly funded by public and corporate donations with its centres located in the grounds of NHS hospitals that treat people with cancer. Founded in 1995 by garden designer Maggie Keswick Jencks and her husband, architectural theorist Charles Jencks, it exists to offer emotional, practical and social support to people with a cancer diagnosis and their family and friends. It offers very practical help, from benefits and employment law specialists, highly trained oncology nurses acting as cancer support specialists who are ready to answer questions about treatment, and clinical psychologists offering structured group courses and individual support. There are sessional workshops including tai-chi, relaxation classes and courses run by nutritionists.



Figure 4 The Artist at Work in Maggie's Manchester by Caroline Johnson. Ink and watercolour on paper, 2018

Many people simply use Maggie's as a 'home away from home' to relax in a non-clinical setting while waiting for appointments or treatments. All this is offered in the most beautifully designed buildings and gardens. The charity was conceived after Maggie Jencks was given a terminal diagnosis in a dingy clinic which had nowhere to go to nearby to process this devastating news. The centres draw upon the values of its founders who believed that beautiful gardens and architecture can be of great help to people who have stressful situations to deal with. On that theme Maggie wrote,

"The NHS is obsessed with cutting waiting time – but waiting in itself is not so bad – it's the circumstances in which you have to wait that count. Overhead (sometimes even neon) lighting, interior spaces with no views out and miserable seating against the walls all contribute to extreme mental and physical enervation. Patients who arrive relatively hopeful soon start to wilt. Waiting time could be used positively. Sitting in a pleasant, but by no means expensive room, with thoughtful lighting, a view out to trees, birds and sky, and chairs and sofas arranged in various groupings could be an opportunity for patients to relax and talk, away from home cares. An old-fashioned ladies' room – not a partitioned toilet in a row – with its own hand basin and a proper door in a door frame – supplies privacy for crying, water for washing the face, and a mirror for getting ready to deal with the world outside again. There could be a tea and coffee machine (including herb teas) for while you're waiting, and a small cancer library...for those who want to learn more about their disease."⁵²

Unfortunately, Maggie died before the first centre opened but her thoughts continue to have great influence: this text has become woven into the brief that is given to each architect who is selected to design a Maggie's Centre. There are currently twenty-one centres open in the UK, three internationally and five in development⁵³. The Manchester centre, with its airy, welcoming lightness, relaxing palette of colours, stunning glasshouse and technically brilliant wooden structure was designed, along with much of its furnishings, by Foster and Partners. It has won numerous awards.⁵⁴ The healing power of art is brought into play: the walls of the centre are adorned by artworks on loan from The Whitworth's collection by artists like William Morris, Bridget Riley and Damien Hirst, and rather wonderfully, Maggie Jencks's 'old fashioned ladies' room' is home to a signed print by Eduardo Paolozzi. The centre, with its dedicated staff and volunteers, its furnishings and garden, make visitors feel valued at a time when the experience of receiving treatment in a very busy hospital can leave one feeling like a number on a list.

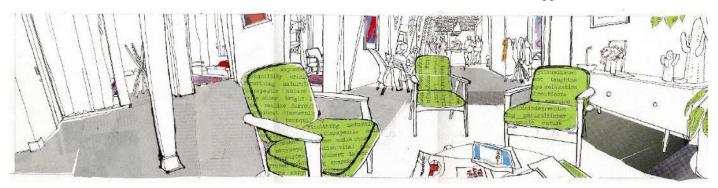


Figure 5 Maggie's Manchester by Caroline Johnson. 2017, Pen and collage on paper

3.1.2 Portraiture as Arts for Health Performance-Evaluation

"" The people who chose to sit for Lucy," ...somebody said to me at Maggie's, "they shine a light for the rest of us. They were brave on behalf of all of us because my disfigurements are under my clothes, but they are no less troubling to me." And I think that's part of the courage of what these people have been prepared to do and part of the creativity and the empathy and the love that Lucy as an artist has demonstrated in being able to take the emotion of these sitters...and bring that out...and make it very, very real."

Sinead Collins. Speech at the Facing Out opening event.

3.1.2.1 Portraiture as Arts for Health Performance, Quantitative Evaluation

3.1.2.1.1 Visitors with the opportunity to see the work in progress

Over the duration of the twenty-month production phase, 37,075 people were recorded as visiting Maggie's Manchester, of these 21,164 were people with a cancer diagnosis and 12363 were their friends and family. These numbers were recorded by centre staff and volunteers. As the artist was working in the main open-plan space and the easel and work in progress was in-situ throughout, it would be right to assess that all these visitors had an opportunity to see the artist at work or the work in progress on display.

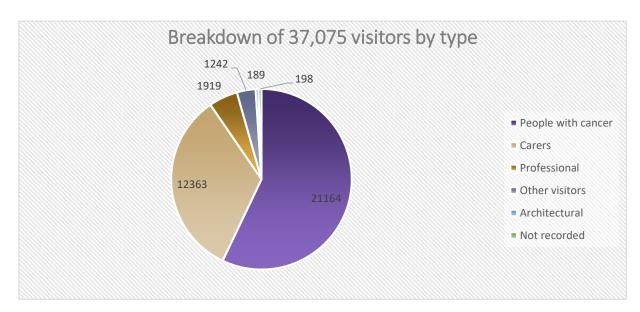


Figure 7 Breakdown of centre visitors by type

3.1.2.1.2 Visitors engaging in conversation with the artist

The artist took twenty day-long recordings of numbers of conversations about the artwork by tally, undertaken monthly throughout the production phase. During these days she spoke to an average of 17.5% of visitors who visited when artist was present. The artist was present approximately 3/5 of opening hours so there were approximately 22,245 visitors to the centre when she was there. Extrapolating from these findings, the artist spoke to approximately 3892 centre visitors about the artwork during the production phase, about 10% of overall visitors. It should be noted that not all these interactions with visitors will be with different people as many would return on several occasions or come in regularly.

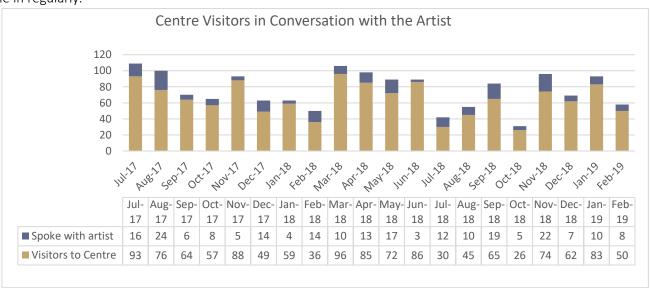


Figure 8 Centre Visitors in Conversation with the Artist

3.1.2.2 Portraiture as Arts for Health Performance Qualitative Evaluation.

Qualitative evaluation was undertaken primarily via feedback postcards which were left close to the artist's easel with a post-box to leave the responses in.



Have you chatted with Lucy, the artist, about her work? Y/N

-Did that help your mood?

Not at all / Not much really / A little / Yes / Yes, a great deal
Have you spent time watching Lucy paint? Y/N

-How many times?

-Did that help your mood?

Not at all / Not much really / A little / Yes / Yes, a great deal
Have you taken part in any Facing Out workshops? Y/N

-Which ones?

-Did they help your mood?

Not at all / Not much really / A little / Yes / Yes, a great deal
Please leave your thoughts about Facing Out below. Many thanks.

Figure 9 Feedback Postcard

3.1.2.2.1 Reported benefits to mood of engaging in conversation with the artist.

Of 118 respondents, 96 had spoken to the artist. In answer to the question, 'Did that help your mood?' all reported that it had, to varying degrees:

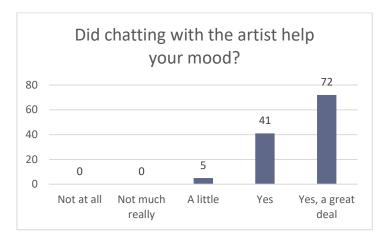


Figure 10 Reported benefits to mood of engaging in conversation with the artist

3.1.2.2.2 Reported benefits to mood of watching the artist at work.

Of the 118 respondents, 106 has watched the artist at work, with 86 of that group having done so several times (with a range of '4-5 times' to 'too many to count').

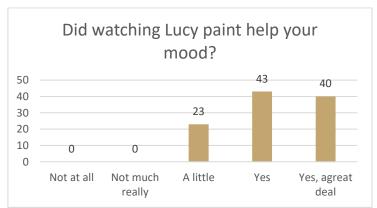


Figure 11 Reported benefits to mood of watching the artist at work

3.1.2.2.3 Assessment of the use of postcards to collect feedback

Pros	Cons
Visitors were able to fill in and return the feedback forms without interaction with the artist, thus avoiding influence	The incentive to fill in the postcards, for the most part, was left with the visitors so not as many were filled in as would have been if the artist was asking them to directly
The task of leaving feedback could be done quickly so visitors were more likely to respond	The space to leave written comments was limited so not much was useful. In future, it would be better only to print on one side
The postcards inspired some people to leave longer written responses	The postcards sought to gather feedback from people who spoke to or watched the artist and workshop participants. These two group should perhaps have had separate forms in order to gain more information
Yes/No, Likert Scale ⁵⁵ and open-ended questions allowed for a good range of data types to be gathered efficiently	Maggie's has a lot of printed material about their services on display so the postcards could get ignored

3.1.2.2.4 The Artist's Reflections on the Residency as Arts for Health Activity

The decision to undertake Facing Out at Maggie's Manchester was absolutely right. The welcoming and friendly atmosphere meant that it felt very natural to foster ongoing and rewarding relationships with centre visitors. Some conversations were one-offs, with people who perhaps came into Maggie's to get some specific advice and didn't return. Others marked the start of evolving relationships with both me and the artwork, and indeed with the subjects of the paintings.



Figure 12 Lucy in conversation with Andrew and Kate, regular centre visitors at Maggie's Manchester

People who hadn't met the subjects said that they felt like they knew them after watching the artworks develop. Many commented on the facial expressions of the sitters and speculated (often very accurately) on their personalities. Others expressed feelings of empathy and connection inspired by shared experiences. As often happens with this model of working, the conversations become richer as the project went on as insights, opinions and experiences are offered by the viewers themselves. The conversations feedback into each other and become more interesting for it. Perhaps most interesting to me were the conversations about the nature of the gaze as it relates to people who look different. Many of the people who stopped to talk didn't have visible disfigurement but felt a kinship with the sitters because of their own chemotherapy-induced loss of hair, or changes to their weight, skin texture or complexion. Drawing people's gaze and unsolicited questions or conversations with strangers are common to people experiencing a variety of cancers. It felt like having that experience acknowledged and talked about was important and somewhat empowering.

Interestingly, a kind of 'hierarchy of suffering' or 'disease prestige' (as described by Stone⁵⁶) was often applied by the viewers with a cancer diagnosis to describe their reactions to the subject's experience of cancer. Phrases like, 'And I thought I had it bad' and 'It puts my illness into perspective' were regularly voiced. It is difficult to know whether this kind of response had a positive impact on the viewer's attitude to their own illness, whether the perception of one's experience as 'less than' that of another cancer patient can be helpful is not known. Certainly, academic research on the subject is hard to find. One suspects that assimilating such a perception could be a double-edged sword where 'putting it in to perspective' is weighed against a more problematic internal narrative of 'if they can deal with that, why am I not coping?'.

As evidenced by the feedback data, which is certainly backed up by my own anecdotal experience, centre visitors' reactions to the residency were overwhelmingly positive. Raising awareness of the particular challenges faced by people with head and neck cancers was seen to be a worthwhile undertaking and doing so within an art project was remarked upon as being an unusual and successful approach. Many of the viewers were very forthcoming about how they felt they had benefited from the 'arts for health' intentions of the residency and their contributions (below) are warmly appreciated.

3.1.2.2.5 A selection of written responses about the Facing Out residency.

"I love the fact that Lucy is part of the centre, not hidden in a room. I think at first that I was a bit nervous about asking questions because I felt so ignorant or scared that I might offend someone, but Lucy has such a passion for raising awareness. She is really approachable. She makes you feel at ease and it leaves you feeling a bit more insightful. It helps me to talk to people I know, mainly to pass on the message and hope that it becomes less of a taboo"

Centre Visitor, Written Feedback

"I know [the portraiture subject] Graeme from the squash club. I think that Lucy has really captured his personality and his bravery. It's inspirational to look at his portraits and see what he has been through. It makes me think- 'Well, if he can get through that...'"

Centre Visitor, Written Feedback

"I love seeing Lucy when I walk into the centre...I have learnt so much about people who are affected by cancer, especially about the face. The people who have posed for the painting. I am in awe and I haven't got the words to express how I feel about their courage"

Centre Visitor, Written Feedback

"I hadn't really thought about how difficult it must be to have scars on your face from cancer. It must be annoying to be stared at in the street and be asked questions [about it] by strangers...I love the painting- the man looks kind, even with his scars"

Centre Visitor, Written Feedback

"I can understand a bit more about how Lucy can capture their souls and allows this beautiful, amazing person to shine through. At first, I saw a person with facial disfigurement, now I watch as Lucy gradually brings this person to life...I am so amazed at people who are willing to show the reality of facial cancer to the world."

Centre Visitor, Written Feedback

"I love watching Lucy paint... I could sit for hours."

Centre Visitor, Written Feedback

3.2 The Portraits

The approach to most of the portraits was to create paintings that told a story relating to the subject's sense of their own identity. This was in order to offer the subjects a chance reflect upon who they are and perhaps in doing so, combat some of the threats to the sense of self discussed above (see 2.2.2). Having any sort of illness can quickly strip one of facets of identity: a working life, a social life, even one's own clothes can be lost, replaced by hospital gowns. The strongest of family and sexual relationships can be strained. Martindale theorises that the experiential elements of [living through cancer and] having an altered appearance has much more of an impact on identity than a physical change to the face itself⁵⁷. Callahan speaks of the successful integration of such experiences as resulting in,

"a transformed sense of self, comprising both body and ego. It moves beyond becoming merely accustomed to facial change and disfigurement, culminating rather in a hard-won sense of pride in one's appearance and identity. It also encompasses a greater refinement of existing or newly discovered ego strengths, as well as growth and maturity through adversity." ⁵⁸

If the project were successful, and if being involved really could act as an experiential modifier (see 2.3.1), the journey towards 'a successful integration of the experience' would be encouraged, expediated and celebrated by becoming the subject of a Facing Out portrait.

3.2.1 Planning the portraits

Identifying the people who were to become portraiture subjects happened under a variety of circumstances. These will be discussed alongside each painting as will the production of the photographs which would be used in developing the portraits.

3.2.2 The Portrait Subjects

3.2.2.1 Bernard Corri, AKA 'Bern'

The artist met Bern in 2015 when he was an in-patient at Manchester Royal Eye Hospital having recently received a cancer diagnosis and the subsequent removal of the cancer along with his left eye. Lucy was creating portraits for the 'CurARTive' project in the hospitals entrance atrium⁵⁹. Bern was showing his altered appearance to the world beyond the ward for the first time. He tells it like this:

""I think it was about 2 weeks after my op to remove my left eye along with the cancer that had engulfed it, that I plucked up the courage to finally hobble my way out of the ward I was in and try and go for a wander around the hospital I was in. It was around 7pm so the M.R.I. in Manchester would be pretty empty at this time and the fact that I looked like an extra from `The Mummy` movie would be least likely to impact on a greater number of people... [I saw a] strange figure sat at an easel daubing away at the canvas before her. This lovely lass had talent, and what's more was using it to highlight the effects any form of facial disfigurement or disease can have on the individual concerned...Her talent, attention to detail, and general enthusiasm for what she was trying to achieve was immediately apparent, and having become an avid fan of art, if a little bit of a late comer to the subject, we soon became friends as a result of this chance encounter. There was something a bit special about this lady that I had stumbled across that night, and I returned to my ward with my faith in humanity renewed."

Lucy was equally impressed by Bern. His warmth and humour aside, the fact that he had approached a stranger for a chat, in the face of the kind of traumatic experience that all too often triggers social avoidance⁶⁰, demonstrated a great strength of spirit. After this encounter they became friends on social media. There Bern posted images of the alterations to his face and poems that told his story. It was following Bern's long and involved process of treatment and reconstructive surgery via his very open and honest social media posts that inspired the artist to think about and begin to research facial disfigurement, head and neck cancers and consider developing a project like Facing Out.

"Inside the CT scanner who should I see?

Deep inside my left socket hypnotising me

I asked her name like a bit of a chancer

She crawled across my face and whispered "Ethmoid Cancer"

An extract from 'Fighting Ethmoid Cancer' by Bern Corri⁶¹

By the time Lucy and Bern met up in person again, at the start of the Facing Out production phase in the summer of 2017, Bern looked considerably different than he had previously, and areas of his head had lost considerable amounts of their functionality. A lot of muscle and bone had been removed from behind his face, including most of his upper pallet which meant speech was severely impaired as was the ability to smell, eat solid food or consume cold drinks. Intensive radiotherapy, delivered at the strongest dose available, caused internal scarring which tightened uncomfortably as it healed. Bern's facial reconstruction had involved several stages, some more successful than others, including the insertion of a saline sack under his forehead which had been added to month by month. This was in order to stretch the tissue and create enough skin and soft tissue to create a pedicled flap⁶², a sausage-like tube of skin and soft tissue with its own blood supply which is rotated around the blood vessel to be transferred to a local area, in this case to create a covering for the hole left where Bern's cancer and eye had been removed. Unfortunately, this flap didn't survive, and Bern was left with an open area which he covers with an eyepatch. Bern's ongoing experience with cancer was extremely intense and physically devastating. After the completion of his portrait he received another terrible blow as, due to the punishing level of radiotherapy he had undergone, Bern all but lost the sight in his remaining eye with only 5% vision remaining.

Bern's is a tragic story which cruelly illustrates the havoc that can be wrought by head and neck cancers. It also is one which highlights the extraordinary resilience that ordinary people can sometimes find to draw upon when the utmost adversity hits. Bern's warmth of personality continues to shine through, as does his humour. He is heavily involved in raising money for cancer charities including Maggie's Manchester and is assistant producer for the Maggie's on the Runway, a charitable organisation that has to date raised in excess of £420k by organising catwalk events where the models are people who have a cancer diagnosis. He is supported by his large family and strong social network which is bolstered by Bern's active social media presence which he manages to maintain despite his loss of sight. He continues to receive treatment for cancer.













Figure 13 Bernard Corri's stages of surgery and reconstruction

3.2.2.2 Bern's Portrait

3.2.2.2.1 Planning and production

The artist painted Bern in late summer and autumn of 2017. A large series of photographs were taken by the artist with a studio set-up, in her (now former) studio at Lime Arts, in the grounds of Central Manchester NHS Trust. Bern and Lucy had been 'virtual' friends online for more than two years so was aware of how much his support of socialist politics played a part in his interaction with the world. Bern often wrote poetry to share his humour, thoughts and experiences, in conversation with the artist, it was decided that lines from one of his poems would help to share Bern's wider identity with the world. He also decided that he would wear a specially commissioned eye-patch promoting his favourite Mancunian band, The Moods. The image that would be worked-up to produce the portrait was decided upon in discussion with Bern and some of his siblings. The artist will often call upon family members or friends of subjects she hasn't spent much time with to help narrow down which image best captures their personality. The image that was decided upon was chosen because it captured Bern's affable personality and the dignity that he maintains despite the physical degradation that he has had to endure.

Bern and his family visited Maggie's regularly during the painting of his portrait. They were hugely excited by their involvement with the project, documenting the experience with numerous of photos which they promoted widely on social media. Over the duration of the project the artist has developed relationships with all of Bern's siblings and is convinced that their practical and emotional support has been invaluable in maintaining Bern's mental health. They have been hugely involved in the project, from the initial photoshoot, through to curating the exibition, celebrating its opening, and attending numerous engagement events.



Figure 14 Bern and his family visited Maggie's regularly to see the work in progress

3.2.2.2. The Portrait

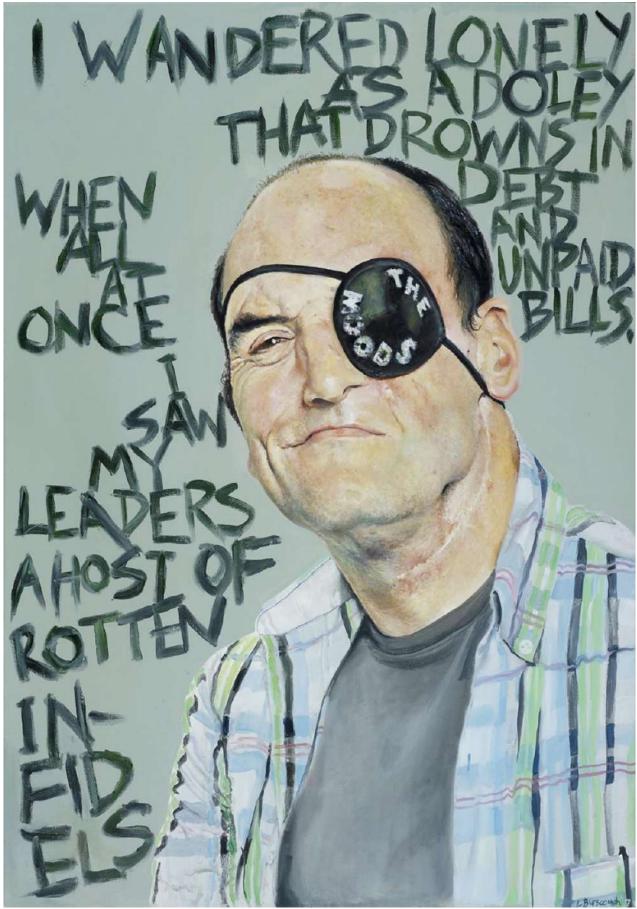


Figure 15 Bern, 2017. Oil on canvas

3.2.2.3 Anne Stroud, AKA 'Annie'



Figure 16 Annie with her portrait in progress

Anne Stroud moved from Dublin to England as a young woman, where she met her husband. They had two children together when he was killed in a car accident. Annie was only thirty-three and her sons ten and seven. She brought them up alone whilst developing her career. Annie spent her working life as a social worker and probation officer. Following retirement, she volunteers at both Maggie's and at a local food bank.

"Gave Shaped Shared Helped Listened"

Gave Shaped Shared Helped Listened"

-An extract from 'Annie', a poem by Tony Curry, commissioned by Facing Out as part of an engagement activity.

The artist was introduced to Annie by staff at Maggie's. Annie volunteers at Maggie's welcoming visitors, introducing them to the centre and its services, and chatting to people as she sets out the fruit, cakes and biscuits that are always on offer.

Shortly before the residency started, Annie was diagnosed with a melanoma under her left eye. She had several operations to remove the cancer until eventually the margins of tissue around the site were clear and the area was reconstructed using a free flap that was harvested from the underside of Annie's forearm. This area was chosen as the donor site as it is soft and hair-free. The operation was initially considered to be a success as the reconstruction was hardly visible. However, as the site healed, the skin became tighter and this began to affect Annie's quality of life as it pulled down on her lower eye lid and meant that the eye could not close and was sore. Annie will be having a further operation in the near future to fix this problem.

3.2.2.4 Annie's Portrait

3.2.2.4.1 Planning and production

Following several informal conversations and the recording of a long 'getting to know you' audio interview, Annie decided that she would like the portrait to reflect her core values which centred around social responsibility and giving back to the community. This would be illustrated by locating the portrait in the Maggie's Centre itself, with its unique wooden structure visible and recognisable, and Annie would be pictured holding a cup of tea in one of the centre's hand thrown cups. This element would serve to illustrate the 'tea and sympathy' or 'tea and a giggle' that is offered by Annie and the team of volunteers to all of Maggie's visitors. The artist was particularly happy with Annie's involvement with the project and the choice of this setting for the portrait. It allowed the subsequent exhibition to talk about and celebrate the invaluable support offered by Maggie's and raise awareness amongst exhibition audiences of what this relatively little-known charity offers.

3.2.2.4.2 The Portrait



Figure 17 Annie. Oil on canvas.

3.2.2.5 Trudi Proctor

The artist met Trudi for the first time as she visited Maggie's to get support as she was experiencing a difficult period after the removal of a basal cell skin cancer (BBC), the most common type of skin cancer. (By coincidence, this meeting was captured by artist Caroline Johnson who was documenting Facing Out with her drawings.)



Figure 18 Meeting Trudi for the first time. Drawing by Caroline Johnson. Pen and watercolour on paper, 2017.

During this period Trudi was struggling to cope following a forehead skin flap operation to reconstruct an area of her nose that was removed along with the skin cancer. Her emotional wellbeing was deeply disrupted by her experience of cancer and the detrimental change to her appearance. Unfortunately, Trudi's judgement was that mistakes made by her clinical care team greatly exacerbated this blow to her mental health. As recognised in Ellis et al.'s conceptual model above (see 2.3.1), one of the experiential moderators that can have an identifiable impact on a person's ability to process body image disturbance is 'preoperative expectations'. 43 She, like many of Ellis et al.'s study group, felt that had she had a better grasp of the potential extent of her surgery, and its effect on her appearance, she would have been able to prepare herself better and mitigate the shock she felt during the first days and weeks following surgery. Trudi had come away from preoperative consultations with the impression that the cancer, which was visible on the skin as the size of 'a pinhead', would be removed and she would return home with a 'tiny plaster'. This wasn't to be the case. The cancer was such that it required a forehead skin flap (of tissue and skin containing its own blood supply⁶⁴) to be harvested to cover the area that was removed. As the flap remains attached at the bridge of the nose/lower forehead, and is rotated down to the nose around the base of the blood vessel, a second operation is required once the flap has bedded in at its new position to remove excess tissue around the nose and at the at the pivot point on the forehead. Trudi wasn't expecting any of this and the shock of coming around from the operation to the realisation that her face would be significantly altered became the over-riding narrative of her experience.

Trudi was very angry and upset when Lucy met her, railing against her cancer experience and the changes it had made to her appearance, but relieved to have found a safe space to express those emotions at Maggie's. Her upset was being added to by unsolicited interactions with strangers ("They were just bloody nosey!") when she ventured out of the house and so social avoidance was becoming her norm and had the potential to develop into a form of agoraphobia.

Before the residency started, a cancer support specialist at the centre spoke to Trudi about her experience and, realising that she had an interest in art, encouraged her to go along to the patient's art group at The Christie. This became Trudi's way back to positive social interactions. She would attend the group three times a week, and, encouraged by her tutor Pat Mountford and the supportive group of fellow patient/artists, she began to create dynamic seascapes which often featured a lighthouse. Trudi saw this as a metaphor for the level of the strength required to 'weather the storm' in a sea of troubles. She began to embody the positive effects that can be achieved by placing supported creative social activities in clinical settings. She was still angry and upset, and troubled by her appearance, but she was out of the house, facing out to the world and getting involved. And then she drew a chair up to the easel at Maggie's and agreed to become the subject of a portrait.



Figure 19 Trudi with members of her art group visiting the exhibition

3.2.2.6 Trudi's Portrait

3.2.2.7 Planning and production

After several meetings and in-depth conversations, it was decided that the portrait should acknowledge Trudi's cancer journey and the transformative experience at the Christie art group by featuring a lighthouse. Trudi had a long relationship with North Wales and its coast as she had holidayed there regularly as a child and continued to do so. Talacre beach was visited for the photoshoot. The journey allowed the artist and subject the opportunity to cement a firm relationship. Talacre was a great choice as the lighthouse there is easily identified and many of the people who watched the work in progress at Maggie's knew the resort well and were pleased to recognise it as they met the artist and heard about Trudi's story.

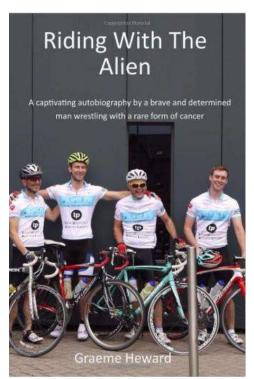
While painting Trudi's portrait, as happened with all the paintings, viewers would speculate about the personality of the subject. Many people would say, 'She looks like she's a strong woman', and indeed she is. One thing that was also regularly commented on was Trudi's 'English rose' or 'strawberries and cream' complexion. Trudi was delighted by these comments, particularly as she was so unhappy about her scarring. She would often repeat them to friends and family who came to see the progress of the painting saying, "It's all natural! No make-up!" (See Appendix 1.1.6) The genuine joy and pride that she radiated at these times, in contrast to the woman who had first come to Maggie's hiding her face under a hood, in the view of the artist, made the project worthwhile and hugely substantiated the assertion that portraiture can be a powerful tool in arts for health practice.

3.2.2.7.1 The Portrait



Figure 20 Trudi. Oil on canvas. 2018

3.2.2.8 Graeme Heward



Graeme Heward was introduced to the artist months before she ever met him, in the very early planning stages of the project, when a MacMillan head and neck specialist nurse recommended that Lucy read his book. 'Riding with the Alien'. The autobiography tells the story of Graeme's cancer journey from his receipt of a diagnosis of adenocarcinoma (a rare form of cancer affecting the mucus secreting cells of the nose) in 2010, to its publication in 2015. This was a tumultuous time for the physiotherapist and his family, with the 'cancer rollercoaster', as Graeme describes it, providing unfathomable degrees of upheaval as he fought cancer through radiotherapy, chemotherapy and, to date, twenty-nine operations. Graeme used the writing of his book, initially as a blog, to help him to process these traumatic experiences and keep his wider family and friends informed. When published, it was an invaluable resource for the artist as it imparted not only the practical details of treatment but along gave a very honest insight into the lived experience of receiving a head and neck cancer diagnosis and its many and varied consequences.

Figure 21 Graeme Heward's Autobiography, Riding with The Alien

Unfortunately, between the publication of the book in 2015 and Facing Out in 2017, Graeme's cancer was found to have returned, this time in an inoperable area. Three rounds of palliative chemotherapy were administered. Graeme was determined to avoid any more chemotherapy, turning down further rounds in favour of making some radical lifestyle changes. "Conventional treatment alone was not going to save me, so I started looking at alternatives/integrative therapies...Out went dairy, salt, added sugar, refined pasta or rice. In came green tea, organic fruit and veg, deep sea oily fish and organic chicken, supplements galore, herbs, meditation and stress reduction. Basically, creating a stronger immune system and an unfavourable environment for the cancer." These changes were successful in keeping the cancer at bay and, when the artist eventually met Graeme at Maggie's and he agreed to be part of the project, he was well enough to be able to consider embarking on some further reconstructive surgery.

3.2.2.9 Graeme's Portraits

The approach to Graeme's portraits differed from the rest of the cohort. Instead of placing Graeme in a situation that reflected his identity in a single portrait, the artist suggested that a plain background should be used, and several paintings made, in order to focus instead on the surgical journey that he would be taking during the production phase. Interestingly, this narrative choice did also serve, if in a more notional way, to illustrate aspects of Graeme's identity: he has a clinical background as a physiotherapist and within his family, both his sons are doctors; his book acts as both autobiography and medical case-history; and the extent to which the cancer has impacted his life and lifestyle is on a comprehensive scale that has made undoubted alterations to Graeme's sense of self. Graeme is not defined by his cancer, but by addressing its reality head-on, in his book and lifestyle choices, Graeme has sought to define *it* in *his* terms.

3.2.2.9.1 Planning and production

Another lifestyle choice of Graeme's has been to maintain, as much as possible, his normal life during treatment. Although 'self-care' changes meant that he was working less hours than before diagnosis, he was determined to return to his physiotherapy practice as soon as possible after surgery. All the photoshoots therefore took place in his clinic between appointments. There are five portraits of Graeme.

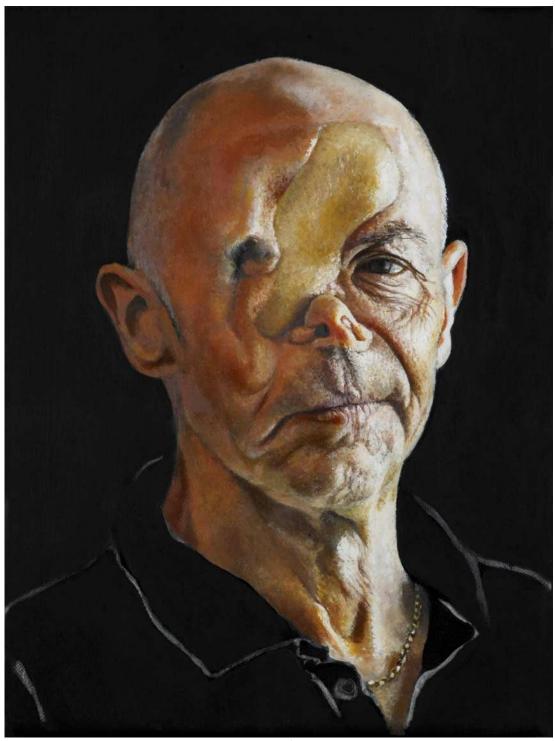


Figure 22 Graeme I. Oil on canvas. 2018

3.2.2.9.2 The Portraits

3.2.2.9.2.1 Graeme I.

This portrait shows Graeme as he looked when Lucy first met him. His right eye has been removed, as has a large amount of the surrounding bone and tissue, including sections of the nose, right cheek and forehead. The flap covering this area was taken from a donor site on his thigh. Graeme also had nerve damage to the right side of his face which affected the movement of his month (specifically smiling) to some extent. You can see a marked depression in his forehead and significant reduction in the length of the nose, such that the bottom of the nose was parallel with the cheeks. This meant that functionality for breathing was impaired and, less obviously a problem, he wasn't able to wear glasses.

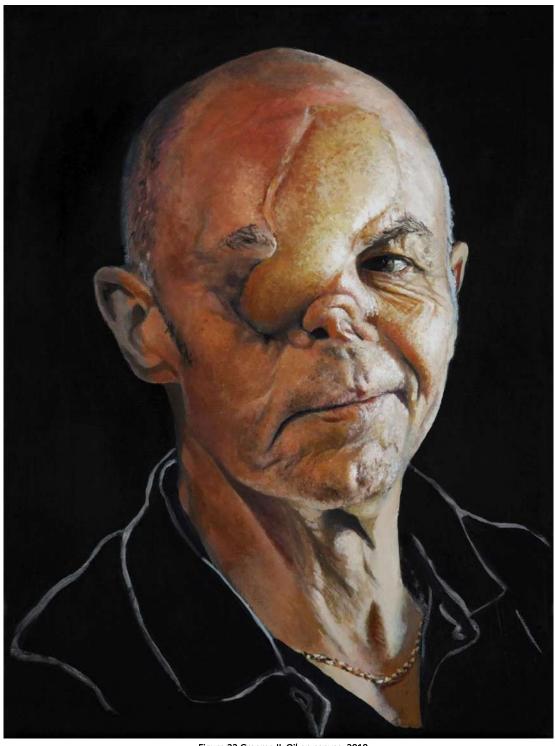


Figure 23 Graeme II. Oil on canvas. 2018

3.2.2.9.2.2 Graeme II.

Prior to this portrait, Graeme had decided to go ahead and follow his surgeon's advice and have further reconstructive surgery. A titanium plate was used to cover the area of bone loss in his forehead and some local flaps were drawn from the cheeks to bring the nose further forward and ease breathing. As perhaps his expression shows, at this point, Graeme was very pleased with the surgery. Unfortunately, between portraits II and III, the surgery began to cause problems and Graeme was rushed into hospital to have emergency surgery. The previous operation had caused tissue fluid to gather around the implant which meant that surrounding tissue became no longer viable. The emergency operation drew some of Graeme's scalp forward to replace the damaged area and try and save the functioning forehead flap and new nasal flaps.

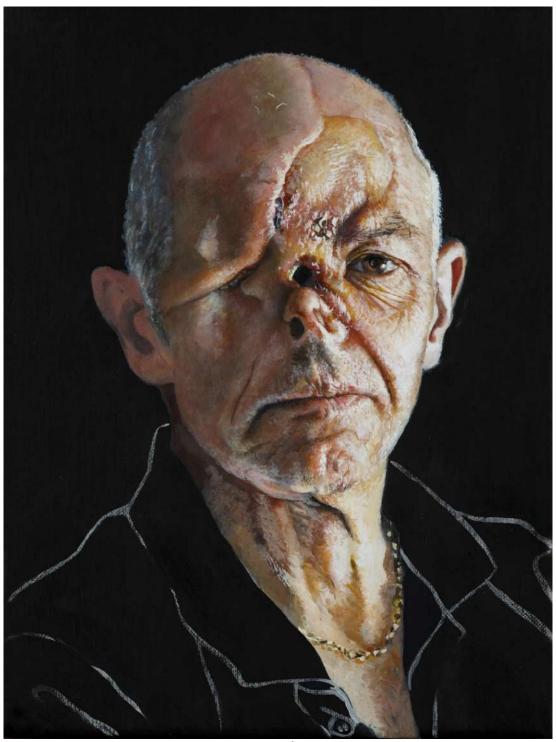


Figure 24 Graeme III. Oil on canvas. 2018

3.2.2.9.2.3 Graeme III

As the time of photographing for this portrait, Graeme was dismayed and indignant at the turn of events that had led to the frightening position he was in now: areas of his face that had previously been stable, if lacking in some aspects of functionality, seemed to be breaking down. There were areas on the nose and forehead that were becoming holes, and the remaining forehead flap appeared to be thinning as if its previously health blood supply was constricted. The artist was shocked by Graeme's worsening appearance and worried about whether his seemingly inexhaustible levels of resilience would, this time, run dry. He was equally angry with his surgeon and with himself for going ahead with this ill-fated surgery. He looked back at the first portrait and wished he hadn't embarked on the surgery.

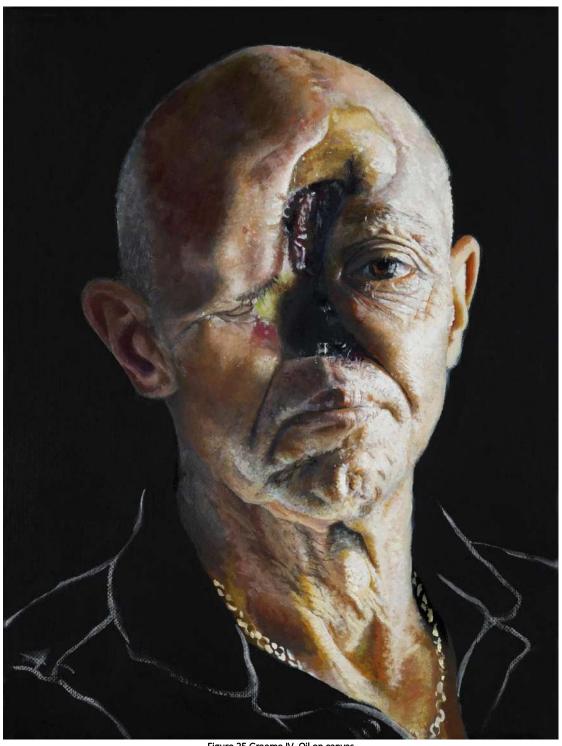


Figure 25 Graeme IV. Oil on canvas

3.2.2.9.2.4 Graeme IV

When the photographs for this portrait were taken, the titanium plate across Graeme's forehead had been removed, as had his nose and the lower half of the original flap from his thigh. It had been decided that the only way for Graeme to move forward was to have a prosthesis made to cover the lost areas, including his right eye. This portrait shows what Graeme had had covered with a dressing for three months. He hadn't showed his face as it now was to anyone beyond his family and medical team up until this point. It is possible to see three magnets that were bedding in around his nasal aperture which would hold the prosthesis in place.

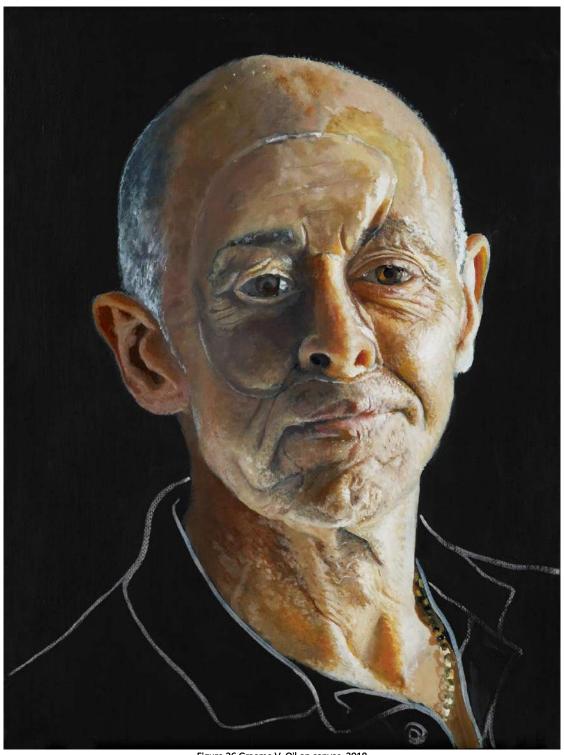


Figure 26 Graeme V. Oil on canvas. 2018.

3.2.2.9.2.5 Graeme V

Graeme's final portrait shows him with his prosthesis in place. It was painted in the final days of the production phase. Graeme, for as long as the artist had known him had said that he had wanted to keep his nose, 'It's a strange nose, but it's mine'. That wasn't to happen but, when Graeme actually got his prothesis, he felt that it was a very positive change. That was certainly the case in relation to how he felt about how his appearance in the previous few months, but he also saw it as an improvement on his appearance in the first portrait. He was particularly happy that he could now walk down the street without drawing people's attention and gaze.

3.2.2.10 Nigel Caldwell

The artist met Nigel when he attended the second day of the Manchester Science Festival 2017 Facing Out Conference at The Whitworth (see 3.3.1). The event had been advertised at The Christie's Head and Neck clinic and Nigel had picked up a flyer and come along. He already had an interest in how creative activities can bring people together and have positive benefits to health and wellbeing as he worked as arts development lead at his local Community Volunteer Support service. His job had seen him develop very successful community festivals and creative groups. He was very impressed by the conference and was interested in the wider project and perhaps becoming a portraiture subject.

3.2.2.11 Nigel's Portrait

3.2.2.11.1 Planning and production

After the conference, Nigel came to Maggie's with his wife to talk about what becoming a portraiture subject would entail. From Burscough's point of view it was interesting to talk to Nigel about the project as he asked questions with a facilitator's insight. He agreed to go ahead and suggested that his portrait should depict his long-running membership of a local veterans five-a-side football team that he had been a member of for twenty-five years. When Nigel was receiving cancer treatment, he had had to step back from the team so, when he managed to make his comeback, it was a significant marker on his road to recovery. Nigel's love of football and having an active lifestyle played another significant role in his cancer experience. It was because of wanting to be able to continue to play football and swim unimpeded that Nigel chose not to have a magnetically attached prosthetic nose, but to go for reconstruction. Nigel's reconstruction involved the use of a free flap that was harvested from his lower arm to reconstruct an area around his upper lip and cartilage for his nasal bone that was taken from his ribs. Although the site of the cancer was successful covered, unfortunately, radiotherapy caused the nasal reconstruction to collapse down and so Nigel's nose was left sloping inwards.

3.2.2.11.2 The Portrait

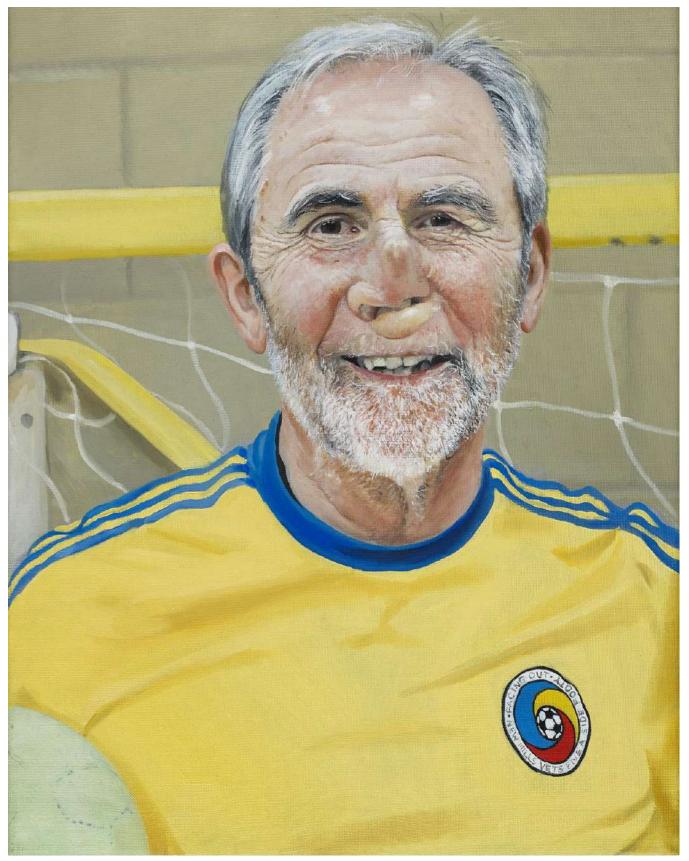


Figure 27 Nigel. Oil on canvas, 2018

3.2.2.12Damir Kosutic

Damir Kosutic met the artist when he visited Maggie's Manchester to deliver an evening lecture on facial reconstruction. Damir is a consultant reconstructive and plastic surgeon at The Christie NHS Trust. There he delivers complex microvascular reconstruction for head & neck cancer and also for lymphoedema, upper/lower limbs, and breast/chest wall following cancer removal. He has a very impressive résumé:

Mr Kosutic has been working as a Consultant Plastic and Reconstructive Surgeon for the past five years at some of the best UK plastic surgery units, having completed fellowships in Microvascular Reconstruction at Imperial College NHS Trust - Charing Cross Hospital London as well as a Fellowship in Breast Microsurgery and Perforator Flaps at Sant Pau Hospital, Barcelona, Spain. He is a Fellow of Royal College of Surgeons of England (FRCS Plast) and Fellow of European Board of Plastic and Reconstructive Surgery (EBOPRAS).

His subspecialty interest is reconstructive surgery for patients with cancer, specialising in microvascular free flap reconstruction. Mr Kosutic possesses a PhD and MS degrees in Biomedical Sciences. He has lectured internationally and nationally on broad range of topics related to plastic surgery and has published 35 papers in international plastic surgery journals, including some of the key papers on preoperative planning of perforator flaps which have been cited 131 times in scientific literature. He is one of the only 20 UK-practising Consultant Plastic Surgeons who is a member of EURAPS. He is a Reviewer for Journal of Plastic and Reconstructive Surgery since 2006. He was awarded the prestigious EURAPS Young Plastic Surgeon Scholarship in 2011 and HCA Scholarship in 2014.

However, what impressed the artist about Damir, was the fact that, despite his success and aptitude as a surgeon, he did not seem to fulfil the stereotypical attributes of arrogance or egotism that successful surgeons are sometimes said to possess⁶⁷ (although he was wearing silver shoes!) He was soft spoken and approachable and spoke about his work with a palpable passion and his patients with a concern that suggested a high level of empathy for their suffering.

Following further conversations with Damir, during which the artist began to gain an understanding of the pressures taken on by surgeons who reconstruct the faces and bodies of people who have had cancers removed, the artist felt that it would enrich the project to have this side of the story told and asked Damir if he would become a portraiture subject.

3.2.2.13Damir's Portrait

3.2.2.13.1 Planning and production

The photographs for the portrait were taken early in the morning at The Christie directly before Damir embarked on a day of surgery. Damir is wearing his surgical scrubs and loops, the magnifying spectacles that allow microsurgery to be undertaken. These loops were bought for Damir by his parents many years ago and so hold an emotive significance for him. He uses them in his day to day practise. This particular image was chosen because the artist felt that his expression spoke of Damir's deep commitment to do his best work for his patients and the time, planning, effort and sacrifice that enables that to happen. Visitors to the Maggie's Centre regularly commented about Damir's portrait, 'Doesn't he look kind?'.

3.2.2.13.2 The Portrait



Figure 29 Damir. Oil on canvas, 2018

3.2.2.13.3 Qualitative Evaluation: Damir's response to his involvement in Facing Out

"I think that the Facing Out project is all about how patient's feel, cope and live throughout, and particularly after their cancer treatment, which often involves both surgery and radiotherapy, particularly surgery being a disfiguring factor that complicates their lives in terms of damaging their functions and aesthetic appearance, which has long term consequences on their social interactions. I feel that the project is also very valuable because it educates both patients and audience about new advances in cancer reconstructive surgery which is something I am very passionate about."

"My whole family was very proud when they heard I was lucky to get involved in this really amazing project and they are all very keen to look at the whole exhibition, and particularly my portrait."

"I hope that my involvement in Facing Out has somehow demystified surgeon's role and position in the treatment of cancer patients. In my personal experience, I often have to detach myself from emotions. However, these things do leave some sort of long-term mark... I think that art, animals, sailing, are good ways to enjoy life and combat all the stress associated with being heavily involved in cancer treatment and patient suffering."

3.2.3 <u>Qualitative Evaluation: Was Facing Out Helpful to 'Reframing' and 'Reintegrating the Experience'</u> of Head and Neck Cancer?

As noted above (see 2.3.1), Facing Out has the potential to act upon its subjects as a 'experiential moderator' or as a 'psychological intervention'. Responses to the project given by its sitters do offer an insight that suggests that it has been of benefit to reframing and reintegrating their experience. The artist's conscious intention when embarking on these projects is to offer the subjects a new story about their illness, an exciting and heartening experience to share with friends and family, a different and positive narrative that can help to combat the more traumatic elements of their illness, a salve for their psychological scarring: to use portraiture to reframe their experience. This selection of quotes from sitters suggest that this intention has been achieved. Some quotes speak directly about the psychological impact (listed first), while others reflect on a more general positive experience.

Bern

"I think Facing Out has more confirmed my acceptance of my altered appearance than anything else... If anything, F.O. has simply helped me confirm to myself that I am walking in the right direction in respect of my battle with this disease and that the only thing that has changed about me is my appearance. For me F.O. is another shelf for me on which I can display that, although they can cut away and rearrange bits of me, that as they do so that they are not able to change the spirit that lies within that body, and in many ways simply enrich and make it stronger than it ever was."

Written Feedback

"One day, it's like, "Sorry, you've got cancer, you've got to have your eye out" but from that, obviously in the back of my mind, "What's happening next? Is that end of everything? You've got cancer. Oh well, that's it". And then, it sounds really - you shouldn't be allowed to say this - it's done me a lot of good, you know what I mean? I've gone out - "Who's that woman painting over there? I'm going to go and have a word with her", now I'm in here! (The Whitworth) How does it all work out? How we're connected. I wasn't really doing anything before this. It was [my friend] Gary...who said, "I've seen all the stuff you've done over this last 4 years and you've really like, come back to life, through the cancer". It's weird. "

Recorded audio interview.

On co-curating the exhibition: "Ya know worrits like. Some rare days ya just feel like saying ``Oh fiddlesticks to it all``, or words of a similar nature... cos ya just can`t seem to find no inspiration for anything. Been a bit like that past few days, wandering around aka Jacob Marley dragging the world and all its worries and feeling bereft of even the minimal in terms of confronting or tackling my miasmatic condition. And that sure ain`t me. But then like the poem says, ``The light will always find a way through somehow``. and today it came rushing like a wildebeest on acid down at the Whitworth Art Gallery in Manchester. There can`t be many days when ya go out thinking you have to choose a piece of art that you can`t even see to sit next to your own ugly mug shot, and end up finding an original Van Gogh is available to pick!!! ...Me and Vinny side by side in an art gallery. Life really is a dream innit. Never give up people! Xxx"

Facebook Post.

"The general consensus among us sitters was that having our mugs painted was an absolutely life affirming, hope inducing, and beneficial way of behaving. It was as if we were being offered an extra form of treatment that would run alongside and even enhance our actual treatment from the hospital."

Written feedback.

"To say that those chosen to be painted were very happy about the decision would be a massive understatement. Make no mistake, each one of us is absolutely delighted, proud, and honoured to have been chosen for this project."

Written feedback.

Trudi

"[Facing Out] has and made me a better person, facing anything that I get thrown at me. Thank you Lucy for helping me get through my dark times, for living again helping me with my painting and getting Trudi back. I will always be grateful for what you have done for me."

Written Feedback

"Facing Out helped me through the traumatic times and I'm painting more than ever now."

Audio Recording

"It just put everything into perspective for me and I was absolutely amazed... It's changed my outlook on my surgery...I've got a different viewpoint on life now"

Audio Recording

"It was the best experience I have had in my lifetime [coming] from a horrendous illness that has caused a lot of disfigurement to my face...the whole exhibition was done very sympathetically."

Written Feedback

"Thank you...for my beautiful portrait. You got me so right. I love it...You have done me proud!"

Facebook Post

Annie

"I'd like people to be more aware of how it feels for someone with facial disfiguration and that they don't keep staring, sometimes it might be event nicer to say, "I'm just interested, you know, about what's happened to you". And then, when you tell your story, I think then people would feel, "oh my god, what you've been through" ...and then they might tell other people, you know, it's really horrible when people stare."

Recorded Interview

"I just love the portrait. People would come in, and obviously Lucy was in Maggie's doing the portraits, and people would look at mine and say 'Oh I know who that is, that's Annie!' and sometimes even if they didn't recognise me I'd make sure they did because I'd go and stand by it and then they'd look and say 'Oh, it's you!'. So, it was very exciting."

Recorded Interview

"I was very pleased with the end result because people were saying how she captured every aspect of me!"

Recorded Interview

Nigel

"The Facing Out project definitely made me feel I was part of a lot of successful surgery and that others had a similar or indeed far worse situation to deal with- it did feel good to have been connected with people who naturally understood what had happened as it had also happened to them- there was a feeling of unspoken solidarity – a sort of brother/sisterhood in a way."

Written Feedback

"I think that whenever you've got a difference there's a danger that people actually look at what's been done, "Oh you're different, I must have a photo of you" or "Must have a painting, do you mind?" But it was more of an engagement with me, Lucy took pains to have quite long conversations with me. More than the facial change it was about the person and the person dealing with the change, and how you look at the person with the changed face. You know, they're still the same person behind. Whether they're dealing with a few psychological issues about the change, but actually, it's still the person."

Audio Interview

"I think it has stopped me from thinking it only happened to me and I have been a bit more humbled about what other people have gone through."

Written Feedback

"It's interesting, it felt quite special to be offered that chance really. And the way it's turned out has been fantastic. Because it's led to a lot of other things and the thinking that's gone on."

Video Interview

"I had the chance to meet up with the other people whose portrait was done, and it was a helpful experience to be able to talk and share experience and views with other people who had similar changes to deal with. — It felt like we were viewed positively for how we handled the changes and

there was a collective feeling – like a band of brothers and sisters! – rather than just a curiosity because we looked different and avoiding the potential for it to be seen like a freak show."

Written Feedback

"I think what was good [about the portrait] Is a positive thing and it's more than just a, "Hey, you've had your nose changed". It's about, "Actually, you've got your nose changed, but you're still doing things,"

Audio Interview

"I think what I've seen in other portraits by Lucy is, yes the subject has a facial change but what struck me is that engagement of the eye, the gaze that came out, that was capturing the spirit. Not just for me, but of Graeme and all the others, where you might have had a change in face but actually the person comes through."

Audio Interview

Graeme

"When so much of today's society calls for 'perfection', having my paintings exhibited and acclaimed lends some sort of approval to my appearance."

Written Feedback

"I've enjoyed it. Lots of people have been down to Maggie's, seen the portraits and come back to me and said, "Hey! I've seen your portrait!" which is nice... Yeah, I've enjoyed the experience of having my portrait painted. Does that sound vain?!"

Video recording.

"I enjoyed watching the paintings evolve and how they progressed and being able to see the differences between the portraits that Lucy had done of me over that period of time. That was very interesting"

Video recording.

"If it helps one person it will have been worth it."

Written Feedback

It is interesting to note that several of these quotes refer to the sitters' satisfaction that the project was helping other people, specifically cancer patients and people living with facial disfigurement. They saw the sharing of their stories, as being of use to the 'next generation' of people to be given a cancer diagnosis, to be helpful in breaking down taboos and raising awareness of the discrimination that afflicts people with a disable difference. Research suggests that altruism itself is intrinsically rewarding⁶⁸ and can be seen to have 'beneficial effects on health and wellbeing.'

3.3 Production Phase Engagement Activities

For Facing Out, Burscough drew upon her collaborative network and experience gained over a decade of designing and delivering arts for health engagement activities, to create an ambitiously broad public engagement offering that sought to reach as many groups as possible, with age groups participating ranging from primary school children to retirees. These were delivered both locally and internationally.

3.3.1 Facing Out Conference at The Whitworth – Manchester Science Festival 2017

3.3.1.1 Funding Partners

The Whitworth; Manchester University, Faculty of Business Medicine and Health Social Responsibility 'Engaging our Communities' Fund and Manchester Science Festival.

3.3.1.2 Day 1- Anatomical Sculpting Workshop with Eleanor Crooke





Figure 31 Anatomy Workshop by Caroline Johnson. Ink and watercolour on paper.

Figure 30 A specialist cancer nurse sculpts the face.

A day-long workshop offered to sixteen participants via the Manchester Science Festival programme. A presentation about Facing Out by the artist was followed by the workshop: an opportunity to sculpt and learn the names and functions of the major facial muscles as, one by one, they were sculpted in wax to be added onto a plaster cast of a skull. Sculptor Eleanor Crooke brought along some models of the early reconstruction techniques developed by Sir Harold Gillies at Queen Mary's Hospital at Sidcup, where he worked with the unprecedented number of soldiers who were returning from the trenches of the First World War with facial injuries. His patients refereed to themselves as 'The Guinea Pig Club' as much of Gillies work involved the use of novel experimental surgical techniques. Eleanor's models brought to life Gillie's black and white photographic images which recorded the stages of pioneering forehead skin flap operations, a technique is still being used today, notably on Facing Out's Trudi Proctor.

Title	Delivered by	Participants	Ticketed/Drop	No. of
			In	Participants
Sculpting Facial	Eleanor Crooke	Interdisciplinary: artists,	Ticketed via	16
Anatomy in Wax		arts for health	Manchester	
		practitioners, people with	Science Festival	
		facial cancers, cancer		
		clinicians, theatre and		
		gallery professionals		

3.3.1.2.1 Participant Feedback

Collected via a Post-it note wall.

"This is the most fun that I have ever had in my entire life! I might have to become an artist!"

— Claire, Trainee Advanced Practice Nurse, The Christie Hospital

"Most wonderful, amazing, informative workshop ever! I am overwhelmed. Thank you so very much"

"Fun, friendly and fascinating"

"I have learnt a lot in a short amount of time"

"Great to understand our facial anatomy and reconstruct!"

"Really enjoyed introduction talk to anatomical sculpture and it's uses"



Figure 32 Sculpting Anatomy: Before and After

3.3.1.3 Day 2 -Facial Difference Symposium⁶⁹



Figure 33Facial Difference Symposium by Caroline Johnson, 2017. Ink and watercolour on paper.

Title	Participants	Ticketed/Drop In	No. of Participants
Facial Difference Symposium	Interdisciplinary: Artists, arts for health practitioners, people with facial cancers, cancer clinicians, facial difference charity professionals, gallery professionals	Ticketed via Manchester Science Festival	18

3.3.1.3.1 Collaborative partners and their presentations/activities

3.3.1.3.1.1 Prof. Partha Vaiude (Consultant Reconstructive Plastic Surgeon and Professor of Art in Science, Liverpool John Moores University)

Plastic Surgery: Where Medicine Meets Art

Abstract:

Even before words are spoken, we introduce ourselves with our face. For some an attractive face is a powerful currency while for others "normalising" the appearance may be a means to survival. It is often at these two ends of the spectrum that a surgeon sees a patient.



Figure 34 Images from Partha's presentation

Surgeons have, over time immemorial, attempted to recreate what is lost or disfigured on individual facial sub-units. Sushruta, in 800 BC, performed the first documented nose reconstruction. It is, however, only in the last decade that there have been significant advances that have given surgeons the skills not only to reconstruct using local or regional tissue but also to bring tissue from other parts of the body. Microsurgery has now equipped us to disconnect and reconnect tissues from other parts of the body or even other individuals. We have now reached a point where a complete face reconstruction can be achieved, with a composite and functional face transplant that includes bone and soft tissue.

These advances aside there will always be certain principles that govern the aesthetics of the face and its reconstruction; symmetry, relationships of facial sub-units and, the play of light and shadow are some. When these core harmonising features and proportions are reconstructed following trauma or cancer disfigurement is minimised. Achieving the perfect living sculpture remains the holy grail of any reconstructive endeavour. However, a surgeon's canvas is bound by ethical practice and available anatomy. An artist's canvas is boundless.



Figure 35 Partha Vaiude delivers his presentation. Caroline Johnson, 2017. Pencil crayon, ink and watercolour on paper.

3.3.1.3.1.2 Prof. Diana Harcourt (Professor of Appearance & Health Psychology, University of the West of England)



Figure 36 Prof. Harcourt presents. By Caroline Johnson, 2017. Coloured pencil and collage on paper.

Appearance Matters: The psychosocial impact of a visible difference or altered appearance Abstract:

People who look in any way different to 'the norm' can face a number of challenges, many of which are related to the reactions of other people. Whilst many people manage these challenges very well, others struggle. In this presentation I will give an overview of the psychosocial impact of 'looking different', particularly in a society that seems to be increasingly focused on appearance and the pursuit of 'the body beautiful'. I will consider the psychological factors that seem to distinguish those who demonstrate positive adjustment from those who might benefit from support of some kind, and explore the body of research into positive outcomes and psychological growth as a result of a visible difference

3.3.1.3.1.3 Lucy Burscough

Painting for Health: Live Art Practice in Hospital and Health Care Settings. Abstract:

In this presentation I will discuss the development of my practice into one that involves working in hospitals to create artworks in a way that actively encourages conversation with patients and staff and seeks to have a positive impact on the clinical environment. I will go on to discuss 'Facing Out', the project that has inspired this event, describe the ideas behind it and its primary aim: to help people who have experienced facial cancers and reconstruction to share their experiences and promote understanding of the challenges they encounter.

3.3.1.3.1.4 Dr Anne-Marie Martindale (Medical Anthropologist, Manchester University) presenting From Ancient Greece to James Bond: Faces, Identities and 'Disfigurement' Abstract:

Dr Anne-Marie Martindale will give an overview of her research into the relationship between faces, acquired 'disfigurement' and identity. The first part will explore the cultural life of faces over the last two thousand years drawing on a range of influences including Ancient Greece and James bond. The second part will explore key findings from her 13 in-depth interviews with facially 'disfigured' across England (2011-2012). She will focus on their stories and experiences of life, 'disfigurement' and identity.

3.3.1.3.1.5 Graeme Heward (Physiotherapist, author and Facing Out portraiture subject) Graeme reads extracts from his book, 'Riding with the Alien' (see 3.2.2.8)





Figure 37 A display of prosthetics

A Display of Prosthetics Abstract:

Many patients require new, custom-made, artificial silicone prosthesis to replace areas of the face and body as a result of congenital defects, disease, surgery or trauma. Conventionally, maxillofacial prosthetics are fabricated by hand carving the missing anatomic defect in wax then creating a mould into which pigmented silicone elastomer is packed. Digital technologies such as computer numerical control, milling and 3D printing have been used to create moulds, directly or indirectly into which a biocompatible pigmented silicone is packed. More recently prosthetists have scanned the defect area, reverse engineered the missing anatomy using specialist software then wax deposition printed prior to trying on the patient and finishing in the conventional manner however the use of such technology is limited within the NHS due to several factors and as a result the traditional method is still applied in many units in the UK.

Further activities

3.3.1.3.1.7 Chris Ball (MadLab)

An opportunity for delegates to have their head and shoulders scanned to create a miniature 3-D printed sculpture of themselves. A demonstration of technologies used in modern reconstructive surgery.



Figure 38 A 3D printed model of a conference delegate

3.3.1.3.1.8 A Round Table Discussion

Introduced by Anne Marie Martindale and Lucy Burscough, across four tables, exploring:

-How would you describe/define the relationship between faces and identity?



Figure 39 How would you describe/define the relationship between faces and identity?

-Does facial 'disfigurement' influence a person's sense of who they are?

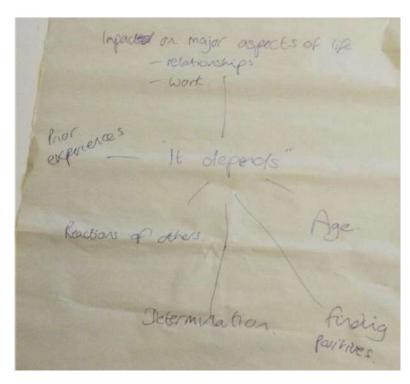


Figure 40 Does facial disfigurement influence a person's sense of who they are?

-What do you think are the pitfalls and opportunities of becoming a portraiture subject as someone who has an altered appearance?

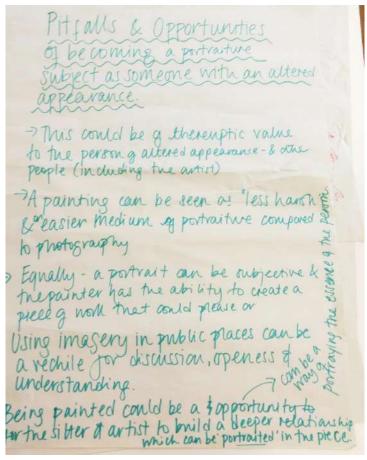


Figure 41 What do you think are the pitfalls and opportunities of becoming a portraiture subject as someone who has an altered appearance?

-Do you think that engaging with arts and craft activities can help people who have experienced facial 'disfigurement'? How do you think that might work?

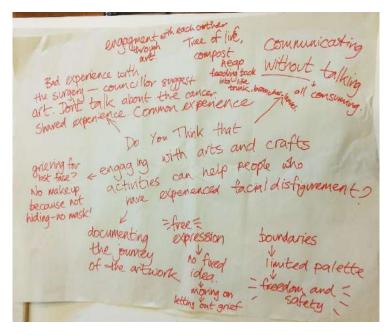


Figure 42 Do you think that engaging with arts and crafts can help people who have experienced facial disfigurement?

3.3.1.3.1.9 A curator-led gallery tour

With a special focus on portraiture an

3.3.1.3.1.10 An arts for well-being workshop led by illustrator and arts for health practitioner Daisy Strang exploring identity and the face.



Figure 43 An art activity exploring identity and the face

3.3.1.3.2 Evaluation

Feedback was collected via a post-it wall.

"Excellent speakers, facilities and just everything. Inspiring, humbling and made me re-think what is really important"

"So pleased to have been able to attend. Very interesting useful information. I feel reassured I'm doing OK and will be OK" -a delegate attending on the first day out after reconstructive surgery

"Seeing how faces have been portrayed throughout the years in the art world was great. Makes me want to learn and discover more"

"I found the work of a surgeon thinking of their work from an artist's perspective very thoughprovoking and progressive"

"Great to have a focus on balancing challenges with positives"

"Made me think about the projection of the self and the vanity of the age but also reassured me==by the alternative confidence that can be gained through a diversity in terms of disfigurement"

"Really good event. Thought provoking. Reflective. Ideas. Safe space. Insight, prompted by the actual art practise at the end"

"The initial conference was really interesting, as it was focussing on many different aspects of facial changes — the history of free flap surgery, the psychological aspects, views from surgeons and attended by people who had also experienced facial changes through surgery. It was an issue I was thinking about quite a lot after my facial cancer and reconstruction and it felt positive to be discussing it with other people. It helped me get some perspective on the issue. I was glad I spotted the flyer for the conference lying on the desk at the main reception in Christies."

Nigel (portrait subject), Written Feedback

3.3.2 Maggie's Centre Creative Workshops for Centre Visitors

"The effect in sickness of beautiful objects, of variety of objects, and especially of brilliancy of colours is hardly at all appreciated ... People say the effect is on the mind. It is no such thing. The effect is on the body, too. Little as we know about the way in which we are affected by form, colour, by light, we do know this, that they have a physical effect. Variety of form and brilliancy of colour in the objects presented to patients are actual means of recovery." Florence Nightingale, Notes on Nursing, 1859



Figure 44 Marbled paper created by Maggie's Centre visitors

3.3.2.1 Arts and Crafts Workshops

These workshops were delivered under the Facing Out umbrella, but the themes of the activities went beyond those of the project in order to appeal to as many Maggie's Centre visitors as possible. They were generally delivered within the centre's main open-plan space with a few 'wet activities' delivered in the glass house or garden. They were all drop-in and were open to people with a cancer diagnosis and their families and friends. They were delivered as therapeutic sessions with the intention of benefiting mental health by utilising the New Economic Forum's '5 Ways to Wellbeing'⁷⁰:

Connect... e.g. build social relationships, spend time with friends and family

Be active... e.g. engage in regular physical activity

Take notice... e.g. be mentally "present", focus on awareness and appreciation

Keep learning... e.g. maintain curiosity about the world, try new things

Give... e.g. make a positive contribution to the lives of others

3.3.2.1.1 Funding Partners

This element of the project was kindly funded by The Kinder Trust via a specific 'arts for health' legacy donation to Maggie's Manchester.

3.3.2.2 Activities and quantitative Evaluation



Figure 45 Maggie's Winter Workshops





Figure 46Maggie's Autumn Workshops



artworks.

The workshops are grop—in with no need to book or stall, for the whole sessor. They are open to centre visitors including family and trienas All materials are arounded with step-buy step instructions and advice on hand from Lucy our artist in residence.

27th April ~ Paper Flowers. Welcome in the flist days of Spring by creating a paper pagy that will last all season long. Learn a few different leachriques that will have you rooting through the recycling when you get hame.

4th May - Marbling paper and badge making. Have some fun with this class paper decorating technique. Find out why the Victorians loved it so much as how modern innovations have simplified the process. Having made your paper, you can have a play with Lucy's marvellaus machine and use your paper to make some funky badges.

11th May ~ Blankets for Maggle's. Come along and pick up some crochet techniques as we work in a graup to jain together some baby blankets that have been donated to the centre. This useful workshop will mean that the blankets can then be used by your fellow centre visitors in the yago and relaxation classes.

18th May - Willow Obelsk. It's the perfect time of year to have a go at making a willow obelsk for the garden and Maggie's is the perfect place to get some inspiration. Have fun and create an attractive structure for supporting your climbing flowers or veggles, whether in the garden beds or in containers.

25th May - Paper Moking. You've seen those beautiful (and very expensive) hand-made papers that incorporate petats and foliage, well here's your chance to make your dwnl You can also have a go at making papers peppered with flower seeds. These can be cut into decorative shapes making lovely gifts for your friends to plant and enjoy.

Ist June ~ The Garden. Maggle's garden is full of inspirational views and this session will give you the apparturity to spend a relaxing time enjoying it creatively. Drawing and pointing materials, together with eastes and drawing boards will be provided and Lucy will be happy to after tips and advice. This will be an open-ended session- if you tency continuing with your artwork in the afternoon, you'd be very welcome to stay all day.





Figure 47 Maggie's Spring workshops

Workshop Title	Number of participants		
Winter block -Winter Wreaths	25		
Winter block -Needle Felt 2D	5		
Winter block -Needle Felt 3D	12		
Winter block -Paper Craft Decorations	7		
Winter block -Still Life Drawing #1	8		
Winter block -Still Life Drawing #2	8		
Winter block -Knitting	13		
Spring Block- Paper Flowers	10		
Spring Block-Marbling Paper	9		
Spring Block-Knitting Blankets	12		
Spring Block-Willow Obelisks	10		
Spring Block-Paper Making	13		
Spring Block-Drawing the Garden	8		
Autumn Block-Knitting	11		
Autumn Block-Corn Dollies	10		
Autumn Block-Natural Materials	13		
Autumn Block-Leaf Lanterns	10		
Autumn Block-MSF Masterclass	17 (See 3.3.4.2)		
Autumn Block-Halloween Special	14		
Total	215		

3.3.2.2.1 Qualitative Evaluation

3.3.2.2.1.1 Reported benefits to mood of taking part in the workshops.

Participant reported impact was collected via postcards on which Yes/No, Likert Scale⁷¹ and open-ended questions were included. Post-it note written feedback and audio interviews with participants were also recorded.

3.3.2.2.1.2 Feedback Collected Via Postcards (For evaluation of this method see 3.1.2.2.3)

Of 118 respondents, 45 had participated in workshops. Most (31) had done more than one, with a range from two to "absolutely loads". In answer to the question, 'Did participating help your mood?', all reported that it had, or had done a great deal:



Figure 48 Reported benefits to mood of participating in workshops

3.3.2.2.1.3 Qualitative Feedback Collected Via Postcard ('Leave your thoughts'), Post-It Notes and Audio Recordings







Figure 49 Still Life Drawing, Seed and Petal Paper Making and Needle Felted Baubles Workshops

In conversation, a recorded interview with two friends who came to Maggie's to participate in numerous workshops together:

Participant 1: "People just started talking about things while you were doing [the activity]"

Participant 2: "and it just flowed. It just came out...There was no taboo subject around the table, and that made us [two] talk a bit more. Obviously, we came as friends...and we've been able to talk openly about so many different things"

Participant 1: "One of the sessions I came from The Christie and we'd been told that Mum was going to lose her hair, and I was a bit upset, I overheard someone [another workshop participant] talking about the fact that she'd lost her hair...and I wondered is it too personal to talk about it...and I asked

her about it and it made me feel a lot better... and that [positivity] was something that I would be able to project to my mum then. And I don't know where else I could have had that kind of conversation with someone in that calm and kind of casual environment"

Participant 2: ..."I think if we'd have all been kind of sat in a group,[saying]"Let's have a discussion", I don't think it would have flowed at all, whereas we were occupied,...and it felt quite natural"

Participant 1: "And the silence felt natural too, because you were doing something,"

Participant 2: "If it was just a talking group, I think personally, I wouldn't have spoken"

Participant 1: "This was just a group of friends, even though we didn't know each other, it was just a group of friends who were having a cup of tea and doing something else. It wasn't, "and now we're going to talk about hair loss", it was free and easy."







Figure 50 Paper Christmas Decorations, Willow Winter Wreath and Needle Felting Workshops

Written Feedback:

"The sessions are engaging, very supportive and encouraging. Coming to Maggie's has helped me get out of bed in the morning on a Friday"

"I look forward to the 'Facing Out' sessions and I have made new friends"

"Really enjoyed the workshops...it gave me time for myself to relax, share experiences and do something not related to my cancer! Facing Out has provided a reason to come to Maggie's and take time to reboot"

"Wonderful. First class. 100% good."

3.3.2.3 The Whitworth/Manchester Museum Workshops

To complement the art and craft workshops, a collaborative programme was devised by Wendy Gallagher, (Head of Learning and Engagement at Manchester Museum and former Arts for Health Co-ordinator at The Whitworth/Manchester Museum). The programme consisted of three six-week blocks which drew on the engagement activities regularly available at these cultural institutions. During these programmes, Maggie's visitors were offered their cultural entitlement during their treatment regime, despite, in many cases, being too ill to consider a trip to a cultural institution.

3.3.2.3.1 Curatorial Talks and Object Handling

3.3.2.3.1.1 Andrew Grey, Curator of Herpetology, Manchester Museum



The first session was led by Andrew Gray who is the curator of Herpetology and an expert on reptiles and frogs. Andrew spoke to centre visitors about his interest in conservation, supporting some of the world's most critically endangered species of frogs which are native to Costa Rica, where he leads expeditions to gather live eggs for breeding and the environment data needed to keep them in good condition. On one such trip Andrew rediscovered a species that was previously thought to be extinct. Through captive breeding programmes Andrew and his team at the museum and university support species that are on the brink of extinction, sometimes breeding species in captivity for the very first time. Participants were fascinated to hear about the frogs, exciting tales from the expeditions and about the fantastic conservation programmes that Andrew's team have initiated.

Figure 51 Andrew Grey Talks Frogs

3.3.2.3.1.2 Rachel Webster, Curator of Botany

The museum's herbology collection is enormous and filled with beautiful botanical drawings, thousands of examples of pressed plants from around the world and the handwritten notes and cuttings from journals made by the Victorian gentlemen collectors who gathered them together. Rachel brought a selection to share with centre visitors. Each object told a wider story, some illustrated the changing environment of the area surrounding us, while others told of the Victorian passion for plant-collecting and the characters whose search for interesting specimens saw them creating global networks of fellow flower fanatics. Participants were able to peruse beautifully bound books of botanical drawings and a box of unusual looking sweetcorn cobs gave an insight into the processes behind the development of modern vegetable varieties.



Figure 52 Rachel Webster with Highlights from the Herbology Collection

3.3.2.3.1.3 David Gelsthorpe, Curator of Earth Sciences

David Gelsthorpe's presentation served to entertain and enlighten Maggie's visitors. He told Marie Stopes's life story



Figure 53 David Gelsthorpe: Fossils and Marie Stopes

through the objects that he brought with him from the museum. Centre visitors learnt of her formidable intellect and strength of personality that saw her able to break through into the male preserve of scientific academia, how she used coal balls to identify new species of fossil plants and how she won a scholarship which led to her travelling to Munich where she fell in love with a Japanese scientist only to be spurned by him when she attempted to be reunited with him in his home country. Not miss an opportunity to further her research, she used her trip to Japan to collect exquisite plant fossil samples laid down in the uniquely suited environment of a still, volcanic lake. Back in Manchester Miss Stopes was introduced to Captain Scott at the Manchester Museum. We know this happened- David found his signature in the Museum's visitor's book. Unable to persuade him to let her join him on an expedition, she did convince him to find examples of the plant fossil record on his expedition to the Antarctic, adding to the proof that the continents were once joined and formed a super continent. When Scott's body was recovered after his fateful mission to be the first people to get to the South Pole failed, plant fossil specimens were found near his body.

3.3.2.3.1.4 Phil Rispin, Curator of Entomology

Phil Rispin joined us to talk about Entomology, the study of insects. Phil brought a selection of insects from the collection along with a font of knowledge that he shared centre visitors who were particularly interested in hearing about local insects and where to see usual ones, how to set up the equipment to attract, observe and record the myriad of moths in our own gardens, and what we can do to make our gardens more insect friendly.



Figure 54 Phil Rispin Answers Questions about Insects

3.3.2.3.1.5 Michelle Scott, Egyptology



Figure 55 Michelle Scott's Ancient Egyptian Chariot Finial

Michelle Scott came to talk about Egyptology. A highlight was hearing about an ancient Egyptian piece originally accessioned into the Museum's collection as a 'miscellaneous object' which turned out to be a piece of technology that told the story of a historic arms race and the ingenuity of these ancient people. The object looked like a white stone bobbin, sadly broken in half but inscribed with beautiful hieroglyphs. Michelle was masterful in building the tension and intrigue as she told its story and eventually revealed what the object was. Egypt was being attacked by its neighbours who came on two person chariots

which allowed one to drive and a second to use a bow and arrow. Egypt didn't yet have this technology and so was losing battles and land. And then, when our object was invented, Egypt began winning the arms race. It is a finial of a yoke-saddle that allowed the Egyptians to build a much more manoeuvrable single person chariot, one which could be steered with the hips whilst firing a bow and arrow. The story didn't finish there, Michelle them turned to looking at the hieroglyphs and what they said was very exciting: "Amenhotep-bringer of fear to foreign lands". This was likely a finial from a royal chariot. Centre visitors were able to pass it round and have a physical connection to a king living around 3,500 years ago. It was this sort of unexpected delights that were really appreciated by participants who often happened upon the presentations between hospital appointments.

3.3.2.3.1.6 Karen Brackenridge, Money and Medical Objects

Karen came along with two of the Museum's volunteers and they brought objects from the money collection and medical pieces, some of which were on loan from the Manchester Museum of Medicine and Health. They brought medicinal minerals, such as barite, which is used in a barium meal, a diagnostic test used to detect abnormalities of the oesophagus, stomach and small bowel using X-ray imaging; calcite, which can be used as an antacid, and gypsum, used in plaster casts. From the Egyptology collection they brought an ear stone amulet, used as a kind of supernatural phone, whispered into to appeal to the



Figure 56 Karen Brackenridge brought Medicinal Materials

god's for good health. More modern items were a Victorian trepanning drill, used to cut a hole in the skull and an infant bronchoscope dated 1910, a very early version of a life-saving device used to extract foreign objects from the throat. The pre-decimal coins that Karen chatted with the group about inspired lots of conversations about days gone by and participants enjoyed Karen's easy manner and the relaxed nature of this session.

3.3.2.3.2 Music Therapy

A six-week programme of music therapy workshops were delivered by Rachel Swanick. Rachel works using a wide range of psychological tools to help people understand their emotional soundscape. She uses tools such as psychodynamic thought, behavioural techniques, family focused attachment therapy as well as creative song-writing and free improvisation. She is a trained APCI assessor - a specialist assessment technique which uses music therapy to assess the clinical needs and emotional 'attunement' of families in distress.⁷² Rachel's developed and delivered a programme of workshops that were inspired by that artworks on display at Maggie's which are on loan from The Whitworth's collections.



Figure 57 Music Therapy

3.3.2.3.3 Horticulture for Health

"As a possible coping strategy for stressful life experiences, gardening has several important dimensions...The gardener has opportunities for control in the life process that in personal life may seem elusive. The seasonal nature of gardening recreates a cycle of growth, maturation and death... [and as such] may have particularly poignant meaning for people who are faced with serious health crises such as cancer"⁷³

This six-week programme was very much inspired by Maggie's Manchester's beautiful gardens. Taking place in the garden and glasshouse, they were developed by Francine Hayfron, The Whitworth's Cultural Parkkeeper and delivered by horticulturalist Liz Cole. They combined art, craft and horticulture to offer centre visitors a peaceful and social break from their cancer concerns in a therapeutic environment. The programme built upon The Whitworth's successful 'GROW' initiative.⁷⁴



Figure 58 Horticulture for Health

3.3.2.3.4 The Whitworth/Manchester Museum Workshops Quantitative Evaluation

Title	No. of Participants (Weeks 1-6)			Total			
Curatorial Presentations	7	8	10	10	11	6	52
Music Therapy	3	6	4	8	6	5	32
Horticulture for Health	6	7	10	6	7	4	40

3.3.2.3.5 The Whitworth/Manchester Museum Workshops Qualitative Evaluation

Qualitative evaluation has been included with 3.3.2.2.1 above.

3.3.3 Manchester University and The Whitworth-Engagement with Young People

3.3.3.1 Perceptions of The Face Masterclass- 14th March 2018

A collaborative cross-disciplinary day-long event delivered to 50 Art and Psychology GCSE and A-level students.

3.3.3.1.1 Collaborative Partners and Activities Delivered

Collaborative Partner	Field	Interest	Activities Delivered
Dr. Karen Lander (MU) ⁷⁵	Experimental Psychologist	Psychology of Recognition	Presentation- The Science behind the Face: Perceptions; How do we read faces? How do we perceive attractiveness? Practical activities carousel: hollow face illusion, 4 legged ducks, celebrity mismatch, are you a 'super recogniser'?
John Merrill ⁷⁶	Artist (and former psychiatrist)	Visual Perception of the Face	Presentation: Portrait as Landscape
Denise Bowler	Learning and Engagement, The Whitworth	Secondary and FE Coordinator	Facilitate discussion- the importance of faces and their role in communication.
Mary Griffiths	Senior Curator, The Whitworth	Modern and Contemporary Art	Lead tour of John Stezaker exhibition of subverted collage portraits with reference to themes of identity
Lucy Burscough	Artist	Portraiture for health/ Perceptions of Disfigurement	Facilitate discussion- How important do you think faces are in terms of identity? Presentation: Facing Out, Identity and Appearance Workshop: Facing Out Printmaking-Considering Disfiguration.

3.3.3.2 ESRC Festival of Social Science- 'Belonging: Perceptions of Facial Disfigurement'. 7th Nov. 18.

Funded by Economic and Social Research Council as part of their week-long 'Festival of Social Science'. A collaboration with Manchester University academics, The Whitworth and Facing Out. Delivered to twelve KS4 and 5 students with an interest in social science and members of 'The Friends of The Whitworth' organisation.

Collaborative Partner	Field	Interest	Activities Delivered
Dr. Karen Lander (MU) ⁷⁷	Experimental Psychologist	Psychology of Recognition	Presentation- The Science behind the Face: Perceptions; How do we read faces? How do we perceive attractiveness? Practical activities carousel: hollow face illusion, 4 legged ducks, celebrity mismatch, are you a 'super recogniser'?
Dr Anne-Marie Martindale ⁷⁸	Applied health anthropologist	Acquired facial 'disfigurement' and identity shift	Presentation: Social and Moral interpretation of Faces in popular culture and literature Workshop: Critical Analysis of appearance tropes in popular magazines
Denise Bowler	Learning and Engagement, The Whitworth	Secondary and FE Coordinator	Tour and workshop: Sir William Hogarth's use of caricature to depict moral judgement
Lucy Burscough	Artist	Portraiture for health/ Perceptions of Disfigurement	Presentation: Facing Out, Identity and Appearance Workshop: Facing Out Printmaking- Considering Disfiguration.



Figure 59 Hogarth tour, Pulling Portraits Apart workshop, Dr Lander-how we recognise faces

3.3.3.3 WAG and MU Events Quantitative Evaluation

MSF18 Event	Attendees
Perceptions of the Face Masterclass	50
Belonging: Perceptions of Facial Disfigurement	12

3.3.4 Manchester Science Festival 2018

Burscough successfully sought further funding from the Manchester Science Festival in 2018⁷⁹ to deliver three Facing Out themed events.

3.3.4.1 Talking Heads Panel Discussion

Facing Out: Talking Heads

Artist Lucy Burscough invites medical practitioners, patients, their friends and family and anyone directly or indirectly affected by facial cancer to join her and a stellar lineup of specialists to get under the skin of facial cancers and redefine traditional notions of disfigurement. Come face to face with the people whose research and work leaves an impactful and visible scar on our lives, from psychologists of facial recognition and reconstructive surgeons to creative practitioners and take part in a lively discussion about the face, identity and the impact of facial cancer.

Audience: Adults 18+ Venue: Maggie's Manchester Date: Tuesday 23 October Time: 5.30pm – 6.30pm Cost and booking info: Free. No need to book



Talking Heads

Tuesday 23 October 2018, 5.30pm – 6.30pm Are you curious about faces?

Would you like to hear from a gifted surgeon about his approach to reconstructing the face after cancer and from a leading pychologist about how our brain recognises faces? Come along to hear the story of one man's unique approach to dealing with facial disfigurement and from the artist who has documented his reconstructive surgery.

Please join us at the beautiful Maggie's Centre near The Christie Hospital at 15 Kinnaird Rd, Manchester M20 4QL for an hour of lively discussion and insights.

Facing Out is a project about facial cancer by artist Lucy Burscough. Follow at www.lucysart.co.uk







Chaired by Wendy Gallagher. Wendy his Head of Learning and Engagement at Manchester Museum and, until recently, was Arts and Health Partnership Manager at the Whitworth Art Gallery and Manchester Museum. Wendy has developed a range of health and culture programmes that are delivered in both clinical and museum settings.

The Panel:

Mr Damir Kosutic Consultant Plastic and Reconstructive Surgeon at The Christie. His specialisms include complex microvascular reconstruction for breast cancer, lymphoedema, upper/lower limbs, head & neck and breast/chest wall following cancer resections, perforator flaps. Damir is regularly called upon to perform plastic surgery on people who have experienced facial cancers.

Dr Anne-Marie Martindale Applied health anthropologist, policy analyst, evaluator, lecturer. Anne-Marie's doctoral research explored the relationship between acquired facial 'disfigurement' and identity shift; and socio-cultural meanings and roles associated with faces.

Mr Graeme Heward, Physiotherapist and author. Graeme has undergone extensive plastic surgery following treatment for a sinonasal adenocarcinoma (a cancerous tumour of the nasal lining). He has written a book about his experience with cancer and his approach to recuperating and raising funds by undertaking a long-distance cycle ride. The book is called "Riding with The Alien" and is available on Amazon. Graeme is currently in training to cycle to every Maggie's Centre in the country in June 2019.

Lucy Burscough, Artist and arts for health practitioner. Lucy is currently artist in residence at Maggie's Manchester undertaking the Arts Council England/National Lottery funded 'Facing Out' project. She is painting portraits of people who have facial cancers which will be exhibited at The Whitworth in early 2019.

3.3.4.2 Portraiture Masterclass and The Science of Recognition

Facing Out: Portrait Masterclass

Get face to face with the intricacies of facial recognition and discover how a psychological lens can help shine a light on different approaches to drawing the human face. As part of a long-term project into facial cancer and reconstructive surgery, artist Lucy Burscough invites anyone affected by cancer, either directly or indirectly, to a life drawing class which redefines traditional perceptions of beauty.

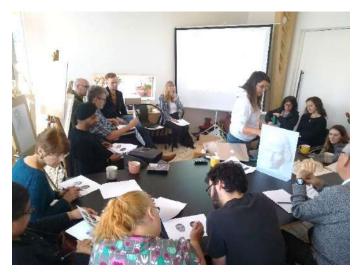


Figure 60 A break from life drawing with Dr Karen Lander

A further collaboration with experimental psychologist, Dr Karen Lander⁷⁷. A day-long portraiture workshop with the artist and a life model, including an hour with Karen delivering her presentation, 'The Science behind the Face: Perceptions; How do we read faces? How do we perceive attractiveness?', followed by her practical activities carousel: hollow face illusion, 4 legged ducks, celebrity mismatch, are you a 'super recogniser'?

3.3.4.3 The Art of Healing

Facing Out: Healing Through Art

Roll up your sleeves and unwind, as artist Lucy Burscough invites anyone directly or indirectly affected by facial cancer to take part in a therapeutic creative arts workshop. Lucy will gently guide you to discover more about your views and perceptions of facial cancer, explore the deep physical, mental and emotional wound it can leave and consider ways in which together, we can harness the healing power of the arts. You'll leave feeling lighter and knowing a little more about how slight shifts in perception and beliefs can propel us towards recovery.

Audience: Adults and families 8+ Venue: Maggie's Oldham Date: Wednesday 24 October Time: 2pm – 4pm Cost and booking info: Free. No need to book A discussion about Facing Out with a practical 'arts for health' workshop at Maggie's Oldham in the style of those delivered at Maggie's Manchester (3.3.2.1). This was an autumn season workshop, 'Wax Lamination Lanterns with Fallen Leaves'.

3.3.4.3.1 MSF18 Quantitative Evaluation

MSF18 Event	Attendees
Talking Heads	37
Portraiture Masterclass	17
Healing Through Art	6

3.3.5 Trauma and Repair: A Medical Humanities Laboratory Workshop

Organised by the Medical Humanities Laboratory at the University of Manchester, thanks to the sponsorship of the John Rylands Research Institute.

Friday, 9 March, 2018 Council Chambers, Whitworth Building, University of Manchester.

Attendees: We particularly encourage postgrads and early career researchers to attend. An archivist from the University of Manchester Library will be available to discuss recently catalogued holdings of interest to medical humanities scholars, teachers, and practitioners.

This workshop brings together speakers and practitioners from several different disciplines – anthropology, history of medicine, visual culture studies, cultural history, and art—to consider the bodily, medical, and cultural meanings

of trauma and repair. Together we will think about and discuss where the experience of injury, especially to the face, and the practices of surgery intersect and interact.

Our first session includes presentations by an anthropologist, an artist, and a historian of medicine who all work on faces, trauma, and medicine. After a coffee break, our second session will feature keynote speaker *Dr Suzannah Biernoff*⁸⁰, Senior Lecturer in Modern and Contemporary Visual Culture at Birkbeck and author of the recent Portraits of Violence: War and the Aesthetics of Disfigurement, followed by a broad collective discussion of the afternoon's presentations and themes.



Figure 61 Trauma and repair symposium: Dr Martindale presenting

Presentations:

Trauma, repair, transgression and transformation: Living with facial 'disfigurement' Dr Anne-Marie Martindale⁷⁸

Facing out: A portraiture project exploring facial cancer and the gaze Lucy Burscough

Between trauma and repair: The surgical operation in Dorothy Davison's medical illustrations Dr Harriet Palfreyman⁸¹

Dr Suzannah Biernoff⁸⁰ (Birkbeck)

Keynote: Facelessness in Georges Franju's Les yeux sans visage

General discussion Led by Prof Ana Carden-Coyne⁸²

3.3.5.1 Quantitative Evaluation

Event	Attendees	
Trauma and Repair	31	

3.3.6 British Council Visit to Taiwan

3.3.6.1 Overview

The artist was invited by The British Council to Taiwan, along with colleagues from The Whitworth Art Gallery, to deliver a keynote speech and practical workshop at the International Museum Academy European Academy Conference (IMA) which was to take place at the Kaohsiung Museum of Fine Arts (KMFA). The theme of the conference was 'Reimagining the Museum's Role in Citizen's Life' and it was primarily aimed at attracting delegates who were museum and gallery professionals and artists with an interest in arts for health from the East Asian region. 250 delegates attended the conference itself (Day1), with 30 delegates remaining for two further days of museum visits and workshops.



Figure 62 The IMA delegates - Conference days 2 and 3

3.3.6.2 International Museum Academy 'Reimagine Museum Engagement in Citizens' Life' Conference Presentation and Panel 29th Nov. 2018

3.3.6.2.1 Keynote Abstract

'Recognising the Role of the Gallery as Mentor Within an Arts for Health Practice' will recognise the place that The Whitworth has played in the development of my career and expertise as an artist and arts for health practitioner. Within that narrative I will talk about how my practice has grown to encompass the development of creative ideas, reimagining spaces and outreach opportunities, and delivering participatory programs for both general visitors and under-represented groups.

I will talk about how my relationship with the gallery began, working



Figure 63 Keynote speakers and Directors of IMA

together with Wendy Gallagher, at the commencement of the position of arts for health programme manager, helping to develop the first arts for health programmes delivered by The Whitworth. Case examples will include 'Who Cares?' engagement programme (delivered in both gallery and hospital settings) and my contribution to Culture Shots (bringing galleries into hospitals).

From those early but ambitious projects, as my experience grew, I was encouraged to develop my own arts for health projects for which I would find my own funding. My relationship with the Whitworth changed as I moved from lead artist on gallery devised projects, to collaborative partner bringing in public funding to produce hospital-based art projects that included engagement threads linking into the gallery's own programme.

I will cite 'Facing Out' as a case example, my current 21-month Arts Council England/National Lottery funded project which is primarily a portraiture project working with people who have had facial cancers. The work is created 'live' in Maggies's Manchester, a cancer support centre (whose artwork is loaned from The Whitworth's collection) which is located in the grounds of The Christie Hospital, Europe's largest cancer hospital.

Engagement threads delivered to cancer patients and their families during the project's production phase serve to open the door and welcome hard to reach groups to the gallery and encourage engagement with the collections. These include:

- Lectures at the Maggie's Centre by six curators from Manchester Museum (The Whitworth's sister organisation) and music therapy and horticulture workshops facilitated by The Whitworth
- Regular art and craft workshops delivered by me
- Hosted by The Whitworth, a two-day conference bringing together facial cancer patients with academics, plastic surgeons, artists and charities to hear about each other's work and experiences in a creative forum
- At Maggie's, a portraiture masterclass delivered by me, social scientists and gallery curator
- A lecture evening aimed at oncology clinicians and nurses

A further programme of activities will be delivered during an exhibition of the portraits which will take place at The Whitworth, opening in February 2019. The exhibition itself will be co-curated by the portraiture subjects who will select pieces from the gallery's collection which reflect aspects of their identity beyond the role of 'patient' or 'cancer survivor'.

I will suggest that delivering this project to cancer patients and their families results in the project being of interest to 'hard to access' groups across society. By hosting engagement activities and art production in a cancer support centre in the grounds of a major cancer hospital, surrounded by artworks from The Whitworth's collection, we re-imagine the cancer-support centre as an extension of The Whitworth Gallery and the arts for health creative practitioner as a valuable collaborative partner.

3.3.6.2.2 Panel Discussion

Title: How Can the Art Museum Get Inspiration from the Artist

Participants: Lucy Burscough / Artist Wei-Cheng Tu / Artist

Jow-Jiun Gong / Associate Professor of Doctoral Program in Art Creation and Theory, Tainan National University of the Arts

3.3.6.3 Museum Visits

28th November (pre conference- accompanied by KMFA colleagues): Kaohsiung Museum of Fine Arts, Children's Museum of Art, National Museum of Taiwan History (NMTH).

This included tours of the museums and a Cultural Accessibility presentation and panel discussion with gallery colleagues at NMTH.



Figure 64 Cultural accessibility presentation at NMTH

30th November (accompanied by IMA delegates): CHIMEI Museum, National Kaohsiung Centre for the Arts (Weiwuying), and Kaohsiung Museum of Fine Arts

3.3.6.4 International Museum Academy Creative Workshops

3.3.6.4.1 Facing Out Printmaking Workshop

This workshop was delivered to two groups of fifteen delegates. The session began with a presentation about Facing Out and how it had used similar workshops to engage with both directly with groups of patients at Maggie's Manchester (3.3.2.1) and with wider educational groups during collaborative events hosted by The Whitworth (3.3.3).

Workshop abstract:

'Pulling Portraits Apart.'

In response to images of my work, including portraits from the Facing Out series, participants will be asked to create line drawing portraits of a partner using pencil on paper. Advice and tips will be given. When the group is feeling relaxed and practised, they will be asked to create self-portraits using mirrors for reference. These drawings will be made using pencil on polystyrene sheet to create a printing block. The drawings will be printed using roller and ink. The participants will be invited to cut up the printing block and reprint the image of their face having rearranged or spread apart the component pieces. They will be asked to reflect upon the process of disrupting their portrait as it relates to the lived experience of facial reconstruction following surgery.











Figure 65 Pulling Portraits Apart IMA workshops

3.3.6.4.2 The Engaging Hard to Reach Groups Quiz Show – A further workshop delivered with Whitworth colleagues

This collaborative workshop challenged small teams of delegates to draw cards to designate a hard to reach group, a museum exhibit and a budget amount which would be starting points for an imaginary engagement programme. After spending time in the galleries developing their programmes, they fed back to their colleagues in a quiz-show format which created a fun and relaxed ending to the conference.





Figure 66 Engaging Hard to Reach Groups Quiz show

4 Exhibition Phase

4.1 Overview

"The relating of personal stories to interested listeners in an affirming and accepting environment can provide the foundation for the development of resilience. Storytelling is a powerful process and method that...has the ability to bring about strength and healing."⁸³



Figure 67 Bern Corri poses for a photograph with his portrait, at the Facing Out opening event

The Facing Out exhibition continued the project's commitment to bolstering resilience in its portraiture subjects by inviting them to reflect upon their identity, acknowledge the place that cancer and facial disfigurement plays in their lives, and go on to tell their new stories by co-curating the exhibition that their portraits would be a part of. The act of doing so, and the storytelling at its heart, would appear to present the participants with a useful catalyst in the psychological process of reframing and integrating their cancer experience into who they are today. In sharing their stories with the wider public, they could be empowered to play a part in combating unhelpful cultural tropes and dismantling societal prejudices. They could inspire others battling cancer to find the positives in their own stories, or those living with a visible difference to also face out proudly towards the world. By offering Facing Out their stories with honesty, openness and warmth, and by drawing on a little of the bravery that cancer had insisted they unearth, the Facing Out subjects created an exhibition to be celebrated.

4.2 Preparation Activities

Co-curation with Portraiture Subjects

"I could not believe that I got to go in the archives and have pick of the crop!"

Trudi Proctor, Written Feedback



Figure 68 Trudi selects 'The Coming Storm to Yarmouth Beach' by Henry Bright

The Portraiture subjects worked with Holly Grange, Curator of the Musgrave Kinley Outsider Collection at The Whitworth to curate the exhibition. Working on information about the participants drawn from short biographies gathered by the artist, Holly shortlisted several artworks from the Whitworth's collections for each participant to use a starting point for their selection. Over several meetings with each subject, which included opportunities to look through The Whitworth's art stores and pick out further pieces to add to the shortlist, a final selection was made. Although the idea of going 'behind the scenes' in the gallery was exciting for all the group, some found the prospect of choosing the artworks a daunting one. They spoke of feeling ill equipped to undertake the task as they 'knew nothing about art' or 'hadn't done anything like this before'. For some of the group, this was the first time visiting the gallery and it wasn't somewhere that they naturally felt at home. However, Holly has a welcoming and easy manner which set the subjects at ease. Once the subjects felt at home, the experience was universally seen as a very positive one, with many of the group saying that they felt that choosing the artworks felt like 'an honour' or 'a privilege'.

"Ya know worrits like. Some rare days ya just feel like saying ``Oh fiddlesticks to it all``, or words of a similar nature... cos ya just can`t seem to find no inspiration for anything. Been a bit like that past few days, wandering around aka Jacob Marley dragging the world and all its worries and feeling bereft of even the minimal in terms of confronting or tackling my miasmatic condition. And that sure ain`t me. But then like the poem says, ``The light will always find a way through somehow``. and today it came rushing like a wildebeest on acid down at the Whitworth Art Gallery in Manchester. There can`t be many days when ya go out thinking you have to choose a piece of art that you can`t even see to sit next to your own ugly mug shot, and end up finding an original Van Gogh is available to pick!!! ...Me and Vinny side by side in an art gallery. Life really is a dream innit?"

Bern Corri, Facebook Post.

4.2.1.1 Adjustments for Accessibility

As Bern Corri's vision was reduced to only 5% by this point in the project, it was necessary to employ the services of Anne Hornsby of Mindseye Description Services⁸⁴. Anne is a professional audio describer who specialises in describing artworks and cultural events. Bern described Anne as 'a treasure'. The process of Bern selecting his artworks with Anne's help and his siblings support, was documented by Caroline Johnson in drawings that later appeared in the exhibition. All these drawings are ink and watercolour on paper and are dated 2018.



Figure 69 Anne Hornsby Describes an artwork to Bern and his sister Cath



Figure 70 Bern with family members, Holly Grange, Anne Hornsby and the artist



Figure 71 Bern and a Van Gogh

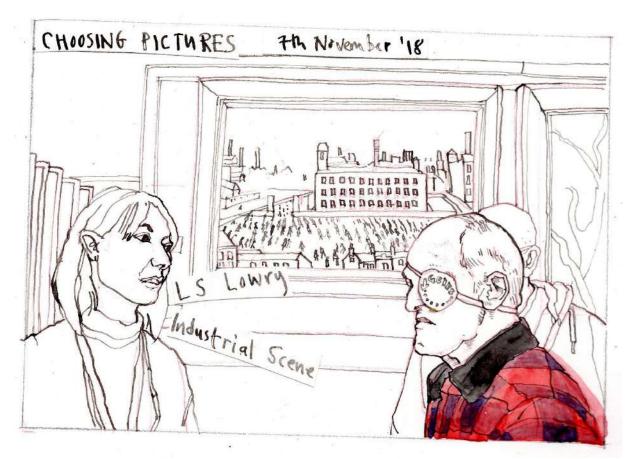


Figure 72 Holly Grange, introduces a Lowry



Figure 73 Bern and Holly with an artwork by Laure Prouvost



Figure 74 In the art stores pulling out the racks of paintings

4.3 Exhibition Interpretation

The artist and curator agreed that the voice of the subjects should be at the centre of the exhibition. This was achieved in several ways:

4.3.1 Audio Recordings

Audio recordings were made of the subjects as they spoke about the stories behind their choice of artworks. These were recorded conversationally, with the artworks present, and then edited by the artist and curator to a ten-minute limit. The recordings were available to exhibition visitors on handheld devices. Transcripts (Appendix 1.1) of the audio were available for the hard of hearing. The recordings can be heard at <u>Soundcloud</u>. 85

4.3.2 Facing Out Film

A film about the project was produced by Triple Dot Makers⁸⁶. It included interviews with the artist and subjects and with Alistair Hudson, Director of The Whitworth. It was made to be shown at the exhibition on a large screen with headphones and a comfortable sofa. The film was shared widely on social media where it has had 3000 views.



Figure 75 The Facing Out Film (click to view)

4.3.1 Text Panels

A wall mounted vinyl text panel welcomed visitors and introduced the project with the question, 'Are you looking at me?' (Full text: Appendix 1.2.1). This was the only interpretation using the words of the curator and artist. The interpretation for each subject's display case was produced using experts taken from their audio recordings (Appendix 1.2.2).

4.4 Supportive Resources for Exhibition Visitors

It was understood that for some visitors, the exhibition might evoke strong feelings and so it was important that resources were in place to help.

4.4.1 Resource Table



Figure 76 Resource table with books/leaflets, audio devices and transcripts, a recording of Graeme reading from his autobiography mirror and magnifiers A resource table was created with help from the subjects who suggested books that had helped them through their cancer journey. Maggie's Manchester also suggested and lent some helpful books and leaflets about where people might seek help if they or someone they loved had cancer or if the exhibition had been an emotive experience for them. A copy of Graeme's book, 'Riding with The Alien' was on display and it was also available to buy from the gallery shop. Graeme very kindly made an audio recording reading exerts from his book and this could be listened to on headphones. Nigel suggested that a mirror should be provided so that people could look at their own faces while they listened to Graeme's story.

4.4.2 Training for Exhibition Volunteers

Potentially the most invaluable resource that would be available to exhibition visitors was The Whitworth's team of volunteers who would be available to speak to visitor about the exhibition. To ensure that they would feel comfortable talking about the project and be able to signpost visitors to support such as that available at Maggie's, Lucy and Sinéad Collins, Maggie's Manchester's Centre Head, delivered two two-hour training sessions to approximately twenty volunteers. They then visited Maggie's to hear more about what was on offer at the centre. This effort was rewarded as the volunteers felt able to approach visitors who were upset, as evidenced by this response to the exhibition:

"The volunteer in the room was lovely. She checked I was ok as I blew my snotty nose and wiped my tears spent a few minutes talking passionately about the exhibition and The Whitworth before handing me a Maggie's leaflet. Really caring and considerate approach"

Exhibition visitor, Rowan Padmore. Facebook post

4.5 <u>Display Cases Curated by Each Subject</u>

4.5.1 Graeme

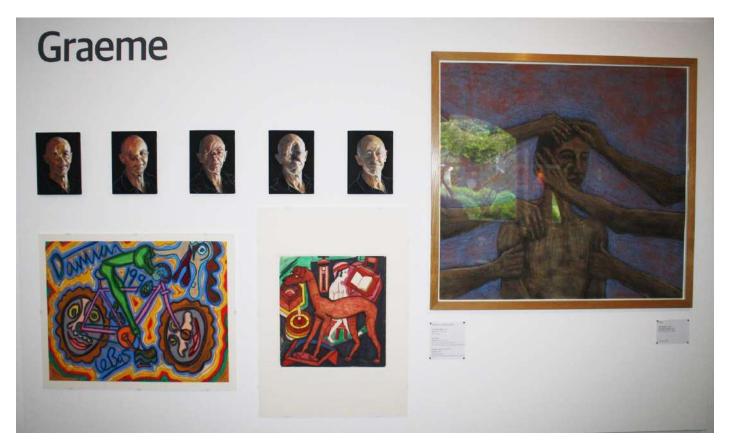


Figure 77 Graeme's Display Case

Graeme chose artworks by Damien Le Bas, Bob Scott and John Davies. He describes why he chose the them at Appendix 1.1.4.

4.5.2 <u>Annie</u>



Figure 78 Annie's Display Case

Annie selected artworks by Degas and Chagall and wallpaper featuring The Beatles. She also included her tap shoes and a photo of herself and work colleagues tap dancing at a charity concert. Her reasons are at Appendix.1.1.1.

4.5.3 <u>Bern</u>



Figure 79 Bern's Display Case

Bern's pieces are by his friend Gary Strickland (top left) and, clockwise, Martha Grunenwaldt, Van Gogh, Walter Crane and Albert Louden. The boxing gloves are those he wore in the Chemothumping video (see 4.7). See also Appendix 1.1.2.

Bern was pleased to select sculptural pieces that were available to touch. As he had lost his sight during the project, he felt that it would be good to include pieces that were accessible by people with low vision. Audio described tours of the other artworks were part of the public programme.





Jacob Epstein 1880-1959 Girl from Senegal (Madeleine Bechet) 1921 Bronze

"In this bust Epstein has managed to convey an air of roughness and immediacy that is fantastic for someone with a visual impairment to pick up on. With the artist's thumbprints clearly obvious to the touch and with her masterfully un-manicured hair available for fingertip examination, along with all her other fine details, this is another favourite work." - Bernard

Bernard Corri, Facing Out participant, is living with 95% sight loss. He has chosen this tactile sculpture, for all visitors, particularly those with visual impairments, to experience.

Please touch

Gifted by Arthur Edward Anderson, 1929

John Davies b.1946 Painted bronze head 1988 Painted bronze

"The Big Fella sculpture. I really wish every person I met had this guy's proportions, and was as brightly coloured. In my visual prison these are the kind of dimensions I need for visitors! I simply love the sheer size and colours in this piece, and he even has a few battle scars just like yours truly that I can feel on his head. I would dearly love to take this Big Fella down the pub one night for a long session of Guinness and inferred chat. Just love it!" - Bernard

Purchased in 1989



Figure 80 Damir's display table

4.5.4 <u>Damir</u>

Damir's selection were displayed in a table cabinet so were to be viewed by moving around the table. Damir included microsurgical instruments in his display and some photographs of his pets. He also chose several drawings by Walter Crane and two prints by Utagawa Hiroshige. He describes the thinking behind his choices at Appendix 1.1.3.

4.5.5 <u>Trudi</u>

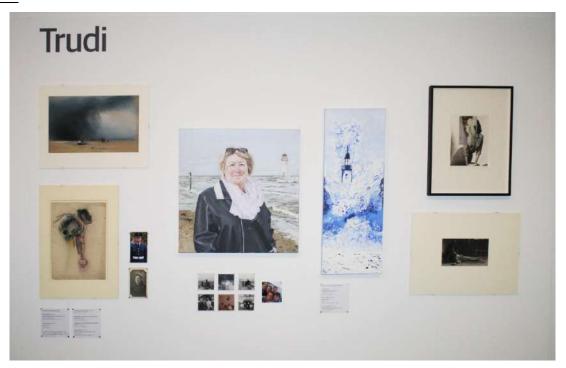


Figure 81 Trudi's Display

Trudi included works by Henry Bright, Henry Tonks, John Stezaker and Sir George Reid. She was very proud to include one of her own paintings and photographs of her family. Her thoughts about them are at Appendix 1.1.6.

4.5.6 Nigel



Figure 82 Nigel's Display

Nigel's display featured a portrait of him by his daughter, a drawing by Turner and textiles picturing turtles and musical instruments. He talks about his choices at Appendix 1.1.5.

Nigel also chose a textile piece by Mathew Harris which was displayed alongside the introductory text panel.



Figure 83 Introductory text panel and Lantern Cloth No.III

Matthew Harris b.1966 Lantern Cloth No. III 2008 Dyed, cut and hand-stitched cloth

"The artist [Matthew Harris] was inspired by Japanese lanterns, how they are not discarded, but repaired and put together. If you look closely, you can see the clever stitching. The fact that stitches come into it are very relevant to my operations; and the number of stitches I have had to reconstruct my nose both internally and externally. This relates to the philosophy of Wabi Sabi, the Japanese philosophy of 'just because it's broken, you don't throw it away.' It has a value in itself. You can repair it and put it back together and it has a different quality about it. It's still vibrant, useful and beautiful." - Nigel

Figure 84 Nigel's Interpretation

4.6 Exhibition Evaluation

4.6.1 Quantitative

Approximately 87,259 people visited The Whitworth during its run and had the opportunity to see the exhibition.

4.6.2 Qualitative

"...I'd just spent the previous hour in an exhibition of Lucy Burscough in the same gallery and was still processing the jewel-like beauty of her work exploring the lives of people who have undergone treatment for facial cancers. Her small portraits of Graeme who has undergone numerous procedures are a thing of troubling beauty. This man exudes dignity and warmth and his, like many other stories in this exhibition, unfold for us all, to slowly take in. Questions of identity and sense of self and a real humanity fill this room, and alongside images of people who have undergone facial surgery, the story of the surgeon is there too. It's an important exhibition of work and further cements Burscough's place in this important field which bridges medical humanities with something altogether very, very human." ⁸⁷

Clive Parkinson, Director of Arts for Health at Manchester Metropolitan University

4.6.3 Audience Feedback to The Subjects' Questions

The feedback about the exhibition was collected in an innovative format. The portraiture subjects were approached to consider what questions they would like their audience to consider. Questions from the curator and artist were also included. These questions were printed on postcards which were then available to be picked up, written on and returned to shelves on a display unit. Interested parties could read the answers given by previous visitors and then choose which question they would like to answer.

The questions were:

- Has this exhibition changed your views and understanding towards plastic and reconstructive surgery being focused on rebuilding patients after cancer removal?
- Surgeons can perform amazing operations. Did seeing the subjects affirm this thought or leave you feeling otherwise?
- Do you automatically assume that someone with a facial disfigurement is of lower intelligence than Joe Public?

- How would you deal with having your facial features changed? Where does "you" reside in your conversation in your caring or what you look like?
- Is it natural to spot the difference in people and be curious, or should you ask the person a straightforward question? Would you be frightened of embarrassing them?
- Has this exhibition changed your views and understanding towards plastic and reconstructive surgery being focused on rebuilding patients after cancer removal?
- Beauty is a layer of skin. Or is it?
- What responsibility do museums and art galleries hold to shape the way that society understands difference?
- Should people with a facial disfigurement be encouraged to abandon aids such as prosthetics and eye patches etc. so that their condition can be more fully appreciated by society?
- What is your perception of plastic and reconstructive surgery? Do you see it as cosmetic surgery?
- As you gazed at the portraits did you imagine what it would be like for the subject or did you imagine what it would be like for yourself in their 'shoes', or both?
- Do you find that you rapidly lose patience when trying to speak to people with a speech impediment?
- What do you think the person with the facial change is thinking?
- What will stay with you from hearing our personal stories?
- Would you accept that children will stare and sometimes laugh at your looks?



4.6.3.1 The Visitors Answers

A selection of the responses is below. The full document can be accessed at Appendix 2.1.

Q: What responsibility do museums and art galleries hold to shape the way that society understands difference?

A: Yes - maybe they do have a responsibility- because they are places where you can take in something, think, have thoughts, process what you have seen and discuss with others. Exhibitions like this can be an opportunity to really focus in on life, how others feel and how you would feel in a similar situation. Exhibitions are gateways to thoughand to consider yourself and others. Form thoughts and learn... you've just got to somehow get people to visit in the first place, in order to have such learning experiences. A wonderful exhibition - thank you.

Q: Has this exhibition changed your views and understanding towards plastic and reconstructive surgery being focused on rebuilding patients after cancer removal?

Figure 85 Feedback Display Unit

A: I have been blown away by this exhibition - and loved hearing all of the stories besides the chosen artworks. I feel I would now be more open to approaching someone with facial reconstruction and talking with them about their experiences- Thank you.

Q: As you gazed at the portraits did you imagine what it would be like for the subject or did you imagine what it would be like for yourself in their 'shoes', or both?

A: I felt the portraits allowed me to place myself in their 'shoes'. I can feel their character, their strength and also their vulnerability. Truly inspired.

Q: Q: As you gazed at the portraits did you imagine what it would be like for the subject or did you imagine what it would be like for yourself in their 'shoes', or both?

A: The portraits were very interesting. I thought about both things: I thought about how awful I would feel if that was me and everyone was staring at me, and what it would really be like to be in that situation. Annabel, aged 11:)

Q: What do you think the person with the facial change is thinking?

A: I think there must be a nervous state of anticipation, hoping that that brave step of self-exposure is met with love and acceptance.

Q: What will stay with you from hearing our personal stories?

A: Trudi's story in particular resonated with me. I had cancer on my neck, and surgery resulted in a partial face lift - (the untouched side) is droopier than the other. I've really struggled with this for 6 years, and this exhibition has been more cathartic than the therapy I have had. I see that I am not alone. Thanks everyone.

Q: Q: As you gazed at the portraits did you imagine what it would be like for the subject or did you imagine what it would be like for yourself in their 'shoes', or both?

A: I loved this exhibition and felt both physically (pain in my tummy) and emotionally moved. The art; the selected pieces and the people's stories are both incredibly powerful, moving and inspiring. I love this jewel of an exhibition.

Q: How has this exhibition changed how you think about people who move through the world with a facial difference?

A: Thank you to all those involved in putting Facing Out together. As a survivor of neck cancer, I have been fortunate not to have needed reconstructive surgery; but I know this was a real possibility and could be in the future. Seeing the paintings and hearing the subjects talking has helped me to face this issue and view it more positively.

Q: Beauty is a layer of skin? Or is it?

A: No. Beauty lies within us all, and our skin can sometimes hide it!

Q: Is it natural to spot the difference in people and be curious, or should you ask the person a straightforward question? Would you be frightened of embarrassing them?

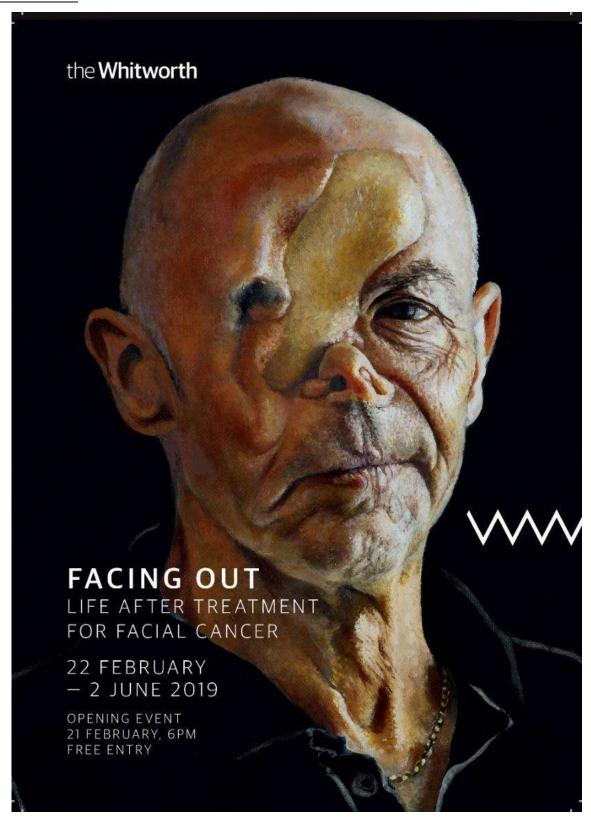
A: I would prefer not to ask anything because I don't want them to feel uncomfortable; or they might think I believe that people give them extra attention. I want them to feel as "the same" like others as possible. In a different case, if they share the story themselves then I would not mind to hear. Is not something I want to 'deny' to hear, and is not frightening.

Q: Has this exhibition changed your views and understanding towards plastic and reconstructive surgery being focused on rebuilding patients after cancer removal?

A: Yes - I found it very moving in its depth and scope and spent a couple of hours in it. What a marvelous piece of work and a fantastic idea - art and life and feeling ta every level. Many thanks.

Q: What is your perception of plastic and reconstructive surgery? Do you see it as cosmetic surgery? A: I came to the exhibition with my mother, Julie, who has had 15 surgical procedures on her head, face and neck, in the past 12 months; and I am absolutely blown away by the expression of art that is displayed. Through pain (physical / psychological) that is expressed in art form. Wonderful.

4.7 Launch Event



The exhibition launched with an evening event on 21st February 2019. The space includes a 'pop-up' Maggie's Centre complete with beautiful designer furniture, arts for health craft workshop and tea and cakes, and a display of artworks made from head and neck radiotherapy masks brought by The Swallows charity. It was attended by over three hundred people and feedback on the night was very positive. He night felt very much like a celebration of the portraiture subjects, an acknowledgement of their cancer experience and their arduous but successful fight for survival. Many of those attending were Maggie's Centre visitors who had received a cancer diagnosis themselves or who had a loved one in that situation. It was an opportunity to celebrate those positives that the portraiture subjects all acknowledge can come from living with cancer.



"The launch was perfect. I enjoyed the evening very much. It was exciting looking at the visitors looking at all the portraits, some smiling, some shedding a tear"

Annie

"I had some good conversations with people on the night – including a woman who had recently had similar surgery to me with a facial change and was unaware of how to contact others with similar issues and she seemed really pleased to have a talk with someone who had gone through what she had"

Nigel

Figure 86 Annie enjoying the launch night The portraiture subjects had a fantastic evening, surrounded by family and friends, talking about their choice of artworks and posing for photographs with their portraits: Trudi said she was as excited as she had been on her wedding day; Bern greeted friends that he hadn't seen for twenty years; Damir explained microsurgery to a rapt audience; Graeme, sporting his new prosthetic, also wore a tuxedo and looked like James Bond; Nigel laughed with friends who had travelled to Manchester to see the show and Annie beamed as crowds gathered around for selfies with her portrait.

"The exhibition opening night was a huge success. It made me feel very special and grateful to be part of such a glorious project."

"I was amazed at how many people turned up!"

"All my family and lots of friends came to the exhibition. They all spoke highly of the Whitworth and the exhibition itself. They remarked how it wasn't simply a few portraits and that it delved much deeper into the subjects and the experience of facial disfigurement"

"The opening night was very special – it felt we were all stars!"



Figure 87 The guests listen to Wendy Gallagher's speech

The Portraiture Subjects, Written Feedback







Figure 88 Images from the opening celebration

Speeches were delivered by Wendy Gallagher, Head of Learning and Engagement at Manchester Museum and former Arts for Health Manager at Manchester Cultural Partnership; Sinéad Collins, Centre Head at Maggie's Manchester, Lucy Burscough, Artist and Nigel Caldwell, Facing Out Portrait Subject.



Figure 89 The Speeches (click to view)88

The speeches were followed by a rousing musical interlude performed by Monica Ward and the Chemothumpers. They performed 'Chemothumping' a reworking off Chumbawamba's 'Tubthumping' by the exhibition's own Bern Corri.



Figure 90 Monica Ward and the Chemothumpers perform 'Chemothumping' with Bern Corri playing the white stick

4.8 Exhibition Engagement Programme



Figure 91 The Facing Out engagement flyer

A programme of events was developed in collaboration with The Whitworth's Learning and Engagement team.

4.8.1 Workshops and Tours

Printmaking with the Artist

Two sessions comprising of an artist's tour of the exhibition and the 'Pulling Portraits Apart' printmaking session that the artist had also delivered to student groups (3.3.3) and in Taiwan (3.3.6.4.1).

Mindfulness

A mindfulness session, open to people who have experienced cancer, and/or their families which took place in the gallery's beautiful Art Garden.

Creative Writing

A workshop for people who have experienced cancer, and/or their families, delivered by Clare Stuart, creative writing tutor at Maggie's Manchester.

Audio Described Facing Out Exhibition Tour Two tours delivered to people with low vision by Anne Hornsby⁸⁴ of Mindseye Description Services

4.8.2 Performances

Poetry Night: An evening of spoken-word performances relating to Facing Out, compared by local poet Tony Curry. Performances by Sharp Scratch, a poetry collective of people who have experienced cancer and who write together at Maggie's Manchester; Graeme Heward, reading from 'Riding with The Alien'; Tony Curry, reading a selection of poems including 'Annie' and 'Trudi' which were commissioned by Facing Out and were created after meeting with the portraiture subjects at Maggie's Manchester, and celebrated local poet Marvin Cheeseman, reading poetry by Bern Corri and his own work

"As I have a major speech impediment, I had long given up on ever hearing my own work read aloud in public. To think that this had been made possible by my involvement with F.O. is both humbling and amazing."

Bern



Figure 93 A video of Marvin Cheeseman performing Bern's poems (Click to view)



Figure 92 Sharp Scratch perform their poetry



4.8.3 Film screenings

4.8.3.1 Loving Vincent

An animated homage to Van Gogh, created from 65,000 oil paintings. With special Q&A with an artist who worked on the film, Sara Wimperis89. The film was chosen by Facing Out participant Bernard Corri whose love of Van Gogh was a featured strongly in his enjoyment of co-curating Facing Out. Bernard had been very helpful in promoting the crowdfunding that allowed the film to be made and so contacted the director to facilitate this event and the presentation and Q&A with Ms. Wimperis.

4.8.3.2 Wonder

Based on the New York Times bestseller, WONDER tells the incredibly inspiring and heart-warming story of August Pullman, a boy with facial differences. This film screening is aimed at families. With special thanks to Lionsgate Films.

4.9 Further Exhibition Phase Engagement Activities

4.9.1 MU Lecture and Workshop

Delivered to MSc Medical Humanities and MSc Science Communication students, a lecture about Facing Out and Burscough's arts for health practice. Followed by the 'Pulling Portraits Apart' printmaking workshop.

"The students found it a really wonderful way to think about how to foster small-group communication amongst professionals and members of the public, as well as a useful chance to think about how to integrate Arts in Health work into a broader health communication programme."

Dr. Elizabeth Toon⁹⁰, Lecturer in Science Communication, Manchester University

4.9.2 Cultural Partners and Impact: Working together to maximise the impact of research

A Manchester University 'Knowledge Exchange and Impact' event. Stand with Dr Martindale⁷⁸ presenting how her research into the lived experience and cultural significance of acquired facial disfigurement^{14 23} played an important role in the development of Facing Out and in the engagement activities that arose from it.

4.9.3 Didsbury Arts Trail- June 2019

A display of the Facing Out portraits and 'meet the artist', to take place at Maggie's Manchester.

4.9.4 Exhibition Engagement Quantitative Evaluation

Event	Attendees
Printmaking and Tour x 2	16
Loving Vincent Screening	200
Wonder screening	3
Mindfulness	10
Christie Art Group Visit	12
Audio Described Tours	2
Creative Writing Workshop	11
Poetry Night	25
Total	279

4.10 Press and Publicity Reach

Reach in Brackets.

"Sensitive Portraits" The Guardian: Selected by Jonathan Jones for listing in 'Art Weekly' (5,391,000)

"Raises a number of intriguing questions, including if the face changes, how does it affect a sense of self?" A-N: The Week's Top Exhibitions Write Up⁹² and listing (unknown)

"I won't look in the mirror but that portrait is me, the new me; the face I've got now and I've come to terms with it"

Open Up: Article 93 focusing on Trudi Proctor's experience as portrait subject in Facing Out (20,000)

"Art itself has created a vehicle for community and recovery" **The F-Word:** A <u>long-form interview</u>94 with the artist in this feminist publication

"Sheds a light on the power of people, the sheer determination to keep going and battle through" Article95 , Cotton On Manchester (unknown)

"Powerful and thought-provoking" Manchester Evening News/City Life: Write-up96 and listing (35,417)

The Swallows, National Head and Neck Cancer Charity, Patients Handbook: Article about the project as a whole (4000)

Total: 5,453,417

4.11 Awards

The Facing Out Portraits of Graeme Heward have been shortlisted⁹⁷ for the <u>John Ruskin Prize 2019</u> which has the theme Agent of Change. Winners will be announced at the opening event on the 11th of July.

5 Project Overview

5.1 Quantitative overview

Activity	Type of participants	Numbers
Watching the artist at work or viewing work in	Maggie's Centre Visitors- with cancer diagnosis	21164
progress		
Watching the artist at work or viewing work in	Maggie's Centre Visitors-friends and family	12363
progress		
Watching the artist at work or viewing work in	Maggie's Centre Visitors-others	3548
progress		
Visitors engaging in conversation with the artist	Maggie's Centre Visitors	3892
Workshop Participants		
Maggie's Arts and Craft Workshops	Maggie's Centre Visitors	215
Maggie's Whitworth/Manchester Museum Workshops	Maggie's Centre Visitors	124
Other Production Phase Engagement Activities	A variety of groups	445
Exhibition Engagement Programme	General public/People with a cancer diagnosis	279
Exhibition Audience		
Launch	General public	300
Gallery Visitors	General public	87,259
Artists/creatives/museum specialists benefiting		34
Participants in activities (inc. in conversation)		4,427
Audience (live)		125,182
Total (Live)		129,643
Audience (broadcast, online, in writing)	Opportunity to see	5,453,417
Total (Including press/online)		5,583,059

5.2 Qualitative Overview



Figure 94 The Facing Out subjects celebrate with project with afternoon tea and prints of their portraits

In accessing the project as a whole, the author hands over to Bern Corri, the man who inspired the project.

"Cancer, facial or otherwise, wherever it occurs, has only one objective, and that is to see you pushing up the daisies long before you have reached your `Best Before` date. Once given a diagnosis, the patient`s prime job is to find the tools, both mentally and physically to absolutely send this invader packing. Facing Out, along with all of its attendant events has come to me like a fully armed battleship appearing on the horizon to help me in my crusade. It has introduced me to some remarkable people, showed me their remarkable stories in fighting this evil disease, and showed me how they have coped. It has also allowed me to get my story out there and let me put on display some of the people and influences in my own life. It has helped illuminate this cancer world that a lot of us live in or surrounded by and to shine a bright light on it, showing that despite many people`s misgivings, that all is certainly not doom and gloom in there. Education is everything, and the more awareness there is around the taboo that is cancer, the more we can all help each other come to terms with this fiend. Facing Out offers beautiful art, sculpture, poetry, music and movie magic to the public. Above all else though, it transcends even art itself by putting on display in public show, the one thing that is to cancer just what a wooden stake is to a vampire. Hope!"

1 Appendix: Exhibition Interpretation

1.1 Edited Audio Interviews with the Portraiture Subjects – Transcripts

1.1.1 <u>Annie</u>

I m a volunteer at the Maggie's centre, a drop-in centre for people with cancer. It is a most beautiful, beautiful building. When people walk in, they're absolutely bowled over by the beauty of the place, plus it is absolutely so rewarding as a volunteer to see their faces and how happy they are to be in such a beautiful place. My role is to meet and greet, and to make them welcome, make them cups of tea or coffee, whatever they want, and let them know this is their place. That they can come and get involved in all the activities that go on in Maggie's, which is every day Monday to Friday 9-5pm. It's a wonderful place and I'm very lucky to be a volunteer there. Lucy came and asked me if I wouldn't mind letting her do my portrait. At the time I was, I had had the reconstruction, and she explained to me what this was about Facing Out. And when she asked me to smile while she was taking the photographs, someone said something in the background that made me laugh. I think she captured that really well, and I was very pleased with the end result because people were saying how she captured every aspect of me!

The reason why I had reconstruction is because I was diagnosed with melanoma, and I had several operations. I was quite an upsetting time because you're always worried that the cancer will come back, but I was reassured when they did the last biopsy that the margins were clear. I'm quite happy now, but I have to have more reconstruction in the near future. We did it in Maggie's Centre, Lucy wanted to show some of the beautiful settings in Maggie's and there was also the cup that we use in Maggie's. And I just love the portrait. People would come in, and obviously Lucy was in Maggie's doing the portraits, and people would look at mine and say 'Oh I know who that is, that's Annie!' and sometimes even if they didn't recognise me I'd make sure they did because I'd go and stand by it and then they'd look and say 'Oh, it's you!'. So it was very exciting.

Underneath my portrait you'll see there's a pair of tap shoes. The tap shoes are something that brings back happy memories to me as a child. When I first went to my tap dance class, then I was in shows. It was wonderful, I loved it! But then as you get into your teens, there are other distractions so... (laughs) the tap dancing went on its head really. And then as I got older I thought- I'd love to do tap-dancing again; a) because it's quite good for you, but b) because I was working in social services at the time and we decided that we would do a concert to raise money for Children in Need. I wore these, as you can see from the photograph beneath. So, after three lots of lessons we all went on and did a show which was quite good really, apart from one of our friends forgot the steps and stopped in the middle of the show. But it was...the audience loved it and we made a lot of money for Children in Need.

To the right of my portrait, you will see I have chosen The Beatles. As they were very, very much part of my youth. I loved them with a passion - still do actually. I liked Ringo very much, but Paul was my favourite - he was so good looking- so gorgeous when he was younger! I certainly would have had tis wallpaper when I was younger on my bedroom wall. It would have made me very very happy to look up at that every night! It's funny if you go to a wedding or a birthday. The minute anyone plays any of The Beatles, everyone gets up to dance and I love that. I was in London and umm, we went to err venues to see The Beatles, and it was in the early days before they were that popular, and I got their autograph. All four of them. They're in my heart, won't ever forget them. I'm probably a bit young at heart and I still love going to gigs. I love music. I love dancing. That's a big part of my life. To the right of The Beatles, bottom right- is the portrait by Marc Chagall of him and his wife. It might look like a painting but in fact it's a print. Really like this one, in particular, I love the way he's looking at her. And then I read up on it and she did a lot of work for him, and he loved her very much. And I just like the look on his face of absolute admiration for her. At the top right is a pastel drawing by Degas. I like this because I like the ballet, I've been to quite a lot of ballet concerts and as a child I did a little bit of ballet and I've always been very very fond of it. It's a beautiful image of children and as I worked in the child social services care team, children have always played a big part in my life. When I'm dancing, I feel very very happy, extremely happy. I feel like a child again – I just love it, I love any form of dancing. If I go to a celebration, I'm always one of the first up on the floor because I just love it, so much. I went to see Robbie Williams in concert in Prague and it was an outdoor concert. Obviously, there were lots and lots of young people - looking back on it I was probably one of the oldest people there. But in the end, I was

surrounded by a lot of young people who wanted to take photographs cause I don't think they'd seen anybody of my age at a concert before. Bit of a rebel really.

After having surgery on my eye, I was determined I wasn't going to stop doing what I love most and that's getting out there and being involved in music. I love music. When my son gets in the car, he says mum can you turn that down- the radio- because I sing when I'm driving. And I think it's important for people to maintain things that they used to do and not let what's happened to them to interfere with their daily lives.

1.1.2 Bern

Hello, I'm Bernard. I came out of major cancer surgery, after two weeks recovery, I went for a walk round the hospital and I seen this little woman sat there painting away at the eye hospital and I thought I'll go and have a natter with her. And this is Lucy who has painted this, and it kind of took off from there. Lucy then decided to paint me, for some unknown reason. I went to her studio and she did a few drawings of me. Took a lot of photographs and decided to include some of my poetry. And this is the result. It's part of a political poem, I do a lot of political! (laughs) I've seen this painting when I could see properly, because I've only got 5% vision now, and it was perfect. I'm going a bit off memory now, and I love it. I've got to have an eye-patch, full-stop, because there's nothing underneath *laughter*, so I thought I may as well glamorise it. The Moods were on this one, The Moods are Manchester's number one band, and I they'll beat me up if I don't say that. And I've also got patches for Maggie's Centre, Maggie's on the Runway, B&M Bargains (laughs).

Top left picture is by my great friend Gary Strickland, and this is the Elephant Man, played by John Hurt. This was the first picture I saw when I went to his house. How old was I then? 25, and it was one of 200 paintings. We ended up chopping half of them up, to make room for more. (laughs) He's really, really into art and really, really into Van Gogh. I've got 13 Olevels and not one of them is in the arts. I had nothing to do with any art. Art was out the window. And I'm no good, I can't draw my breath, never mind draw pictures. So I gave it up. And then I met Gary and he introduced me to Van Gogh, and then he sort of introduced me to the writings of Van Gogh, the Van Gogh letters and then I started to understand what it's all about. For me, the letters are more important than the paintings. Thus, I fell in love with Van Gogh (laughs).

Now the second picture down is by Martha Grunenwaldt who was a violinist in her young days, a prodigy, and then was forced to stop when she ended up working for a rich family as a servant, who couldn't abide the violin so was told to get rid of it until she was the age she painted this, 80 years old, when it all came to the surface again. She's painting with musical notes in her head and decided to put it to canvas. And this reminds me of what's happened to me because I'm a very visual person, whose now only got 5% vision, and my world is very black during the day. But at night-time, the dreamtime, it's hard for to describe now, the urgency to see things comes through at night, I'm at the IMAX cinema. And I've gone from darkness...like the Wizard of Oz when they open the door in Oz. It's another world! 3-D hologram. Everything is crystal clear! It's like a magical place, you almost don't want to wake up. I never had that before I went blind and I believe that's compensation. And I'm sure Martha had the same thing, compensation for taking her violin away – this is the result, and I understand *laughter*

This picture is the Triumph of Labour by Walter Crane. Celebrating the introduction of the 8-hour working day around 1890-1900, and really the start of the Labour movement. Personally, I think the move towards workers' rights was massively inspired by Charles Dickens, who I think had more influence in that direction then any bills of parliament. Because he made people aware, in any entertaining manner, of what's going on around them. Oh, he was the main man, wasn't he? The Ken Loaches, the Bleasdales, the Jimmy McGoverns, they're the Dickens of today. Because the people in power, like the people at the time of Walter Crane, they knew 'we better put a lid on this, or we'll all out of a job". So good luck to them, and to Walter, and the rebels of 1891.

Above the Walter Crane, number one artist in my opinion, the Van Gogh, it's just a simple watercolour done in his last year. It seems quite peaceful, though he was obviously in some distress at the time, and its hay-bales, painted in St Remy I think, yeah. I must say, how anybody can not like Van Gogh is beyond me, though I can understand that if you just look at the paintings and you don't read the letters of Van Gogh. For me the letters of Van Gogh are up there with Dickens. It is the same year as the Walter Crane painting and at that time socialism was really coming to the fore and Van Gogh was

documenting that in his paintings, in his letters. Van Gogh is just a treasure. He only started painting at 25 and what he left, a thousand paintings. The urgency to get the message out there- how society treats people is so important- we must value the individual! No matter how much they want to cut their ears off – which he never did by the way! I wish I'd have met him...I think we'd have got on. (laughs)

The painting top right is by Albert Louden, who was a van driver and self-taught artist. He painting looks to me like a choir. I tried to join one, but I've got no voice as you can tell. If you've got punk origins like me, and you're looking for a punk choir, get onto The Commoners Choir, because you'll absolutely love em, and they talk about real issues, real people, and this picture reminds me very much of them...I suggest that you tune in.

The boxing gloves are the ones I wore for Maggie's on the Runway. Somebody four years ago set me a challenge to go and become a catwalk model. This was just after I'd had my eye removed and half of my mouth, so I presumed it to be a wind-up. Being me, I just went along anyway for a laugh. And I ended up being Assistant Producer of Maggie's on the Runway, and in total we've raised £420,000, I think. A fashion catwalk every two years, underneath concord, totally glam, bringing on board 60 models, who have all been affected by cancer. So, what do these models need to finish off the night? A rousing song, so I got in touch with Chumbawamba, I know them quite well, and I told them we're going borrow your song 'Tub-thumping' and we're going to change all the words to suit us. After being threatened with violence, they gave in and joined in, and allowed us to use it on the night and to make a video. We needed some boxing gloves so I could get knocked down to get back up again, and we found these in a charity shop but they turned out to be the actual real gloves worn by Charlie Magri in his world title fight (where he got beat, unfortunately). But they're all signed up by Reg Gutteridge, Juan Diaz, Charlie Magri, Jim Watt, And I'm glad to say that they're now mine. And it seems befitting to wear them because they symbolise the fight against cancer. We do get knocked down, but we can get back up (laughs) and what more fitting emblem of our fight, than a pair of World Championship boxing gloves?

One day, it's like, "Sorry, you've got cancer, you've got to have your eye out" but from that, obviously in the back of my mind, "What's happening next? Is that end of everything? You've got cancer. Oh well, that's it". And then, it sounds really...you shouldn't be allowed to say this: it's done me a lot of good, you know what I mean? I've gone out, Assistant Producer of Maggie's on the Runway. All this... "Who's that woman painting over there? I'm going to go and have a word with her", now I'm in here! How does it all work out? How we're connected. I wasn't really doing anything before this. It was Gary who did the Elephant man, who said "I've seen all the stuff you've done over this last 4 years and you've really like, come back to life, through the cancer". It's weird.

1.1.3 <u>Damir</u>

My name is Damir Kosutic, and I am a Consultant reconstructive plastic surgeon. I work in The Christie NHS, which is one of the biggest cancer centres in Europe. My area of expertise is complex reconstruction for cancer patients, particularly micro-vascular free tissue transfer following cancer treatment. In the centre of the table you can see my portrait. I feel humble talking about it. You can see I'm wearing my surgical gloves, surgical hat, as well as micro-surgical loops, which is in fact a piece of equipment that was bought for me by my parents many years ago, and I still use it in my day to day practice. My whole family was very proud when they heard I was lucky to get involved in this really amazing project and they are all very keen to look at the whole exhibition, and particularly my portrait. Surrounding my portrait, you can see a number of pictures, prints and drawings that are related to my own personal interests. I have chosen two beautiful prints by Hiroshige. On the left, there is a beautiful but somewhat disturbing print called 'The Whirlpool'. And this was something that immediately captured my attention, as someone very keen on sailing, I have found myself many times in some rough waters. However, I have never felt a fear whilst at sea. This print has a deeper meaning for me as it reminds me of many calamities and difficult situations I had to overcome throughout my career- working in different countries and environments- I had to adjust to succeed. In contrast to previous print, this particular picture called 'Autumn Moon' represents everything I love about japan. The picture depicts tranquil waters, mountain and full moon and transpires peace, which is something I aspire. Throughout my childhood I was very much involved in martial artists, especially karate,

zen Buddhism and Japanese culture- which still continues to fascinate me to this day. If you walk around the table to your right, there is a beautiful sketch by Walter Crane. It depicts a butterfly resting on a white flower. The picture reminds me of unsettled beauty of nature and my own inability to settle throughout my career and personal life for different reasons. And this drawing reminds me of the past. It's really beautiful, I wish I could have it! *laughter*

The next group of sketches and watercolours that you can see by Walter Crane to your right are very much linked to my love of animals. I grew up in a family where we used to have 17 cats and 3 big dogs at some point, and I have to say I miss my animals very much. These drawings and sketches remind me of different scenes from my childhood. The dog playing reminds me of my Catalan Shepherd Benjie, who was very playful and a lovely dog, but also very protective of our cats, funnily enough, as well as of our family. If you keep walking around the table, you will notice some micro-surgical instruments. You can see a special type of forceps used to perform microvascular anastomosis for the vein with a copper device. The connection of small vessels under microscope is crucial to the survival of free tissue transfers, which we often use to rebuild body parts after cancer surgery, after borrowing tissue for elsewhere. If you look closely, you may be able to see the tiny opening within the end of the forceps, which is used to mount the edges of each side of the vein before anastomosis is performed. Microvascular anastomosis is connection between two sides of the vessel either artery or vein to re-establish the blood-flow between the transplanted body part and recipient side where the cancer was removed. Next to it you can see a microvascular needle size 10. In surgery sizes 9-12 are used for microsurgery and supermicrosurgery, where vessels of less 1mm up to 3-4mm are connected. I'm sure you can appreciate that the thread is thinner than the hair. If you look closely and catch the light you may be able to see that the tiny thread is connected to the needle.

Next to it you can see Walter Crane's drawing of human anatomy. Ever since I was young, I was fascinated by anatomy of the human body. During the course of my studies I became Assistant Professor of anatomy in Slovenia, where I worked for 5 years and where I have undertaken my plastic and reconstructive surgery training. During the course of my PHD studies I dissected human bodies many times and this was invaluable experience that helped me become a successful surgeon in the years thereafter. The benefit of learning from anatomical drawings is that they have much more detail. You can never really dissect a cadaver with that much precision. You can't really, because we see nerves for when we learn, we see nerves drawn with yellow, arteries with red, vein with blue. So, in real life, yes veins are blueish, but arteries and nerves are kind of white-ish. I think drawings help students focus their attention to specific organ systems for example nervous systems in yellow, arterial systems in red, muscles are usually red/brown. So, I think this makes some sort of imprint in our brains for later on, we always associate arteries with arterial blood that is lighter red in colour, venous blood with darker, it's not blue, but its darker red in colour for example. But as a result of that the vein and the venous wall looks blueish, even in real life. So, I think the beauty and value of drawings will help students and future doctors memorise and learn these things more effectively, I think.

I hope that my involvement in Facing Out has somehow demystified surgeon's role and position in the treatment of cancer patients. In my personal experience, I often have to detach myself from emotions. However, these things do leave some sort of long-term mark. Um, and I think that art, animals, sailing, are good ways to enjoy life and combat all the stress associated with being heavily involved in cancer treatment and patient suffering.

1.1.4 Graeme

I got involved in the project when Maggie's centre contacted me, and they said there was an artist who wanted to do a project on Facing Out, which was about how people with cancer looked out on the world. And initially I was quite reluctant because having my face painted... I wasn't particularly enamoured by the way I looked, and I wasn't sure I wanted to project that to the world. But Lucy had read my book and she was quite keen for me to be involved, and it came at a time during my treatment when I was undergoing facial reconstruction, so it presented the chance to have some serial paintings done, which you can see, and you can see the changes and those changes didn't take place as we thought it was going to do, I was really only meant to have three paintings, and my reconstruction was to take place over a short period of time, but as it was it took place over a longer period of time, and that's why we've got 5 paintings. And I have to say I'm very pleased with the last painting because I think that shows me in the best light.

The first painting shows me with a skin and muscle flap where my right eye would have been. I had an operation in late 2013. It was 16-hour operation, it was a long operation, but it was very successful, and that flap graft took extremely well. The next picture shows where I've had an implant, which is a forehead and nose implant inserted underneath the flap, and you can see there's a changing contour underneath my forehead. Unfortunately, the implant had problems, and to try and recover the situation I had a further operation, which is detailed in the third of the series. Where my whole cranium skin was rotated forward to try and bring some viable skin to the area to try and get it to heal. Unfortunately, that didn't have viability either and within a short space of time it was decided that I would have to have my nose removed completely. And we proceeded then to a full prosthetic, which you can see in the final picture. That prosthetic was made at Aintree hospital in Liverpool and it's the second largest one that they've ever made.

The healing hands painting is one that I choose from the collection. We went into the back storage and looked at all the Whitworth collection, and I happened to pull this one out and I was immediately drawn to it. I was drawn to the warmth of it. And as a physiotherapist I felt a real affinity with this because I spend most of my day using my hands to try and help and heal people and make them feel pain-free and return them to full function. And this I felt that this gentleman was being soothed by these very gentle hands and um, it was a very...pain-relieving thought to see him like that. And it reminded me of many times when I've touched my own skin and rubbed it to relieve it. Very much as a mother would do when a child falls and she would say "I'll rub it to make it better" and this is the epitome of that.

And the second painting has a very interesting background to it, and the background to the artist and how he became an artist of some reputation. I have two whippets and this dog is very reminiscent of a whippet physique, and the gentleman here reminds me perhaps of me writing my book or researching about lifestyle changes to try and overcome this very difficult disease. And there are some other elements in this painting, and I'm not sure they're there, but it does make me smile! The gentleman in the picture who is either writing or reading a book reminds me of writing Riding with the Alien, which I wrote shortly after the bike-ride in 2014. I wanted to leave my book on an inspirational note and my book isn't a sad book, it's more about providing people with the experience of what it's like to have cancer. So, if you'd like to listen to an excerpt from my book in the resource centre. There are some copies for you to read yourselves if you'd like.

The cyclist is a very vibrant painting, full of colour, full of energy. It makes me think about riding up a hill and feeling exhausted as this chappie is on his bike. I was never a cyclist I was always a squash player, but after that flap graft operation in 2013. My sons and I wanted to do something, to give something back and to help those people in the future so we decided we would cycle between the four peaks of Great Britain. That's Ben Nevis, Scafell Pike, Ben Nevis and Slieve Donard in Northern Ireland. It was 860 miles and we averaged about 100 miles a day, and we raised a considerably amount of money for them, and I vowed that my new challenge was not to accept challenges. However, I was on Radio Manchester with Sinead Collins, the Head of Manchester Maggie's, on the Mike Sweeney show. And afterwards she said to me "you don't realise how much difference that's going to make Graeme, particularly to the guys out there." So, it got me thinking what I could do to make a difference, so my next challenge is to ride between all 22 Maggie's centres in Great Britain. I'll be starting in Swansea on the 26th May and I'll be finishing in Inverness on the 14th June. And I'll be spending an hour, at least an hour, at each Maggie's centre. And the purpose of it really is to raise awareness that Maggie's centres are there to support everybody; patients, family and their friends. And at the same time to raise some money for them. So, if you're of that ilk and you'd like to sponsor me, please go on Maggiestour.co.uk and have a look at Maggie's Centres.

1.1.5 <u>Nigel</u>

Hi, I'm Nigel Caldwell and I got involved in this project by going to the Facing Out conference all day looking at and talking about different aspects of facial changes, which was something I was beginning to have to think about. I found it really interesting both professionally speaking and psychologically speaking. A facial surgeon speaking and other people who were going through the same as me in different ways. There was a lunch break and Lucy very kindly came up to me and asked whether I would mind or be very interested in having my picture painted. Then we had the discussion about where and how, and I thought it would be a straight forward head and shoulders but actually Lucy wanted a bit more of the character come through and I'd be telling her that two weeks before my operation I'd still been playing football – 5-a-side football with the old guys, the vets team in New Mills. And after my operation, that was my target. If I could get back to

playing 5-a-side that was a true mark of my recovery. I think what was good about the (around 1.10) Is a positive thing and it's more than just a hey you've had your nose changed. It's about actually you've got your nose changed but you're still doing things, you're ... and I think what I've seen in other portraits by Lucy is, yes the subject has a facial change but what struck me is that engagement of the eye, the gaze that came out, that was capturing the spirit. Not just for me, but of Graeme and all the others, where you might have had a change in face but actually the person comes through. And I think that that's the skill of Lucy really. Erm I think that whenever you've got a difference there's a danger that people actually look at what's been done ' "Oh you're different, I must have a photo of you" or "Must have a painting, do you mind?" But it was more of an engagement with me, Lucy took pains to have quite long conversations with me. More than the facial change it was about the person and the person dealing with the change, and how you look at the person with the changed face. You know, they're still the same person behind. Whether they're dealing with a few psychological issues about the change, but actually it's still the person.

The next one I want to talk about is top-right. It's actually a portrait of me by my daughter Sarah while she was doing A-level art. She was doing a focus on family portraits and that's a close-up. I find it a very interesting and a sensitive picture. And I'm glad that sound of my family can feature in this as well as family is really important. But the piece of work itself is also good but it shows maybe what I was like a few years before my operation. Going back over to the left now, that's a striking piece of lively fabric, chosen by me really because it captured one of my great passions and involvements, and my family's involvement, in samba drumming in a community band in High peak that played at Edinburgh Festival and lantern processions and carnivals across the peak district. And that has always been a really powerful part of what I've enjoyed doing, engaging the community, but being full of community spirit and life and fun. And that picture, it captures the excitement, the vitality and the life of the samba band. It was actually printed just half a mile from where I spent a lot of my time living in New Mills, at Strines, and that's only a few hundred yards down from where I lived.

So, moving now to bottom left- there's a Turner painting of a very natural scene high up in the mountains. And, since in my mid-twenties I've spent a lot of time climbing, walking in the hills, fells and the mountains and the alps and all over. And for me this was one in the Whitworth collection that captured that spirit of being out in the wild. And it actually has an echo – where a bunch of friends of mine had gone into the mountains behind Llanberis. We spotted a waterfall with a patch of grass next to it and we decided to pitch our tent there. Everything was fine until about half five in the morning, when my ground sheet had turned into a waterbed. The waterfall had been massively expanded through heavy rainfall over the night and we had to scarper quickly. And if you look closely there are characters moving about in the landscape, and you have to look quite closely to find them.

So, the last picture I choose to go alongside, or the image, is the piece of woven fabric, which is from Japan. And it actually I understand now is used, was used, as very high-class wrapping for presents that had been given. I didn't know about that, but the image struck me because one of the things that I had to think about before I hand the operation, and whether I would have any nose left, whether I could be needing to have a prosthetic. And this is where my wife comes in really because she was my advocate trying to preserve a most functional result. I've always really been into swimming, diving, swimming under water and this has a turtle in there, which kind of represents a really nice image, but also reminds me of the time I dived into water off Zante and swam with turtles. I was doing breaststroke, and ten feet below me a Turtle was doing the same beneath me. And I wondered whether once the nose had gone, I'd be able to do that, or if I had a prosthetic whether that would float to the surface. My wife championed my cause and said "well if the skin around the nose isn't effected, can you not just reconstruct? It may not look absolutely perfect, but it functions then". And sure enough, a couple of years later, we went on a family holiday and I did dive off 10 feet into the water and only then did I think "Oh, I wonder if I should have done that?" and I wondered whether a prosthetic nose would have actually had withstood that. But the image in that is good and I like the pictures that sort of lead you into other images, other landscapes. The turtle represents that to me, resonated with me, and that's why I choose it.

Okay, and lastly. It's not in the area where my portrait is, but as you came into the exhibition – you will have seen a large pink fabric and that's *Lantern Cloth* by Matthew Harris. And he was inspired by Japanese lanterns, by how they were – not

discarded, but repaired and put together. And for me and my family, lantern procession is really important. My wife and I introduced the lantern procession into New Mills back in the year 2000, to celebrate the Millennium walkway. And we had 350 lanterns cross that walkway and people wanted to come back and keep coming back. And about 10 years later we had 5000 people and I think since then it's got even bigger. The lantern procession has a bearing with this because it resembles the lantern cloths that have been put together- and if you look closely you can see the stitching, the clever stitching. The fact that stitches come into it are very relevant to the operation, the number of stitches I had to reconstruct my nose both internally and externally. A very strong image for me. And it relates to that philosophy of Kintsugi, that whole Japanese philosophy, of just because it's broken, you don't throw it away. It has a value in itself. You can repair it and put it back together and it has a different quality about it. It's still vibrant and useful. That's pretty much the end of why I choose all my pieces, thank you.

1.1.6 Trudi

I'm Trudi and I'm known as the light-house lady now, through the portrait that Lucy has done and through some of the paintings that I've done at the Christie art class. When I got diagnosed with skin cancer, I didn't realise how much it was going to change my face. I was on my own and lighthouses have got to be sturdy, strong of all the elements and that's me really. I had to stand strong because it was just a small spot on my nose, as big as a pinhead and then it's caused all this disfigurement to my face. It was upsetting, knowing that this was a disfigurement for life, and no one could have prepared me for what happened.

I got involved in the Facing Out project because one day I was going into Maggie's, more than likely just to have the cup of tea that's always welcome when you go in there and I just walked over to Lucy and just started talking, and then next minute Lucy turns round to me and say "Can I paint your portrait?" And wow! Yeah. Me and Lucy had a fantastic day, bit nippy as you can see by the sea – a bit choppy. We had a great journey down there; Lucy was just chatting to me and it was just a natural picture and I didn't really pose for it and Lucy got it right. I just think the atmosphere and everything that day. It was a rotten day as we was driving down to Talacre beach, and we was dead surprised, the sun just came out for a matter of minutes. It was the right time, right place. And when Lucy was painting it at Maggie's, I used to pop in for a quick brew and a chat with Lucy to see how I was getting on, and people were just coming up and to me and letting on like "Do you wear make-up?" "No I don't it's all natural" and Lucy did say to me that she enjoyed painting me cos I had a strawberry complex and everything she said "It was a joy to paint" and I thoroughly love it, I can't thank Lucy enough for portraying me in that way — I just love it.

Facing Out helped me through the traumatic times and I'm painting more than ever now. The blue lighthouse that's the second painting that I did at The Christies art class. I did go to private art classes, but it was one of the ladies at Maggie's who said you know there's an art class at The Christie. Went there, enjoyed it and it has helped me, you know, we have more laughs than down days now. And it just helped me through the bad times, and I just enjoy painting now. If you take a good look at the painting, it's quite a lot of finger-blobbing, as children do at school. There's just something about the lighthouses, that sometimes we have got to stand strong, and we've got to be strong for ourselves as well as the family.

Top left painting is one that I've picked is Henry Bright 'The Coming of the Storm at Great Yarmouth'. Very atmospheric with me painting seascapes. I did go to Yarmouth with mum and dad as one of the family holidays. But there's just something soothing and the storm's coming in and there's something about it that's peaceful and calming to me. Seascapes, I just love.

Henry Tonks recorded quite a lot of Harold Gillies procedures. He worked a lot with Harold Gillies as an assistant, but he was an artist as well. Gillies was a surgeon in the first wold war. My operation that I had was forehead skin-flap. Gillies was one of the surgeons that pioneered the procedure. You know the soldier holding out the cup, that was really, what Maggie's did for me. It was my lifeline- it was what I needed. Cos I'd hit rock-bottom at this time and Maggie's was my salvation when I was going through what I went through so. They're there for you as a patient, as family. They've helped me through the bad times and the good times. And Maggie's was the lifeline and always will, and I can't thank them enough for what they do. They're just there for you.

So, you can see my Dad. My dad was in the forces. And you can see my son in his RAF uniform, now he's working for the Red Arrows.

The selection of photographs- I'm the little one without the glasses, that's my sister there with the glasses Dianne. I was Daddy's little girl, and every year we always went to Wales and as you can see the two photographs at the top- left and right- one with Mum and one with Dad. And that was us all over, we were really family orientated. And every year it was the same weeks in August and Wales was like my second home.

The portrait of me that Lucy did is at Talacre beach in Wales, and we thought it was appropriate with us, with me spending a lot of family holidays there and that's why everything blends in to do with the seaside and Wales, and then this last photograph that's in colour is me with my sunglasses on my head again and Susan my daughter with her three children. The one next to me is Summer, and then there's Tyler and then there's Conor next to Susie. And it's another family picture in Wales. If you look closely at it, it's a month before I found the spot on my nose, so it's pre-cancer.

Top-right collage is John Stezaker 'Siren Song'. Bit quirky like me. You can see half the face is missing and it's been put over by a postcard and yeah, it's me, I like it. There's something about it. You can see where the postcard has been put over the picture is like the hair; you can see the nose and everything. Well if everybody knows me, it's me hair, me hair's my first priority and yeah there's something about it that I like, and you can see, look deep into the postcard that you can see the other side of the face. The picture on the bottom right Sir George Reid — why did I pick it? If you look at the other paintings and especially mine — the lighthouse- it's the storm and then it's the calming after the storm where we've got to rest after all the treatment we've been through. And you know, is it a healing hand? Or is it somebody passing something really? Something spiritualist about it as well. It's just calming, and that's why I picked it. Because we've got to rest after what we've been through. The trauma we've been through, and this is the period where we start healing ourselves within ourselves.

To put the showcase together was a bit of a minefield. At first, I just thought that it was my portrait in a showcase and that was it- I didn't realise that I was building my own showcase as well around my portrait. Pat, my art teacher at The Christie, just give me a computer one day and said, "there you go, go for it!" So, looking through the archives was a bit hard but yeah, I found the right paintings to go with my portrait and it was great seeing paintings and having a choice of all these paintings that some people won't ever get to see. And I've picked the right ones and I just hope that the people enjoy the paintings that I've picked.

1.2 Interpretation Panels

1.2.1 Introductory Text Panel

Facing Out: Life after treatment for facial cancer 22 February – 2 June 2019

Are you looking at me?

Facing Out, is an exhibition of portraits of people who have experienced facial cancers. They are shown with artworks from the Whitworth's collection, chosen by the sitters to illustrate valuable aspects of who they are. Artist Lucy Burscough painted the portraits during her residency at Maggie's Manchester, located close to The Christie, Europe's largest cancer treatment centre. Maggie's Centres are a network of drop-in centres, offering free practical, emotional and social support to people with cancer and their families and friends.

The face acts as our interface with the world. If treatment causes it to change, how does that affect one's sense of self? Our sitters speak of being acutely aware of the gaze of others, and they recognise that people's eyes can naturally be drawn to unusual faces. Becoming the subject of a portrait under these circumstances is an empowering act of defiance. Welcoming people to take time to look at one's face, scars and all, is an invitation to acknowledge a shared humanity and triumph over this indiscriminate illness.

The participants commented that the experience of being painted was a cathartic one, and the final portraits are a testimony of a process of engagement, trust and collaboration between sitter and artist.

The participants hope that exhibition visitors will be challenged to confront their preconceptions and leave with an increased understanding and empathy for what it is like to move through the world as someone with a facial difference:

'I'd like people to be more aware of how it feels for someone with a facial disfigurement... they might think about what we've gone through and understand.' Annie

An important part of this exhibition are the stories of the portrait subjects. To hear them, please ask for an audio guide.

1.2.2 Interpretation Beside Each Subject's Display Case

1.2.2.1 Graeme

Initially I was quite reluctant to get involved with the project ...having my face painted... because I wasn't particularly enamoured by the way I looked, and I wasn't sure I wanted to project that to the world. But it came at a time during my treatment when I was undergoing facial reconstruction, so it presented the chance to have some serial paintings done to show the changes.

The first painting shows me with a skin and muscle flap where my right eye would have been. The next picture shows where I've had an implant, which is a forehead and nose implant inserted underneath the flap. Unfortunately, the implant had problems, and to try and recover the situation, I had a further operation, which is detailed in the third of the series. In the last painting, we have proceeded to a full prosthetic. I have to say, I'm very pleased with the last painting because I think that shows me in the best light.

The healing hands painting is one that I choose from the collection. I happened to pull this one out and I was immediately drawn to the warmth of it. As a physiotherapist, I felt a real affinity with this because I spend most of my day using my hands to try and help and heal people and make them feel pain-free. I felt that this gentleman was being soothed by these very gentle hands and it was a very pain-relieving thought to see him like that.

These are edited excerpts. To hear Graeme's full story press 1 on the audio guide.

1.2.2.2 Bernard

Hello, I'm Bernard. I came out of major cancer surgery, after two weeks recovery, I went for a walk round the hospital and I saw this little woman sat there painting and I thought I'll go and have a natter with her. Lucy then decided to paint me, for some unknown reason! I've seen this painting when I could see properly, because I've only got 5% vision now, and it was perfect.

The second picture [bottom left] is by Martha Grunenwaldt who was a violinist in her young days, a prodigy, and then was forced to stop when she ended up working for a rich family as a servant, who couldn't abide the violin so was told to get rid of it. Until she was the age she painted this, 80 years old, when it all came to the surface again. She's painting with musical notes in her head and decided to put it to canvas. This reminds me of what's happened to me because I'm a very visual person, whose now only got 5% vision, and my world is very black during the day. But at night-time, the dreamtime, I'm at the IMAX cinema. I've gone from darkness - like the Wizard of Oz when they open the door in Oz. It's another world!...like a magical place, you almost don't want to wake up. I never had that before I went blind and I believe that's compensation. I'm sure Martha had the same thing, compensation for taking her violin away.

The boxing gloves are the ones I wore for Maggie's on the Runway [charity event]. It seems befitting to wear them because they symbolise the fight against cancer. We do get knocked down, but we can get back up and what more fitting emblem of our fight, than a pair of World Championship boxing gloves?

These are edited excerpts. To hear Bernard's full story press 2 on the audio guide.

1.2.2.3 Annie

I am a volunteer at the Maggie's centre, a drop-in centre for people with cancer. It is absolutely so rewarding as a volunteer to see the faces of visitors and how happy they are to be in such a beautiful place. My role is to meet and greet, and to make them welcome, make them cups of tea or coffee, whatever they want, and let them know this is their place.

While Lucy was taking the photograph [for the portrait], someone said something in the background that made me laugh. I think she captured that really well, and I was very pleased with the end result because people were saying how she captured every aspect of me!

To the right of my portrait, you will see I have chosen The Beatles, as they were very much part of my youth. I loved them with a passion – still do actually. I liked Ringo very much, but Paul was my favourite, he was so gorgeous when he was younger! I certainly would have had this wallpaper when I was younger on my bedroom wall. I'm probably a bit young at heart and I still love going to gigs. I love music. I love dancing. That's a big part of my life.

After having surgery on my eye, I was determined I wasn't going to stop doing what I love most and that's getting out there and being involved in music. I think it's important for people to maintain things that they used to do and not let what's happened to them interfere with their daily lives.

1.2.2.4 Damir

These are edited excerpts. To hear Annie's full story press 3 on the audio guide.

My name is Damir Kosutic, and I am a Consultant reconstructive plastic surgeon. I work in The Christie NHS, which is one of the biggest cancer centres in Europe.

In the centre of the table you can see my portrait. I'm wearing my surgical gloves, surgical hat, as well as micro-surgical loops, which is in fact a piece of equipment that was bought for me by my parents many years ago.

Surrounding my portrait, you can see a number of pictures that are related to my own personal interests. I have chosen two beautiful prints by Hiroshige. On the left, there is a beautiful but somewhat disturbing print called The Whirlpool. This was something that immediately captured my attention, as someone very keen on sailing, I have found myself many times in some rough waters. This print has a deeper meaning for me as it reminds me of many calamities and difficult situations I had to overcome throughout my career- working in different countries and environments, I had to adjust to succeed.

If you keep walking around the table, you will notice some micro-surgical instruments. You can see a special type of forceps used to perform microvascular anastomosis. Microvascular anastomosis is connection between two sides of the vessel either artery or vein to re-establish the blood-flow between the transplanted body part and recipient side where the cancer was removed.

I hope that my involvement in Facing Out has somehow demystified the surgeon's role and position in the treatment of cancer patients. In my personal experience, I often have to detach myself from emotions. However, these things do leave some sort of long-term mark. I think that art, animals, sailing, are good ways to enjoy life and combat all the stress associated with being heavily involved in cancer treatment.

These are edited excerpts. To hear Damir's full story press 4 on the audio guide.

1.2.2.5 Trudi

I'm Trudi and I'm known as the light-house lady now, through the portrait that Lucy has done and through some of the paintings that I've done at The Christie art class. When I got diagnosed with skin cancer, I didn't realise how much it was going to change my face...lighthouses have got to be sturdy, strong [against] all the elements, and that's me really.

The portrait of me that Lucy did is at Talacre beach in Wales, and we thought it was appropriate with us, with me spending a lot of family holidays there ... Me and Lucy had a fantastic day, bit nippy as you can see by the sea. We had a great

journey down there. Lucy was just chatting to me and it was just a natural picture and I didn't really pose for it and Lucy got it right. I just think the atmosphere and everything that day...the sun just came out for a matter of minutes.

Facing Out helped me through the traumatic times and I'm painting more than ever now. The blue lighthouse that's the second painting that I did at The Christies art class.

[Bottom left of the case] Henry Tonks recorded quite a lot of Harold Gillies procedures. Gillies was a surgeon in the first wold war. My operation that I had was forehead skin-flap. Gillies was one of the surgeons that pioneered the procedure. You know the soldier holding out the cup, that was really, what Maggie's [centre] did for me. It was my lifeline- it was what I needed. I'd hit rock-bottom at this time and Maggie's was my salvation.... They're there for you as a patient, as family. They've helped me through the bad times and the good times. Maggie's was the lifeline.



These are edited excerpts. To hear Trudi's full story press 5 on the audio guide

1.2.2.6 Nigel

Two weeks before my operation I'd still been playing football – five-a-side football with the old guys, the vets' team in New Mills. After my operation, that was my target. If I could get back to playing that was a true mark of my recovery. I think what was good about the picture is that it's a positive thing and it's more than just a "hey you've had your nose changed". It's about actually "yeah, you've got your nose changed but you're still doing things, you're playing football." I think what I've seen in other portraits by Lucy is, yes, the subject has a facial change but what struck me is that engagement of the eye, the gaze that came out, that was capturing the spirit. More than the facial change it was about the person and the person dealing with the change. You know, they're still the same person behind. Whether they're dealing with a few psychological issues about the change, it's still the person.

One of the works I choose to go alongside, is the piece of woven fabric, which is from Japan. It actually was used as very high-class wrapping for presents that had been given. The image struck me because one of the things that I had to think about before I had the operation, was whether I would have any nose left, whether I could be needing to have a prosthetic. I've always really been into swimming, diving, swimming under water and this has a turtle in there, which kind of reminds me of the time I dived into water off Zante and swam with turtles. I was doing breaststroke, and ten feet below me a Turtle was doing the same beneath me. And I wondered whether once the nose had gone, I'd be able to do that. And sure enough, a couple of years later [after the reconstruction], we went on a family holiday and I did dive off into the water.



These are edited excerpts. To hear Nigel's full story press 6 on the audio guide.

2 Appendix: Exhibition Evaluation

2.1 Visitors Answers to Subject's Questions

Q: Has this exhibition changed your views and understanding towards plastic and reconstructive surgery being focused on rebuilding patients after cancer removal?

A: A GREAT IDEA! I found it very moving, informative and gave me some perspective of acceptance of the fact that cancer can be life changing; and how the people came to terms with living and coping with disfigurement through art. WELL DONE!

Q: Surgeons can perform amazing operations. Did seeing the subjects affirm this thought or leave you feeling otherwise?

A: Yes, it was truly interesting but more importantly thought provoking for myself and my 7 year old daughter <3

Q: Do you automatically assume that someone with a facial disfigurement is of lower intelligence than Joe Public? A: Not at all. I think that they are just like me, a human being who has experienced difficulties in their life. I would not consider I would not consider their disfigurement as a statement of anything other than - someone having had surgery.

Q: How would you deal with having your facial features changed. Where does "you" reside - in your conversation - in your caring or what you look like?

A: It would be very hard to face the outside world, no matter how much I try to convince myself that this external shell is not "me".

Q: Is it natural to spot the difference in people and be curious, or should you ask the person a straightforward question? Would you be frightened of embarrassing them?

A: It is natural to be curious - but, depending on cultural backgrounds, it could be rude to ask; or disrespectful; or cold be seem as a sign of compassion etc. I personally would be curious but would try my best not to stare - and would treat them normally.

Q: Has this exhibition changed your views and understanding towards plastic and reconstructive surgery being focused on rebuilding patients after cancer removal?

A: I have been blown away by this exhibition - and loved hearing all of the stories besides the chosen artworks. I feel I would now be more open to approaching someone with facial reconstruction and talking with them about their experiences: - Thank you.

Q: Beauty is a layer of skin? Or is it?

A: Beauty should not have the value in society that is has today.

Q: what responsibility do museums and art galleries hold to shape the way that society understands difference?
A: Yes - maybe they do have a responsibility- because they are places where you can take in something, think, have thoughts, process what you have seen and discuss with others. Exhibitions like this can be an opportunity to really focus in on life, how others feel and how you would feel in a similar situation. Exhibitions are gateways to thoughand to consider yourself and others. Form thoughts and learn... you've just got to somehow get people to visit in the first place, in order to have such learning experiences. A wonderful exhibition - thank you.

Q: Surgeons can perform amazing operations. Did seeing the subjects affirm this thought or leave you feeling otherwise?

A: Thank you for sharing your experiences and your wonderful art. This is an empowering project for participants and the public. It should tour the UK. I am amazed at the transformative work of surgeons, and your honesty. Thanks.

Q: How would you deal with having your facial features changed? Where does "you" reside - in your conversation - in pylori caring or what you look like?

A: It would be very difficult for me, and I would lose my self-confidence.

Q: Should people with a facial disfigurement be encouraged to abandon aids such as prosthetics and eye patches etc. so that their condition can be more fully appreciated by society?

A: I believe that a person should be comfortable in their own skin.

Q: What is your perception of plastic and reconstructive surgery? Do you see it as cosmetic surgery?

A: We don't have surgery if we don't feel we need it or think something is wrong. If appearance is important to how we navigate the world and experience our mental health, is it even 'cosmetic'? I would say that if fixing a broken leg with surgery is okay, therefore plastic/surgery is okay for those whose mental health depends on it!:)

Q: As you gazed at the portraits did you imagine what it would be like for the subject or did you imagine what it would be like for yourself in their 'shoes', or both?

A: I felt the portraits allowed me to place myself in their 'shoes'. I can feel their. character, their strength and also their vulnerability. Truly inspired.

Q: Do you find that you rapidly lose patience when trying to speak to people with a speech impediment?

A: No but when I was young my cousin had a really severe stammer and I think playing as kids we just accepted it and in late life I realised how much he would avoid conversation because he was uncomfortable.

Q: What do you think the person with the facial change is thinking?

A: I think these people will feel desperate. They would want to hide their face from the world. They would also feel unhappiness and loss. People, mainly women (I think) would feel most unhappy about the physical change.

Q: What will stay with you from hearing our personal stories?

A: Bernard's description of "dream time" is both beautiful and moving. Thank you, Bernard.

Q: Do you automatically assume that someone with a facial disfigurement is of lower intelligence than Joe Public?

A: Terrible cancer. But very good exhibition.

Q: What responsibility do museums and art galleries have in shaping the way that society understands difference?

A: Museums have a huge responsibility for this! They have the power to show difference in an area in which people are willing to learn.

Q: What responsibility do museums and art galleries have in shaping the way that society understands difference?

A: Friday 22nd March 2019: I visited the Whitworth Art Gallery today for the very first time, especially to see the Facing Out Exhibition and found it so inspiring and moving having read Graeme's book 'Riding with the Alien'. I feel that this exhibition will be a constant help to anyone facing cancer. Well done to all involved, and to the skill of the medical team involved.

Q: Has this exhibition changed your views and understanding towards plastic and reconstructive surgery being focused on rebuilding patients after cancer removal?

A: Yes, it has! I had no idea that medical science had progressed so much, and how it has helped people living with facial disfigurement. Thank you for the exhibition!

Q: What do you think the person with the facial disfigurement is thinking?

A: 'I feel vulnerable. Society is a frightening place to be'.

Q: How would you deal with having your facial features changed? Where does "you" reside - in your conversation - in your caring or what you look like?

A: What a fantastic exhibition! Breaking down taboos about cancer. My facial features changed from an accident requiring stitches near my eye. I am lucky - it was temporary, and I healed well. It has been a privilege to listen to each of the journeys through from their diagnosis through to recovery from their traumatic operations. I am humbled by their humour, courage and positivity.

Q: How has this exhibition changed how you think about people who move through the world with a facial difference?

A: Verry, verry good. Amazing stoof. Ayesha Amissi 7 years old.

Q: As you gazed at the portraits did you imagine what it should be like for the subject or did you imagine what it would be like for yourself in their 'shoes', or both?

A: I have visited he Whitworth today with my parents and boyfriend. Graeme is someone who I am grateful to call a friend. His journey has been long; but to say I am proud and in ore of him is an understatement. Facing Out and the people involved are pure angels. The work they have done and the courage they have shown in tough times makes you feel grateful for life. Congratulations to all involved, Liz x

Q: Would you accept that children will stare and sometimes laugh at your looks?

A: Absolutely. One thing important to learn in life is that the features which define us as individuals are the most beautiful.

Q: Would you accept that children will stare and sometimes laugh at your looks?

A: No, I do not accept that they will laugh. They may look, but parents should challenge their behaviour to help them understand why people look different to each other.

Q: Do you find that you rapidly lose patience when trying to speak to people with a speech impediment?

A: Definitely not - we all deserve to be truly heard and listen to.

Q: What do you think the person with the facial disfigurement is thinking?

A: Exhibition both humbling and inspiring. Thank you. L. Sharp.

Q: Is it natural to spot the difference in people and be curious, or should you ask the person a straightforward question? Would you be frightened of embarrassing them?

A: Not frightened; I would be unhappy if I upset them. However, I think that humans are naturally curious. FAB exhibition - amazing people!

Q: Should people with a facial disfigurement be encouraged to abandon aids such as prosthetics and eye patches etc., so that their condition can be more fully appreciated by society?

A: This should be the decision of those who have the facial disfigurement.

Q: Should people with a facial disfigurement be encouraged to abandon aids such as prosthetics and eye patches etc., so that their condition can be more fully appreciated by society?

A: No - they should do what they want. Great exhibition!

Q: What is your perception of plastic and reconstructive surgery? Do you see it as cosmetic surgery?

A: Reconstructive surgery is because people need it to improve their appearance and wellbeing; whereas those who have face lifts, lip fillers etc. when there is nothing wrong with their appearance is totally wrong! JUST VANITY! Then when it goes wrong serves them right for being vain! ALL ABOUT BODY IMAGE!

Q: Surgeons can perform amazing operations. Did seeing the subjects affirm this thought or leave you feeling otherwise?

A: To peapol in the piccher I hop you get better soon. Love from Coralie.

Q: Q: As you gazed at the portraits did you imagine what it would be like for the subject or did you imagine what it would be like for yourself in their 'shoes', or both?

A: The portraits were very interesting. I thought about both things: I thought about how awful I would feel if that was me and everyone was staring at me, and what it would really be like to be in that situation. Annabel, aged 11:)

Q: What do you think the person with the facial change is thinking?

A: I think there must be a nervous state of anticipation, hoping that that brave step of self exposure is met with love and acceptance.

Q: Do you find that you rapidly lose patience when trying to speak to people with a speech impediment?

A: No, not at all. All I want to do is make the person feel at ease so that they don't get embarrassed often. I am not sure how best to do this?

Q: What will stay with you from hearing our personal stories?

A: I thought it was all really powerful. The joy that comes from being able to resume former hobbies, and the magic that is the Human mechanism, that gifts us in other senses when another is deprived.

Q: What is your perception of plastic and reconstructive surgery? Do you see it as cosmetic surgery?

A: This exhibition touched me and made me cry. Watching the film of the participants helped to bring to life the people behind the paintings. This reinforced the qualities of the work, and the way in which it is shown. Wonderful.

Q: Has this exhibition changed your views and understanding towards plastic and reconstructive surgery being focused on rebuilding patients after cancer removal?

A: Yes definitely. Inspirational: So grateful that the participants shared their stories and experiences.

Q: Beauty is a layer of skin? Or is it?

A: It might be. But the people featured in this gallery hold a different sort. Their souls are beautiful, even though they're folks like you and me. Thank you.

Q: What will stay with you from hearing our personal stories?

A: I love them.

Q: Beauty is a layer of skin? Or is it?

A: Yes it is, but it is the first layer to be seen. It's of no more importance, in fact less, than everything underneath. But it is also the first layer we communicate with, particularly in this fast moving, superficial world <3 <3

Q: Do you automatically assume that someone with a facial disfigurement is of lower intelligence than Joe Public? A: No. There is no such reason to assume that due to the way someone looks they are not intelligent. Even within the definition of intelligence, people can be intelligent and knowledgeable about a variety of topics, situations or aspects.

Q: What will stay with you from hearing our personal stories?

A: Trudi's story in particular resonated with me. I had cancer on my neck, and surgery resulted in a partial face lift - (the untouched side) is droopier than the other. I've really struggled with this for 6 years, and this exhibition has been more cathartic than the therapy I have had. I see that I am not alone. Thanks everyone.

Q: Q: As you gazed at the portraits did you imagine what it would be like for the subject or did you imagine what it would be like for yourself in their 'shoes', or both?

A: I loved this exhibition and felt both physically (pain in my tummy) and emotionally moved. The art; the selected pieces and the people's stories are both incredibly powerful, moving and inspiring. I <u>love</u> this jewel of an exhibition.

Q: How has this exhibition changed how you think about people who move through the world with a facial difference?

A: Thank you to all those involved in putting Facing Out together. As a survivor of neck cancer I have been fortunate not to have needed reconstructive surgery; but I know this was a real possibility and could be in the future. Seeing the paintings and hearing the subjects talking has helped me to face this issue and view it more positively.

Q: Is it natural to spot the difference in people and be curious, or should you ask the person a straight forward question? Would you be frightened of embarrassing them?

A: I think humans naturally spot differences, but it's about not making anyone feel singled out or insecure. I would never stare if point out a difference between me and someone else because I want to consider more the things that me and other people have in common and celebrate what's different.

Q: Beauty is a layer of skin? Or is it?

A: No. Beauty lies within us all, and our skin can sometimes hide it!

Q: What will stay with you from hearing our personal stories?

A: Hope! Thank you, W x

Q: Is it natural to spot the difference in people and be curious, or should you ask the person a straight forward question? Would you be frightened of embarrassing them?

A: I would prefer not to ask anything because I don't want them to feel uncomfortable; or they might think I believe that people give them extra attention. I want them to feel as "the same" like others as possible. In a different case, if they share the story themselves then I would not mind to hear. Is not something I want to 'deny' to hear, and is not frightening.

Q: How has this exhibition changed how you think about people who move through the world with a facial difference?

A: Yes, The re-animation is very good. It has progressed so much since I worked with these patients in 1981.

Q: What is your perception of plastic and reconstructive surgery? Do you see it as cosmetic surgery?

A: Definitely not! I had plastic surgery by Mr. Kosutic and it was <u>not</u> cosmetic! Thank you Mr. Kosutic.

Q: What responsibility do museums and art galleries have in shaping the way that society understands difference? A: I admire this kind of art exhibition, focusing on a subject that is often hidden away. It has been wonderful to hear the stories of the people involved in the surgery especially through the audio tape. So positive and inspiring; thank you!

Q: what responsibility do museums and art galleries hold to shape the way that society understands difference?
A: They have so many examples from the past, so much material that shows how people and artists have previously understood difference. This material should be brought to light. Museums and galleries also have a responsibility to engage with their audiences. They can help them represent their views and facilitate engagement with other views. The Whitworth does this incredibly well and should be proud.

Q: Do you find that you rapidly lose patience when trying to speak to people with a speech impediment?

A: I don't get impatient, but worry if I don't understand what is being said and are having to get he person to repeat themselves.

Q: Where does your sense of self reside - what part does physical appearance play in this?

A: My belief is that society has played the biggest part in enforcing us as human beings on how we <u>should</u> look, through social media, magazines and keeping up with celebrities. This exhibition has showed me how these individuals have overcome hoe their physical appearance affected them and made them stronger - it's inspiring.

Q: Surgeons can perform amazing operations. Did seeing the subjects affirm this thought or leave you feeling otherwise?

A: Definitely. What an amazing craft.

Q: what responsibility do museums and art galleries hold to shape the way that society understands difference?

A: By presenting it in an institutionalised space it condones the discussion of topics one might not engage within the course of ones ordinary life. To present difference as something to be celebrated instead of punished - to develop our empathy and to hear different stories and experiences. Art is a means of framing experience, and the more

varied the experiences we are exposed to, the more able we will be to navigate the complex and nuanced world that currently exists. So I should argue a very large responsibility.

Q: How has this exhibition changed how you think about people who move through the world with a facial difference?

A: I think it is important to see past the visual, and hear about their journey, the before and after. Recognising their amazing inner strengths I feel humbled by this exhibition.

Q: What will stay with you from hearing our personal stories?

A: That different is not a bad thing.

Q: Would you accept that children will stare and sometimes laugh at your looks?

A: Yes

Q: Has this exhibition changed your views and understanding towards plastic and reconstructive surgery being focused on rebuilding patients after cancer removal?

A: Yes - I found it very moving in its depth and scope and spent a couple of hours in it. What a marvelous piece of work and a fantastic idea - art and life and feeling ta every level. Many thanks.

Q: What is your perception of plastic and reconstructive surgery? Do you see it as cosmetic surgery?

A: I came to the exhibition with my mother, Julie, who has had 15 surgical procedures on her head, face and neck, in the past 12 months; and I am absolutely blown away by the expression of art that is displayed. Through pain (physical / psychological) that is expressed in art form. Wonderful. Anna, Julie and Kate.

Q: What is your perception of plastic and reconstructive surgery? Do you see it as cosmetic surgery? A: it was an interesting sort of exhibition I thought

Q: Where does your sense of self reside - what part does physical appearance play in this?

A: My sense of self is multi-faceted: Within and out with my physical and emotional being. Have part in within - a in a quiet place, deep in myself, visited when on my own and in a calm place. Also, there are myriad reflections of me from others; be they human or animal, like our dog for example. Then those fundamental aspects interact, and reside just behind my eyes, in my own head. I am aware of my physical appearance. In many ways, I dream for myself (I think) or maybe not. I would be very aware of any personal disfigurement that I. Isn't have in the future. My father-in-law was very aware of this himself - he suffered from skin cancer for years - a recognised wound from WWII. The sunlight in the desert. This exhibition had started me on a long journey of reflection about this question.

Q: Do you find that you rapidly lose patience when trying to speak to people with a speech impediment?

A: I believe that I very rarely lose patience as I can use what I can call intensive listening, a look at the whole person. It helps with people who can't speak English. Joe Regan.

Q: Is it natural to spot the difference in people and be curious, or should you ask the person a straightforward question? Would you be frightened of embarrassing them?

A: As a gay man, I have always felt that I am an 'outsider', but as a teenager I realised that that was a positive. I didn't have to conform to straight white norms! I see exhibitions like these and say, 'be yourself', it is harder for them to believe you!

Q: What will stay with you from hearing our personal stories?

A: It is scary to think that this might happen to anyone. I'm glad that you amazing people found the courage to face all of this and to share this experience with people that are mostly concerned with their daily stupid bullshit. Humanity is beautiful because of people like you.

Q: What will stay with you from hearing our personal stories?

A: I really loved this exhibition - particularly Bernard's inclusive sculpture. My children were excited to be told 'please touch':)

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