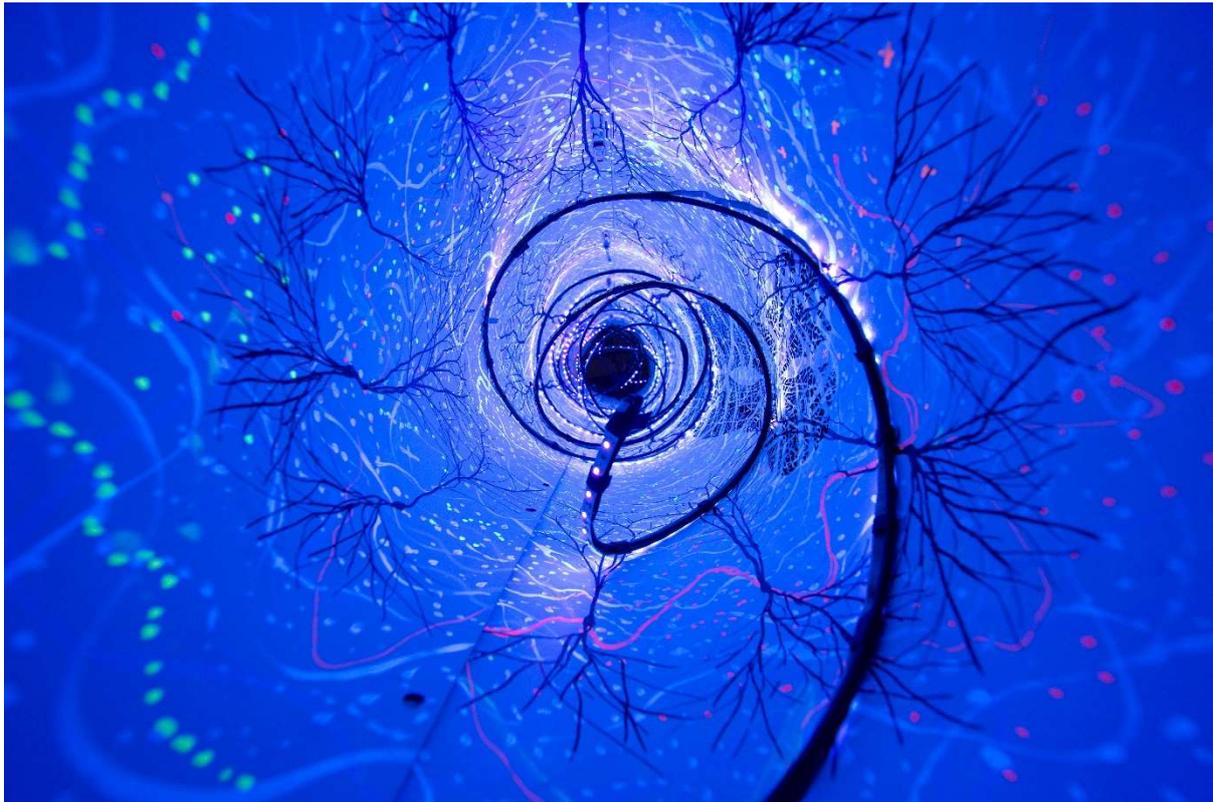


CANDO: Controlling Abnormal Network Dynamics using Optogenetics

Engagement Programme



Andrew Carnie, 'In Praise of the Scope'. Photo: Colin Davison

Evaluation Report

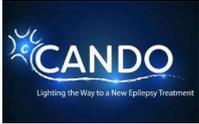
Report produced by Susan Priestley, July 2021



Vane



Imperial College
London



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Executive Summary

“There is a long history of fruitful collaborations between artists and scientists. The exhibition ‘Illuminating the Self’ shows the strong connection between two fields often assumed to be polar opposites. The process of creating work was driven by in-depth investigation and research, collaboration and experimentation, before final artworks were conceived and developed. The best art that comes from this kind of collaboration, however, does not try to illustrate or simply explain the complex science and engineering. It is a creative response to those discussions and observations, a reaction, or reflection, that aims to cultivate curiosity and provoke further responses from those who encounter it.”¹

CANDO (Controlling Abnormal Network Dynamics using Optogenetics) is a world-class, multi site, cross-disciplinary project to develop a cortical implant for optogenetic neural control. The goal is to create a first-in-human trial in patients with focal epilepsy. This seven year, £10M Innovative Engineering for Health Award, funded by the Wellcome Trust and the Engineering and Physical Sciences Research Council (EPSRC) involves a team of over 30 neuroscientists, engineers and clinicians based at Newcastle University, Imperial College London, University College London and The Newcastle Hospitals NHS Foundation Trust.

The purpose of this report is to assess the outcomes and impacts of the CANDO engagement programme, a science/arts collaboration between scientists, artists and performers which took place between February 2018 and June 2020. The primary aim of the engagement was to establish and engage in an informed dialogue with the public about the key themes of the CANDO project through a comprehensive programme of art exhibitions, performances, workshops and events. The programme looked to: help promote awareness of epilepsy and provide a voice for people experiencing the condition; and explore societal issues around the use of emerging technologies like gene therapies and implants in the brain.

The breadth and scope of engagement activity has been vast, from ‘Meet the Scientist’ events in public venues to exhibitions in galleries and libraries, workshops with schools and community groups, talks given by scientists and artists, and performances in theatres and churches. Underpinning the whole programme has been extensive collaboration across science and the arts, between artists and performers and scientists, neuroscientists, clinicians and engineers. The result has been an authentic cross-disciplinary programme which has raised awareness, explored, and questioned issues relating to epilepsy and the wider topics of neurological disorders and brain implants.

The project and the themes and topics it explored has had a wide geographical reach. Local audiences have been engaged through exhibitions, events and activities, whilst online information provided through the CANDO and partner websites, social media, and press and media have reached people nationally (and potentially internationally). For example, a BBC

¹ Lucy Jenkins, Curator Essay, ‘Illuminating the Self’.

Radio 4 programme 'Art of Now: The Algorithms of Epilepsy', made by Sara Jane Hall about the making of Susan Aldworth's work, 'Out of the Blue', was broadcast to between one and two million people.

The response to the programme from the people who have engaged with it has been overwhelmingly positive; visitors and audiences of all ages have enjoyed, learned, created, and been moved and inspired by both the science and the human perspective presented within the exhibitions, performances, workshops, talks and events. A key objective of the programme was *"to engage with harder-to-reach audiences who may not be drawn to conventional public science events and coverage"*. This objective has been at least partly achieved, with engagement from a broad and diverse range of people, many of whom had minimal awareness and knowledge of the key themes of epilepsy and the brain implant technology being explored as part of the CANDO project. The programme would undoubtedly have reached even more people had the onset of the Covid19 pandemic in March 2020 not resulted in the closure and cancellation of some key areas of work, which limited opportunities for the project to reach its full audience potential. That said, the programme has achieved some impressive outcomes and impacts and leaves behind a strong legacy:

New interest in and engagement with science for more people, as a result of the enjoyable, engaging and informative exhibitions, performances and activities, which have inspired interest and developed new knowledge, not least amongst the students who took part in workshops – potentially the scientists of the future.

A voice for people living with epilepsy, through opportunities not only to engage with the exhibitions and performances as audiences, but also as contributors. People with epilepsy acted as advisors and provided valuable source material through discussion and collaboration with scientists, artists and performers, and almost 46 people directly contributed testimonies about living with epilepsy as part of one of the artworks, Susan Aldworth's 'Out of the Blue'.

Increased public awareness and understanding of epilepsy, through opportunities to see and learn about the condition and the effects it has on people, their lives and their families. Presenting this human side of epilepsy has played a key role in making the scientific messages accessible to a broad and non-scientific audience. In addition, informed discussion and dialogue about the use of emerging technologies like gene therapies and implants in the brain for epilepsy and other neurological conditions have clearly introduced people to new scientific research and the issues and ethics associated with it.

A contribution to teaching and learning through new information and skills gained by teachers to pass on to wider groups of students; and through the Operating Theatre online teaching resources linked to its 'Deep Mind' film performance, both of which can be accessed through the CANDO website and the National STEM Learning Centre resource website (www.stem.org.uk)

A strong working model for science and art collaborative working, which has proved its effectiveness in explaining and disseminating scientific research in creative and accessible ways to new audiences, which can be replicated in other cross-disciplinary projects.

A body of work exploring epilepsy and other neurological conditions, including the artworks made for the exhibitions, which can be exhibited elsewhere; the films made, which not only documented the making of the artists' work, but also their ideas and thought processes; the scripts and performances, which can be used and performed again.

The Engagement Programme

8299 people of all ages and abilities have participated in-person in the CANDO engagement programme between February 2018 and March 2020.

“The more common ‘engagement’ routes for science projects often end up being simply social media accounts and websites that almost no-one follows. In my experience, arts engagement – while mostly limited to the local population – is infinitely more effective at reaching the general public...”²



Meet the Scientist event at Centre for Life, Newcastle. Photo: Michael White.

This report focuses on measuring the impacts and achievements of the CANDO engagement programme ‘Illuminating the Self’, a complex interweaving of science and arts activity, designed, developed and delivered by a skilled inter-disciplinary team of artists, scientists, engineers, clinicians and neuroscientists. The main aims have been to promote awareness and increase understanding of epilepsy, and to introduce CANDO’s work in developing a cortical implant for optogenetic neural control. The programme has included:

- A launch event on 15 May 2018 was attended by 15 representatives from North East creative and scientific industries.

² Scientist, CANDO project

- ‘Meet the Scientist’ events, often linked to wider science events and initiatives, which offered a range of activities to increase awareness and understanding of neurotechnology. Activities included an immersive opportunity to explore the brain, the effect of epilepsy on the brain and the CANDO therapy through a partnership with software developers AnimaVR, which demonstrated the effects of a cortical implant for optogenetic neural control on the brain using Virtual Reality. The software was also free to download from the CANDO website.
- A series of performances and readings by Operating Theatre, including ‘Making for the Light’, a theatre performance about epilepsy, which premiered at Live Theatre and subsequently toured to church venues across Newcastle and Northumberland; and ‘Deep Mind’, originally planned as a performance about the future of neurotechnology, but adapted as a film and shown online due to the Covid19 pandemic. Both the performance and film were followed by panel discussions between Operating Theatre, CANDO team members, invited speakers and audiences.
- A major exhibition ‘Illuminating the Self’ shown across two Newcastle galleries - Newcastle University’s Hatton Gallery and Vane - presenting the work of internationally renowned artists Susan Aldworth and Andrew Carnie, produced following two years of research and collaboration with the CANDO project team.
- A series of talks and presentations by artists and scientists for groups and audiences at a range of galleries and community venues.
- A programme of combined science and arts workshops in secondary schools across Newcastle, Gateshead and Northumberland, which included a talk about the science and engineering behind epilepsy and optogenetics, following by artist-led workshops exploring the science through practical creative activity.
- A series of films made by filmmaker Alan Fentiman, documenting the making of Susan Aldworth’s and Andrew Carnie’s work from the earliest research and ideas stage to installation at the Hatton Gallery and Vane.

The Covid19 pandemic had a major impact on the engagement programme, with the ‘Illuminating the Self’ exhibition at the Hatton Gallery only showing for nine of its planned 16 week run. No visitor feedback from the Hatton has been available for this report. In addition, planned performances of the Operating Theatre performance, ‘Deep Mind’ at Alphabetti Theatre in Newcastle and Ushaw Historic House, Chapels and Gardens in Durham had to be cancelled due to the first Covid19 lockdown. This performance was later adapted as a film and shown online. Workshops and other events planned for the final months of the project were also cancelled, although a few talks have been able to take place online.

The Evaluation Process

The primary aim of the evaluation process has been to measure the impacts, outcomes and achievements of the CANDO engagement programme on the broad range of people who have been involved, including: artists, scientists and other contributors to the programme; exhibition visitors; audiences for Operating Theatre; and participants in workshops, talks and events. Feedback and information has been gathered face-to-face, through questionnaires and visitor feedback forms, by email, and through observation and conversations at workshops and events. The main areas monitored and measured have been:

- people’s existing awareness, knowledge and connections with epilepsy;
- improved understanding of epilepsy as a result of engaging with the project;

- to what extent engaging with the exhibitions, performances and activities caused people to think about issues relating to epilepsy and other neurological disorders in new ways;
- whether people agreed that arts projects can influence understanding of science; and
- what visitors and audiences thought about the technology being developed by the project.

Evaluation has gathered information and feedback from a broad range of people, including some *'harder-to-reach audiences who may not be drawn to conventional public science events and coverage'*, a key objective of the project. This process has however been negatively impacted by the cancellation of some key elements of the engagement programme due to Covid19, which has limited opportunities for the project to reach its full audience potential.

Operating Theatre

“Thought this was a totally absorbing production that moved and informed. Certainly helped me to understand epilepsy in terms of its effects on the individual.”³



Operating Theatre: ‘What a Piece of Work is Man’, Hatton Gallery. Photo, Colin Davison

“Being part of such an important project, with the express aim of engaging the public in open and honest debate, has been invaluable. It has reaffirmed our belief that any discussion about health and the future of healthcare must involve all of us. We were supported and encouraged by the CANDO team throughout the process, and this allowed us to be ambitious in terms of our creative output. The work we produced, whether it was for schools or a theatre-going audience, never forgot the science but always put the individuals involved at its heart.”⁴

Operating Theatre is a North East based company providing bespoke theatrical experiences that can transform the way people think about health and wellbeing. The company worked with the CANDO research team and people from 17 to 70 years with epilepsy, to develop and deliver a body of film and performance work presenting and exploring the issues raised within the research work. Each performance was followed by a panel discussion involving representatives of Operating Theatre and CANDO, to open up a conversation with audiences.

Operating Theatre developed and performed the following work as part of the CANDO engagement programme:

³ Audience member, ‘Making for the Light’.

⁴ Carol Clewlow, Operating Theatre.

- ‘Illuminated Self’ for the CANDO launch at Northern Stage on 15 May 2018.
- ‘Making for the Light’, premiered at Live Theatre, Newcastle, on 22 November 2018. St George’s Church, Jesmond, Newcastle; Newcastle Cathedral; Hexham Abbey, Northumberland; and All Saints Church, Gosforth, Newcastle.
- ‘What a Piece of Work is Man’, as part of the ‘Illuminating the Self’ exhibition preview at the Hatton Gallery in Newcastle on 17 January 2019.
- ‘Deep Mind’, which was to have been performed at Alphabetti Theatre, Newcastle and Ushaw College, Durham, but which was cancelled due to the Covid19 Pandemic. A film version of the play, adapted with additional funding from Catherine Cookson Foundation, was premiered online on 3 December 2020.

Making for the Light

91 people attended ‘Making for the Light’ performances at Live Theatre, Newcastle and church venues in Newcastle and Northumberland.

“The piece was superb – identifying many aspects of epilepsy that I didn’t know BUT raised MORE questions (that’s education!)”⁵



Vincent Van Gogh, ‘The Starry Night’ (detail used for performance publicity)

⁵ Audience member for ‘Making for the Light’ at Live Theatre

“Our first major piece, ‘Making for the Light’, took its cue from a Van Gogh quote: ‘So let us go forward quietly, each on his own path, forever making for the Light.’⁶. The central figure in the drama was a woman artist with epilepsy who recounted her history after having had her first seizure as a teenager in front of Van Gogh’s ‘Starry Night over the Rhone’. She was now being offered the opportunity of a new therapy and was questioning whether it would affect her perceptions and therefore her art.”⁷

‘Making for the Light’ was a series of performances written and performed by Operating Theatre and presented in conjunction with Newcastle University and the CANDO project. The performance premiered at Live Theatre, Newcastle (30 people attended) and subsequently adapted and toured to four church venues to reach a broader audience: St George’s Church, Jesmond, Newcastle (30 people attended); Newcastle Cathedral ((5 people attended); Hexham Abbey, Northumberland (11 people attended); and All Saints Church, Gosforth, Newcastle (15 people attended).

Each performance was followed by a post-show discussion with members of the CANDO project team.

47 people completed evaluation forms – the findings were as follows:

- 30 of the 47 people in the audiences had an understanding of/personal connection to epilepsy. This ranged from professional connections such as teaching/caring for people with epilepsy, through to personal experiences of the condition, either by suffering from epilepsy themselves or having a friend/family member who was living with/had died from the condition.
- When we were asked to rate their responses to three questions about the performance on a scale of 1 to 5, with 1 being ‘not at all’ and 5 being ‘very much’. The results are as follows:

The mean average score for ***the performance improved my understanding of the experience of persons living with epilepsy*** was 3.23

The mean average score for ***the performance caused me to think about issues relating to epilepsy and other neurological disorders in new ways*** was 4.13

The mean average score for ***the format (performance + discussion) was a useful way of learning about the personal, subjective effects of epilepsy*** was 4.0

- 40 of the 47 respondents (around 86%) agreed that ***arts projects can influence our understanding of science.***

When asked “Do you think arts projects can influence our understanding of science?” Responses included:

“By helping others to see the ‘human’ side and help relate the treatment to the people involved.”

“Much more than reading a leaflet.”

“Yes, knowledge and understanding help people to be listened to/informed to deepen their understanding of what the condition is and the need for more updated treatments.”

⁶ Vincent Van Gogh, who was believed to have suffered with epilepsy

⁷ Operating Theatre

Deep Mind

An audience of 35 people attended an online showing of the 'Deep Mind' film and after-performance discussion on 3 December 2020, which has since had over 300 views on YouTube.



Operating Theatre: 'Deep Mind' online film. Screenshot, Meerkat Films

The race is on for the Golden Key, the tool which will revolutionize the treatment of human disease, diagnosing more quickly and efficiently, establishing what drugs will work and what will not, eradicating error.

PNN have been working on Apogee for the last twenty years. Now they believe they're ready. But with an important press conference coming up, disagreements about the future of Apogee have started to surface. Therefore important and difficult decisions need to be made. Who should get the Key? Who will benefit and who will not?⁸

Originally, Operating Theatre developed a new performance exploring the future impact of technology on the human body, 'Deep Mind' to be performed at Alphabetti Theatre, Newcastle upon Tyne and at Ushaw Historic House, Chapel and Gardens, Durham in March 2020. However, the performance was cancelled due to the COVID-19 pandemic and thanks to additional funding from the Catherine Cookson Foundation, Operating Theatre collaborated with Meerkat Films to film the show. The film premiered online on 3 December 2020 to an audience of 35 people. It is available to watch online here <https://youtu.be/dnR05r1QkLg> and has already had over 300 views to date. A range of teaching and learning resources for schools was produced to support teachers to explore issues around brain-machine technology with students.

⁸ 'Deep Mind' summary, Operating Theatre

'Illuminating the Self' Exhibitions

The 'Illuminating the Self' exhibitions attracted a total of 6517 visitors across two venues: 1988 people visited the exhibition at Vane between 16 January and 29 February 2020; and 4529 visited the exhibition at Newcastle University's Hatton Gallery between 18 January and mid-March 2020, when the gallery was forced to close due to the Covid19 pandemic (the exhibition had been due to run until 9 May 2020).

"(I particularly enjoyed) The telescope – I felt as if I was looking into the brain."⁹



Andrew Carnie, 'In Praise of the Scope', Vane. Photograph: Colin Davison.

'Illuminating the Self'...has two broad goals. First, we want to help provide a voice for those who experience epilepsy. For example, Susan Aldworth has collected testimonials from people around the country, and these form an integral part of her new installation for the exhibition. Second, we wanted to explore societal issues around the use of emerging technologies like gene therapies and implants in the brain. As scientific and engineering progress advances, what are the benefits and risks of manipulating brain function and how should we safeguard ourselves in the bioengineered future? Andrew Carnie's art explores what we mean by the self,

⁹ Visitor to 'Illuminating the Self' at Vane Gallery.

through notions of hybridity in biology and medicine. Both artists have spent time interacting with the CANDO team and produced an astonishing range of artworks that reflect and examine the scientific and clinical ambitions of the project.¹⁰

Internationally renowned artists Susan Aldworth and Andrew Carnie were commissioned to work alongside researchers to develop new work in response to the CANDO project. The artists did not set out to illustrate, but rather to explore and respond to the complex scientific, emotional and ethical issues involved, from revealing the inner workings of the brain to expressing how it feels to have epilepsy. The works were brought together in 'Illuminating the Self', an exhibition shown across two galleries in Newcastle upon Tyne, Newcastle University's Hatton Gallery and Vane. Each artist took a different approach:

*"My work for the two exhibitions reflects on the CANDO project's scientific and engineering aspects of the implantation into the brain of an electrical device and further gene manipulation to make this device effective, whilst also considering some of the ethical and moral questions surrounding it."*¹¹

*"I wanted to get under the skin of what it is about epilepsy that makes it so hard to live with – why the project scientists, clinicians and engineers are so keen to find a way to target, monitor and stop focal epileptic seizures with such experimental treatments."*¹²

As well as the different ways in which each artist approached their work, the exhibition shown across two venues allowed for a broader public reach in terms of the different audiences at each venue. The installations at each venue allowed visitors to be fully immersed in the works, encouraging people to spend longer in the galleries and engaging more fully with the exhibitions.

*"A real strength of the project was the length of time for the artists and scientists to work together and for Susan and Andrew to develop a full and deep understanding of so many different aspects of the CANDO project. This is reflected in the quality of the work that they made and in the engagement that visitors had with the art. My own observations of visitors to both exhibitions was that many visitors stayed in the exhibition for long periods, spending much time absorbing the artworks and the interpretation."*¹³

The following pages give an overview of each exhibition, along with artist explanations of the thinking behind the works and how they were made, and comments and feedback from audiences and others who have engaged with the exhibitions and associated activities.

¹⁰ Professor Andy Jackson, CANDO research project, interview with Epilepsy Research UK, 17 January, 2020.

¹¹ Andrew Carnie, Artist.

¹² Susan Aldworth, Artist.

¹³ Lucy Jenkins, Curator, 'Illuminating the Self'.

The Hatton Gallery

4529 people visited 'Illuminating the Self' at the Hatton Gallery between 18 January and 20 March 2020, which is slightly higher than the original target figure for the period. Information provided by the Hatton Gallery suggests that if the exhibition had run until its original closing date (9 May 2020) visitor numbers were expected to be 4000 higher than previous years for the same exhibition slot.

The preview took place on Friday 17 January and was attended by 120 people.

"The exhibition as a whole is a brilliant representation of what goes on in that lump of grey matter called brain."¹⁴



Blue Matter, Andrew Carnie, Hatton Gallery. Photo: Colin Davison

"Science and art are hand in hand here. Not only have they brought epilepsy and the CANDO project to a wider audience, but they have also found a way to communicate while holding artistic integrity. You leave with empathetic knowledge."¹⁵

Each artist's work was displayed in separate galleries within the Hatton: Susan Aldworth's piece 'Out of the Blue' used 45 testimonies by people with epilepsy, which were embroidered onto 106 antique undergarments by first year degree students from the Royal College of Needlework and other groups and individuals; and Andrew Carnie's work reflected on the CANDO project's scientific and engineering aspects, whilst also considering some of the ethical and moral questions surrounding it.

¹⁴ Visitor to 'Illuminating the Self'.

¹⁵ Review in Darkus by Beverley Knight, 8 February 2020.

Susan Aldworth: 'Out of the Blue'

"What a fantastic, thought-provoking exhibition... Once Hazel mentioned the clothes were from vintage shops and were authentic Victorian and Edwardian pieces, I had a true visual of seeing folk shuffling around a sanatorium/institute in Victorian times, just as the Victorians did hide their lovely people, whom unfortunately suffered medical issues. Excuse the pun but it was like a bolt to the brain, the impact and message your lovely artwork gave me."¹⁶



'Out of the Blue', Susan Aldworth, Hatton Gallery. Photo: Colin Davison.

"Fantastic. Unbelievable. I saw it at the preview, The students saw it on the film."¹⁷

Susan Aldworth's installation, entitled 'Out of the Blue', is the artist's response to reading testimonies from people with epilepsy, or with connections to the condition through family and friends, about living with epilepsy, and to the science which is developing ways to control some focal epilepsies with a combination of brain implants and blue light. The testimonies were hand embroidered onto 106 Victorian undergarments by Royal College of Needlework students and community embroiderers from diverse backgrounds, using UV sensitive threads.

"Why Victorian underwear? Because they are beautiful objects, because like epilepsy, these garments were worn concealed beneath the surface and in their vintage their very fabric would contain hidden histories. Because they shine under UV light. Lined up in rows in the installation,

¹⁶ Visitor to The Hatton Gallery

¹⁷ Community group which contributed to the embroidery for 'Out of the Blue'.

*these white clothes also reference the institutionalisation of many people with epilepsy in Victorian England.*¹⁸

Susan Aldworth on ‘Out of the Blue’:

“The project gave me the opportunity, time and funding to research and make a very ambitious large-scale work - ‘Out of the Blue’ – which weaves together the narratives of the science involved in the research project, with the stories of people living with the condition, whilst referencing the stigma associated with the condition historically. Their words form the foundation for my installation ‘Out of the Blue’. The installation consists of 106 antique garments embroidered with the words of people living with epilepsy, suspended from the ceiling of Newcastle’s Hatton Gallery in a single block of one hundred, lit by natural and ultraviolet light. The garments move on pulleys programmed by computers to correspond to the algorithms of electrical activity in an epileptic brain... I had access to cutting edge information, imagery and knowledge about epilepsy from a huge range of scientific and other disciplines – neuroscientists, engineers, clinicians, computer programmers and ethics lawyers. I wanted to get under the skin of what it is about epilepsy which makes it so hard to live with – why the project scientists, clinicians and engineers are so keen to find a way to target, monitor, and stop focal epileptic seizures with such experimental treatments. I also wanted to understand any ethical issues around human hybridity which a brain implant might raise, and to find out the impact that living with epilepsy might have upon someone’s sense of self. Before responding in some way to the science of these radical treatments, I wanted my work to bear witness to the experience of those who live with epilepsy. The Epilepsy Society agreed to circulate a questionnaire for the project asking a number of questions. “What does epilepsy mean to you? How do you feel at the onset of a seizure?”

Collaboration with the Epilepsy Society and Royal School of Needlework

“What is epilepsy? For the scientists, pharmacists and doctors seeking an effective treatment, it is a neurological conundrum... For most of us, by contrast, it’s just a word... But for those who have epilepsy, it is something else. It is a lived and living experience. For them, the question is more personal: what is it like to live with epilepsy? Only they can answer it.”¹⁹

To inform her response to the science of the CANDO project, Susan Aldworth collaborated with the Epilepsy Society to circulate a questionnaire to people living with epilepsy. Questions included: What does epilepsy mean to you? How do you feel at the onset of a seizure, and how do you feel afterwards? Are there any positive words to describe your epilepsy? Is there anything else you would like to say?

*“Almost one hundred people responded. They described with candour and in detail the reality of how they – and their families – are affected by the condition. Their words are extraordinarily powerful, moving and illuminating. They form the foundation for ‘Out of the Blue’.”*²⁰

¹⁸ Susan Aldworth, Artist.

¹⁹ Susan Aldworth, Artist.

²⁰ Susan Aldworth, Artist.

“The embroidery was incredible, and the way it matched the testimonials created very powerful emotions...”²¹



‘Out of the Blue’, Susan Aldworth, Hatton Gallery. Photo, Colin Davison

The Royal School of Needlework set ‘Out of the Blue’ as a first-year BA embroidery project – thirty-five staff and students took part. Other embroiderers heard about the project and 106 people signed up to sew in total. Each volunteer was sent an individual antique undergarment, chosen by the artist because they, like epilepsy, were hidden from the public eye, and a selection of ultraviolet embroidery threads in yellow, light blue and black. The instructions were to keep to the colours scheme; sew a single word on the back; and the testimony on the front. Some of the Royal College of Needlework students also modelled the embroidered garments at Hampton Court Palace for the Arts Council funded ‘Out of the Blue’ Artist’s Book, which has contributed to the work’s life after the exhibition.

Excerpts from embroiderers’ accounts of their work for the project include:

Devastating: *“This was one of the most challenging embroidery projects I have ever done. For me, it was all about time, emotional power and the mental and physical endurance of stitching the thread in and out, day in, day out. It affected my understanding of what it must be like to live with epilepsy... I used the ultraviolet sensitive thread across the entire testimony, not only so each word can be read in all strengths of light, but also to highlight the significance of every word and every moment in life.”* (Helena Baker)

Invisible: *“I was given words by the mother of a son with epilepsy. There were so honest, so heartfelt; I was determined to respect her experience... My word for the back was ‘invisible’. I created a small black set of tight running stiches, like a tattoo, with a flourishing finish so it*

²¹ Scientist, CANDO project team.

would sit on the nape of the wearer's neck. I imagine that with long hair they could again render themselves anonymous, invisible. But I also covered the entire back of the gown with fluorescent pen, free-writing the word over and over so it would shine out, like the spirit of the mother and her son." (Sarah-Cate Blake)

Darkness: *These are my partner's words about his epilepsy. My first thoughts on reading them were of a train inside a tunnel, the smoke clouding and confusing everything, and the feeling of release in the moments after it leaves the tunnel... I wanted the imagery to remain quite simple so that Mark's words were the focus of the piece. I used a basic black back stitch to achieve a solid line, and French knots for the river detailing."* (Catherine Gould)

Ambushed: *The word 'ambushed' is interesting. I thought about how you could be going about your daily life and then get trapped. It just happens; there's no avoiding it. I embroidered 'ambushed' very large; it's such a loud word and I wanted people to be able to read it and know what it says..."* (Lauren Cheetham)

Agitated: *"Tambour work is really hard to explain – it involves a simple chain stitch which is pulled through and twisted by a tambour hook. I wanted it to look like handwriting, and tambour work makes it look like a real chain. The text ended with 'I want my mum', which absolutely broke my heart; I left the long threads hanging down because my word for the back was 'agitated'."* (Isabella Thorpe)

Clusters: *"It was a fantastically visceral description of what an epileptic fit actually feels and even tastes like. With the stitching, I used the fluorescent thread to highlight particularly striking words and changed the colour every word to reflect the varied nature of a seizure. (Alexander Jordan)*



Students from Royal School of Needlework with artist Susan Aldworth. Photo: Susan Aldworth

'Out of the Blue' Artist's Book

***"Many thanks for the Artist's Book. I read it from cover to cover... Gut-wrenching but so sensitively compiled, as was the radio programme. As someone living with epilepsy it encapsulated all my emotions and feelings around the condition perfectly. This experience has, at long last, made me come to terms with the condition and be at peace. I no longer feel like a misfit or a freak. I have you to thank eternally for this."*²²**



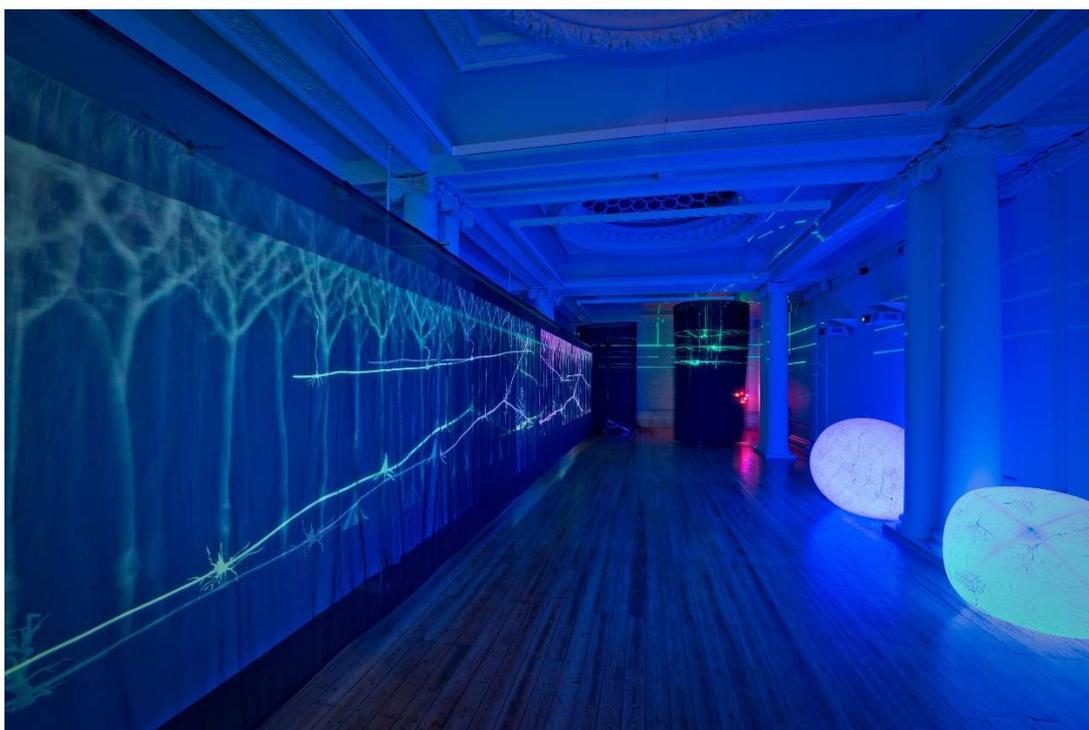
Artist's Book, 'Out of the Blue', Susan Aldworth. Photo: Colin Davison

Susan Aldworth's Artist's Book 'Out of the Blue' was produced in an edition of 15 copies. The book contains 120 pages of text and images, including the full testimonies written by contributing writers about their experiences of living with epilepsy, as well as two original cyanotype prints, made especially for the project. The book also contains 62 photographs of the embroidered Victorian garments from the 'Out of the Blue' installation, some of which are modelled by students from the Royal School of Needlework who embroidered testimonies.

²² Email to Artist Susan Aldworth from a contributor to 'Out of the Blue' at the Hatton Gallery

Andrew Carnie: 'Blue Matter'

"Andrew has made a large-scale new film, 'Blue Matter', which immerses the visitor in an imagined landscape of the brain. Visual metaphors are created through a combination of drawing and computer animation. Silhouettes of the brain emerge as beautiful and powerful, yet at the same time mysterious and enigmatic. Tree-like forms move and shift mesmerically; jagged lines intermittently cut across them like activity in the brain disrupted by a 'seizure'..."²³



Left: 'Blue Matter', Centre: 'Storm Level: Fair Isle', Right: 'Sounding the Blue', Andrew Carnie, Hatton Gallery, Photo: Colin Davison

Andrew Carnie's large-scale film, 'Blue Matter' immersed the visitor in an imagined landscape of the brain, with visual metaphors created through a combination of drawing and computer animation. Interventions within the landscape alluded to the science and raised questions over the dilemma of interfering with such beauty, reflecting the artist's interest in the application of optogenetic technology beyond the CANDO project: "optogenetics research using light to control cells in living tissue may have an impact beyond epilepsy and upon us all".

Andrew Carnie on 'Blue Matter'

"Blue Matter is a large-scale video piece – it's projected onto two layers of black voile with a white screen at the back. It gives a strange and eerie spatial effect of falling into a kind of world, of being mesmerised... and it slowly dissolves between one work and the other. Most of it is hand drawn – it includes a few photographs of trees that I took where I live in Winchester,

²³ Lucy Jenkins, Curator's Essay, 'Illuminating the Self'.

and the surrounding area where there's a lot of mistletoe – and I thought they were analogous to the epileptic centre, this focal epilepsy in the brain - they reminded me of something going awry and I like that side. I use those as a kind of metaphor going through the video, of it being controlled or contained, but difficult to contain... it's about an adventure into our own brains in a way, and a reflection on that and the space, about us not really knowing. Each of the trees is isolated from the others and they float around the space and it seems to be a kind of metaphor for the science – we don't know a lot, we don't know about the connections – we know bits, but the totality we don't understand. It has a mesmerising effect to it, of not understanding but being in a different world, which I think our brains are – they're another world that we don't really know.”²⁴

Also shown at the Hatton was a series of sculptures by Andrew responding to the disruption and balance during an epileptic seizure, when the natural rhythms of brain activity are disturbed, and the equilibrium the CANDO project is seeking to restore. The sculptures involve different objects in changing states - meteorological balloons, illustrated with brain cells, inflate and deflate, and the lines of light from laser levels are broken and fragmented. In each case, the change is triggered by the sound or movement of exhibition visitors. A still state is unsettled before a period of calm returns.



'Sounding the Blue', Andrew Carnie, Hatton Gallery. Photo: Colin Davison.

“...I also have some weather balloons that I've been drawing on and again they'll be in a sense a sort of stasis, of settled-ness, that will then be disrupted by a fan going on and one of them blowing up, going off and then settling into a kind of normal.”²⁵

²⁴ Andrew Carnie, Artist.

²⁵ Andrew Carnie, Artist.

'Illuminating the Self' exhibition: Vane

1988 people visited 'Illuminating the Self' at Vane Gallery, Newcastle over the period 16 January to 29 February 2020. The preview took place on Wednesday 15 January and was attended by 80 people.

"I was just spellbound by it all. A wonderful exhibition. Certainly made me think a lot more about epilepsy."²⁶



'Crack of Light' and 'In Praise of the Scope', Andrew Carnie, Vane. Photo: Colin Davison.

'Illuminating the Self' at Vane Gallery included a combination of old and new prints, and sculptural installations made individually and collaboratively by Susan Aldworth and Andrew Carnie.

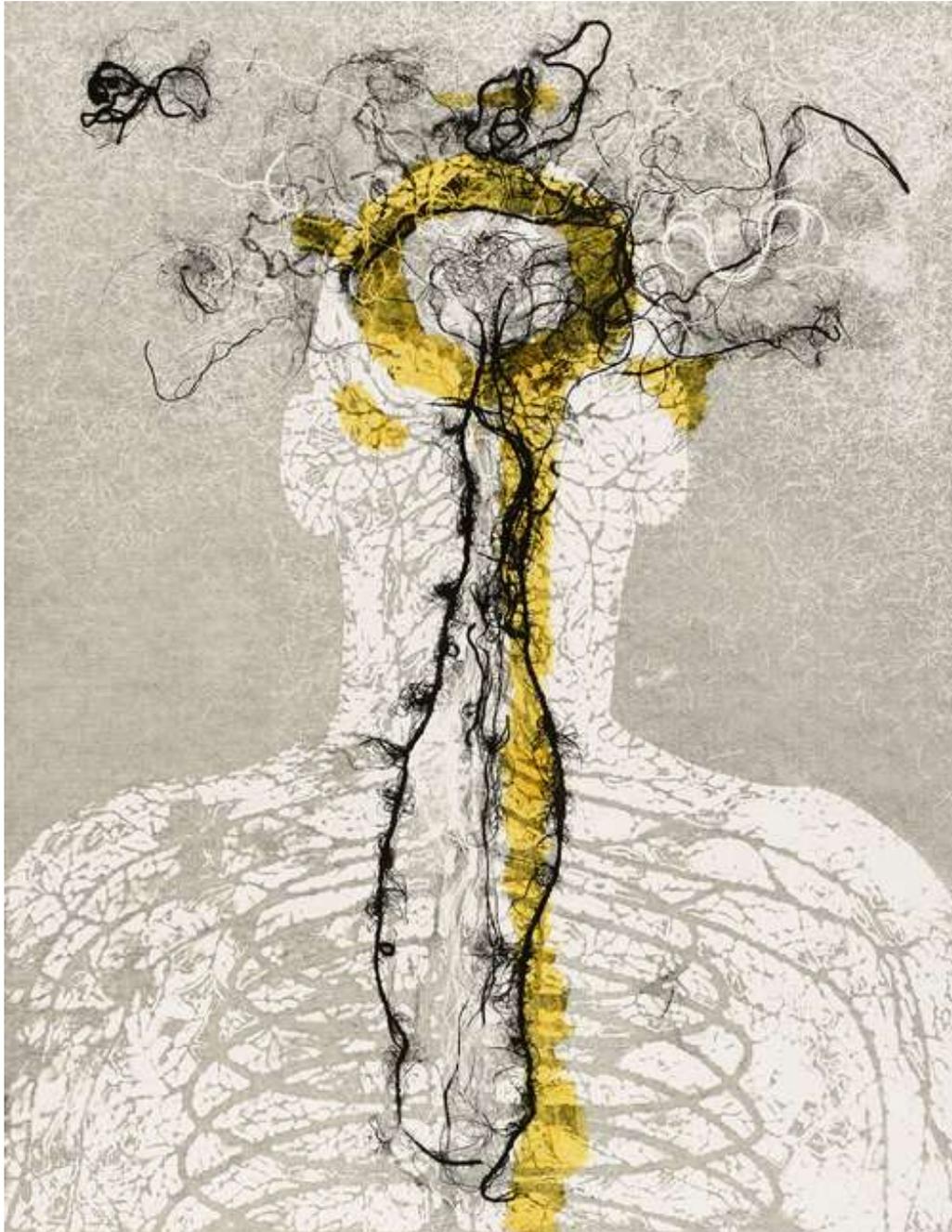
"It was a wonderfully positive experience to be part of the CANDO project, both through hosting the 'Illuminating the Self' exhibition at Vane gallery as well as contributing to some of the many outreach projects that assisted in communicating its aims."²⁷

The 'Enlightened' suite of monoprints was produced jointly by the two artists in 2015 to explore more general ideas around optogenetics and how external manipulation of the brain

²⁶ Visitor to 'Illuminating the Self' at Vane Gallery.

²⁷ Paul Stone, Director, Vane Gallery.

might alter our sense of self. The prints were the first response to examining the early research of the CANDO team at Newcastle University and were the trigger for 'Illuminating the Self', first connecting Susan and Andrew to the CANDO project.



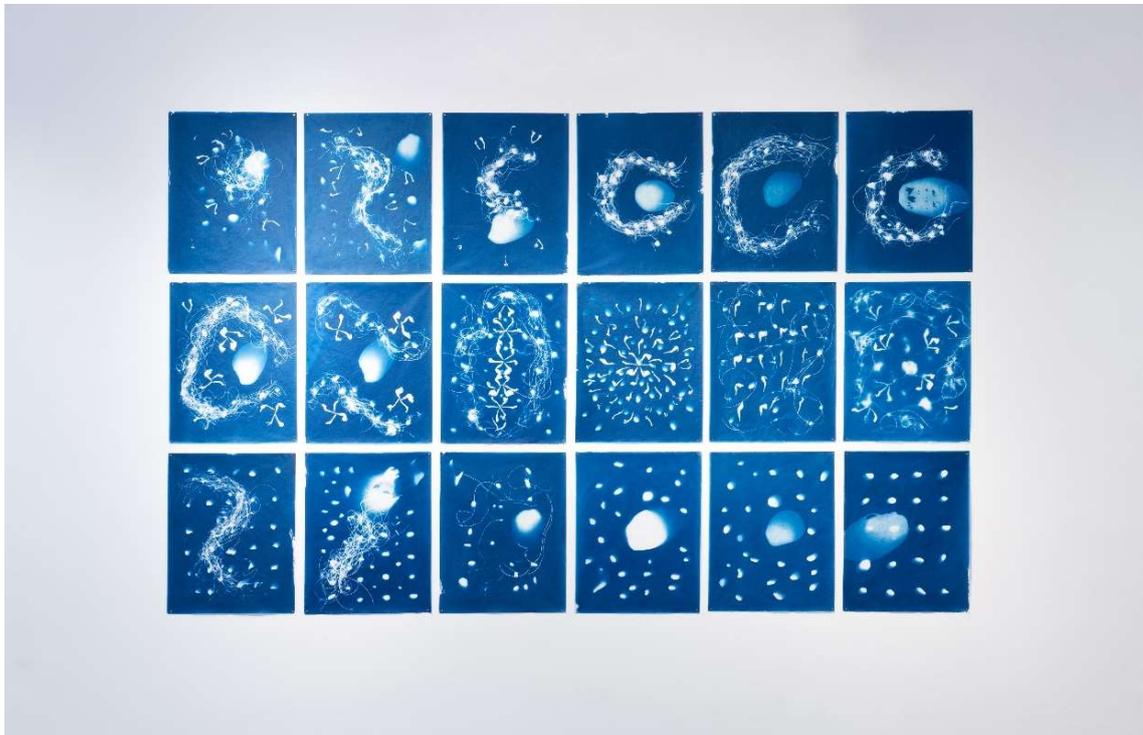
Print from the 'Enlightened' suite, Susan Aldworth and Andrew Carnie, 2015.

"In this work, Carnie contributes a human setting, a sense of self as viewed through science, while Aldworth portrays the workings of the brain through delicate and urgent line work – a thought happening or a neuron firing."²⁸

²⁸ Vane gallery exhibition information.

Susan Aldworth's 'Out of the Blue'

The 'Out of the Blue' series of prints (2019) echo the patterns and shapes of brain activity during an epileptic seizure. The works were made using the cyanotype process, a historic photographic technique that produces a cyan-blue print, a process used by architects and engineers well into the 20th century to produce blueprints.



'Out of the Blue', Susan Aldworth, Vane. Photo: Colin Davison

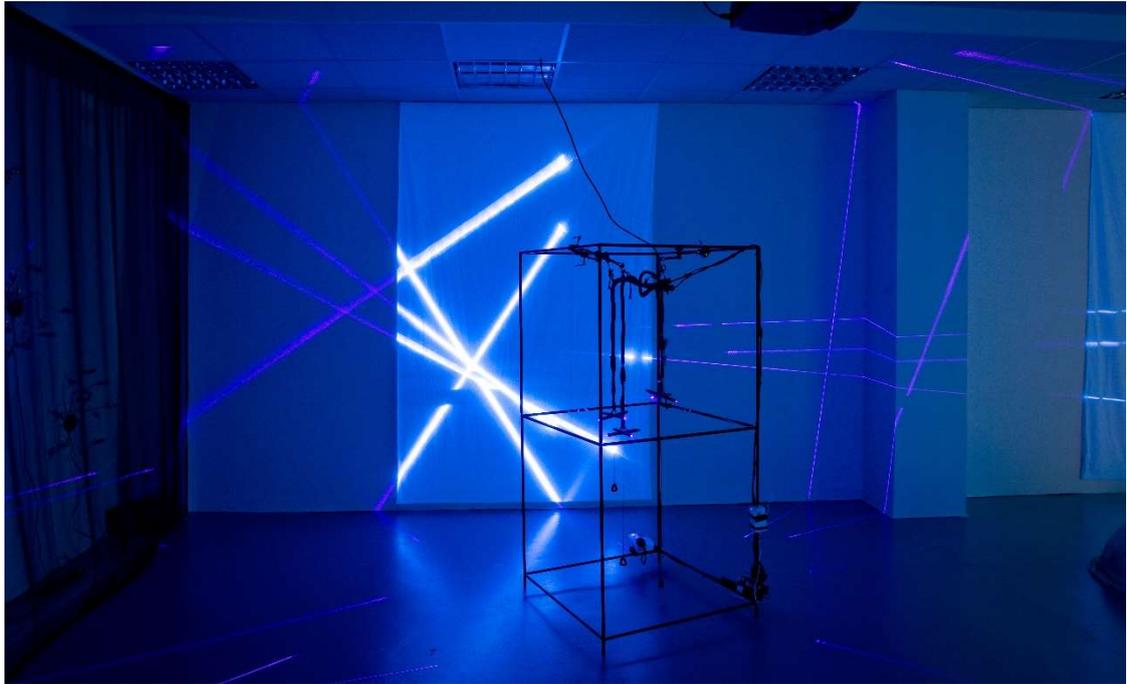
"The cyanotypes are made using ultraviolet light, a process which mirrors the use of light in the optogenetic therapies being developed by the scientists. These prints explore, through pattern, the synchronisation that occurs in the brain during an epileptic seizure."²⁹

Andrew Carnie's Abys (2019) was one of a series of kinetic sculptures triggered by visitors as they walked through the exhibition, reflecting on the nature of epilepsy and balance and stability, and how this can be interrupted and realigned.

"... I bought all these sets of devices and things I was going to work with, and I was quite interested in this notion of level, of coming back to normal. Every so often, a fan and a soundtrack disrupt the situation and the fan blows the voiles and disrupts and puts into a wave the normal level of the lasers, and when the fan goes off, it quietens down and goes back to level. And in the space, no one quite knows where the sensors are that switch things on and off, so there's this sense of mystery – a kind of understanding of the relationship that would be in people's brains, of not really understanding what goes on and when it goes on, because the algorithm is set by a group of scientists outside them... The role of the audience is critical, as they form a part of the work triggering some of the sculptures' actions. While focused upon the CANDO research, epilepsy is not an isolated condition, its effects are social as well as

²⁹ Susan Aldworth, Artist.

*medical. While the optogenetics research using light to control cells in living tissue may have an impact beyond epilepsy and upon us all.*³⁰



'Abys', Andrew Carnie, Vane. Photo: Colin Davison.

Susan Aldworth's *The Portrait Anatomised*, 2012 were depictions of three individuals with epilepsy originally displayed at the National Portrait Gallery.

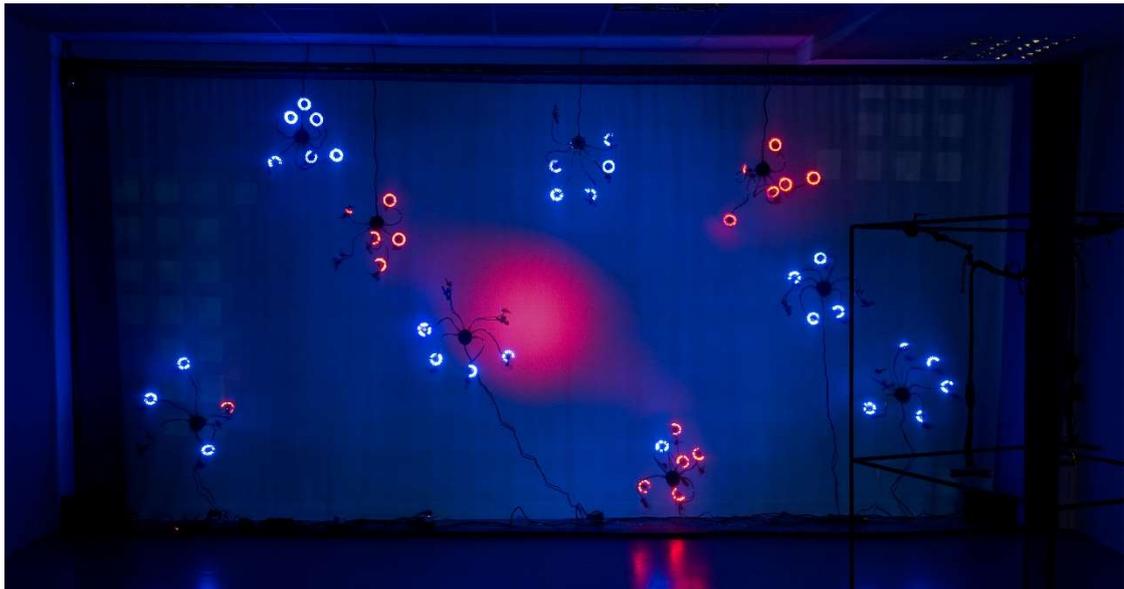


'The Portrait Anatomised: Max and Fiona', Susan Aldworth, Vane. Photo: Colin Davison.

³⁰ Andrew Carnie, Artist.

“Questions about personal identity fascinate me. It seems fragile – we might feel a strong sense of who we are at any one moment, but the more you try and make sense of some fixed notion of personal identity over a life time the more it seems to unravel. The challenge is for a portrait to recognise this.”³¹

Andrew Carnie’s video work, *A Tale of Two* (2019), consisted of a series of ‘bouquets’ of USB programmable word fans, each with texts in blue and red that reflected different aspects of implants and implantation. The texts partly referred to documents on the legal, ethical, and emotional aspects of implantation, and partly derived from texts on ‘Everyday Cyborgs’ – people with attached and implanted medical devices such as artificial joint replacements, pacemakers, total artificial hearts, and limb prostheses – as well as Carnie’s own writing.



Andrew Carnie, ‘A Tale of Two’, Vane. Photograph: Colin Davison.

Visitor feedback for ‘Illuminating the Self’

35 people completed visitor feedback forms for ‘Illuminating the Self’ at Vane Gallery. Visitors rated their responses to two questions about ‘Illuminating the Self’ at Vane on a scale of 1 to 5 (where 1 was ‘not at all’ and 5 was ‘very much’):

The mean average score for the exhibition improved my understanding of the experience of persons living with epilepsy was 3.97.

The mean average score for the exhibition caused me to think about issues relating to epilepsy and other neurological disorders in new ways was 4.09.

When asked what visitors found most interesting or surprising about the exhibition, responses included:

“The work was very moving and beautiful as well as being thought-provoking. The two artists’ work meshed well together whilst still being highly distinctive.”

“The variety and skillful/creative application of ideas in so many visual forms.”

“The combination of spiritual imagery, scientific imagery and portraiture. It was truly beautiful. The thought process behind medium (cyanotype in particular) is inspiring.”

“Electric power used in the installation art, flashing lights and lasers. One amazing, creative show.”

“The dynamics of the installation and my impact on it.”

“The concept of light being used to change neuron activation and how to put that into therapeutic practice.”

“The dark room, how the use of lights are linked to the effects of epilepsy.”

“I was moved and interested by people’s individual experiences of epilepsy.”

“The artists connect this work, rafting with the CANDO project and shows their own understanding to disease and moral implications.”

“The installations made by Andrew. It’s quite interactive and thought provoking.”

“The interactivity.”

“The beauty.”

“I enjoyed how the lights had sensors to your footsteps.”

Schools' engagement

181 pupils (aged between 13 and 19 – Years 8, 9 & 10) and 12 teachers from six schools engaged with CANDO workshops led by artists and scientists.



Student embroidery work. Photo, Michael White

“Students enjoyed working on the project and feedback was positive. We found it to be a be a very informative and refreshing approach to creating work...They gained insights into research into research being carried out into epilepsy which will hopefully give them a greater understanding into the work that research scientists undertake.”³¹

³¹ Art Teacher/Vocational Course Leader

Artists Melanie Kyles and Nick Christie worked with CANDO research scientists to design and deliver workshops for six schools across the region: Moorbridge Pupil Referral Unit (PRU), Shiremoor; Heworth Grange School, Gateshead; St Mary's Catholic School, Longbenton; Cardinal Hume Roman Catholic School, Gateshead; The Duchess's Community High School, Alnwick; and Ashington Academy, Northumberland. Workshops took the form of a talk or discussion and practical activity linked to the science and engineering behind epilepsy and optogenetics, followed by an artist-led workshop for students to explore the project themes through two main arts processes – printmaking and embroidery.

“Historically, embroidery has been loaded with symbolism, from storytelling tapestries to political statements via painstakingly embroidered banners... The practical part of this workshop teaches students how to embroider onto card and work with existing imagery, in this case MRI brain scans... The act of hand embroidering and spending time creating a personal response to the project helps to generate more empathy and understanding with what it is like to live with epilepsy, as well as providing a voice to students who have or are close to someone living with the condition.”³²

“I found leading the printmaking workshops for the CANDO project to be an enriching collaborative experience. While guiding the participants through the stages of the art making process, I got to see them organise and express the pieces of information that they had picked up during the scientific lectures like the pieces of a puzzle. Using the light sensitive photography technique of cyanotype, the workshop participants made drawings inspired by neurones, cells and other imagery provided by the CANDO scientists. Getting the students to understand this process coupled well with their new knowledge of the light sensitive implants being designed by CANDO.”³³



Practical activity, making neurons. Photo: Susan Priestley.

³² Melanie Kyles, Artist.

³³ Nick Christie, Artist.

Feedback following the workshops from 103 students and four teachers clearly shows the benefits gained:

- **Students gained new awareness and learning about epilepsy.** The majority of students knew nothing or very little about epilepsy before the sessions, with most knowing only that epilepsy causes fits and that it is affected by light. Students said that the most surprising things they had learned about epilepsy were: that there are 6 different kinds of epilepsy; 1 in 100 people are affected; it's not contagious; around 600,000 people in the UK are affected; and that it is caused by abnormal brain activity resulting from head trauma, brain damage and genetic disorders.

*"There were lots of great outcomes: they (the students) learnt a lot; most grasped the science although some struggled to translate the scientific concepts into a creative visual image at first; and everything was well explained and there were well-paced activities."*³⁴

- **Students enjoyed the science and art links and enjoyed the activities.** When asked what they had enjoyed most about the sessions, responses included:

"I enjoyed using what I have learnt and creating a piece of art which represented my understanding of it."

"I enjoyed making a model of a neuron."

"I enjoyed learning about the condition and responding creatively."

*"From drawing a rough line of their chosen image, to taking a print from the inked up block, the students were able to express their own opinions and feelings about the subject that they had just learnt so much about."*³⁵

- **The sessions encouraged new thinking and discussion around the question "What do you think about the technology being developed by the project?"** Interestingly, student responses to this question were much more considered and cautious than adult responses across the programme, but this could have been because the school sessions explored the topic in more depth and so the students were better informed.

"Useful for the prevention of seizures but not for everyday tasks".

"I think it will be good for the world and hope it's successful."

"I think that it is good but will take a lot of the world powers' time and focus and that is not easy to get. I believe it should only be available to those who medically need it."

"It is interesting but scary and controversial."

"It's good but what if it is hacked?"

"I think it's very good and useful but we can't let technology take away basic human characteristics."

- **The sessions have left a legacy in relation to future teaching and learning in schools and new ways of working for artists.** The learning gained from the sessions was not limited to

³⁴ Teacher, St Mary's Catholic School.

³⁵ Nick Christie, Artist.

students, but also extended to teaching staff, some of whom said the topics explored and processes used would inform future areas of learning.

“I as a teacher learnt a lot about the science behind the CANDO project and cross-collaboration of subjects. The techniques demonstrated of lino and cyanotypes furthered ideas about how these could be developed in the department in the future.”³⁶

“The main highlight of the project was the opportunity to cross-collaborate with current scientific research... I found it personally very interesting, and it challenged me to apply my creative skills in a way I wouldn't typically work...”³⁷

During our linocut sessions, it was great to see so many variations and exciting prints on the theme of epilepsy. Every student got stuck in and carved their own printing block by hand. Overall, I like to think that those coming to these art making workshops had an avenue through which to engage with a subject which is still very experimental. I also learnt a great deal about the benefits of learning through making”.³⁸

³⁶ Teacher, St Mary's Catholic School.

³⁷ Melanie Kyles, Artist.

³⁸ Nick Christie, Artist.

Impacts and Outcomes

“(What I found most interesting about the exhibition) was the successful links between the concepts of art and science. Extremely thought provoking.”³⁹

Consultation for this report has drawn responses from across the broad range of people who have engaged with the programme as audiences and contributors, including: artists, scientists and others involved in the wider CANDO project delivery; visitors to the exhibitions at the Hatton and Vane Galleries; audiences for the Operating Theatre performances (physical and online); and participants in workshops, talks and events, including schools and community groups. Whilst levels of activity and therefore audience feedback in the latter months of the programme have been affected by Covid19, the data and information collected from audiences, visitors, participants and project contributors up until March 2020 highlight a number of clear outcomes and achievements.

The project has reached new audiences for science. Visitor and participant feedback and consultation with the CANDO project team suggests that the key objective of the engagement programme ‘to engage with harder-to-reach audiences who may not be drawn to conventional public science events and coverage’ has been at least partly met. Activities and events have reached a broad audience across a variety of venues, including galleries, churches, schools, libraries, public and community buildings, which has encouraged and facilitated engagement from people with a varied starting point in terms of prior knowledge of science, epilepsy and the wider themes and issues of the CANDO project.

“I think we did better with some audiences than others. There was a lot of interest from, say, older retired people... I had great fun talking to the Horsley Women’s Institute who I don’t think usually talk about brain implants.”⁴⁰

“I don’t know what the usual reach is for engagement, but I did attend outreach events (particularly printing and craft workshops) which went into schools and to pensioner groups who I imagine would not usually be reading scientific journals.”⁴¹

“I think the schools’ workshops certainly reached an audience that would not engage with science or go to theatres or galleries. From that perspective, getting them thinking about the brain, epilepsy and implants has been most successful.”⁴²

Public awareness of epilepsy has increased. Levels of awareness and understanding of epilepsy have varied enormously across the programme, from people with epilepsy or with connections to the condition through family and friends, to people with some basic knowledge, and others with no awareness at all.

³⁹ Visitor to ‘Illuminating the Self’ at Vane Gallery.

⁴⁰ Andrew Jackson, Professor of Neural Interfaces, Newcastle University.

⁴¹ Frances Turner, CANDO project team.

⁴² Michael White, CANDO project team.

Of 84 people who completed evaluation feedback forms across the exhibition at Vane Gallery and the Operating Theatre performances, around 45% said they had had no understanding of/personal connections to epilepsy before their visit/attendance.

*"Nephew died from epilepsy age 21. He was 17 when he had his first seizure."*⁴³

*"I understand it but have no close personal connection."*⁴⁴

*"I only know that they cause seizures."*⁴⁵

*"Everyone in the group has witnessed someone having a fit – they felt scared. Some students have epilepsy... (Engagement with the project) definitely made some of our tutors/helpers more aware."*⁴⁶

8299 people have directly engaged with the CANDO exhibitions, performances, workshops and events, but the project has reached out and informed many more people through: extensive information on the CANDO, Hatton and Vane websites; the films by filmmaker Alan Fentiman documenting the project and the making of the work, which have been available to view on the CANDO website; through social media – an Instagram Takeover delivered through North East Contemporary Arts Network (CVAN) resulted in 1859 interactions; and press and media coverage, including the Radio 4 programme, *Art of Now: The Algorithms of Epilepsy*, which attracted an audience of between one and two million and drew powerful feedback from listeners.

*"Last year I lost my eldest son to this debilitating little understood illness... I accidentally (serendipity) caught the Radio 4 programme 'Art of Now' and sat and listened in a Sainsbury's car park with tears rolling down my cheeks... Listening to the programme was so moving. I hadn't realised how he must have suffered, being a man, he didn't talk about his feelings but the testimonies in the programme were so moving and it made me wish I had realised how difficult some things in his life were... It was a painful but enlightening listen."*⁴⁷

The project has increased knowledge and understanding of epilepsy. The breadth and scope of the programme has allowed for 'layered learning', with opportunities to simply enjoy the visual elements of the exhibitions and/or performances, or to dig deeper through gallery talks and interpretation, post-performance discussions, 'meet the scientist' events, combined science and arts workshops, and the media and other coverage exploring epilepsy and the CANDO research. Feedback from across the programme indicates that most people have gained new knowledge and understanding and/or have thought about epilepsy in new ways, regardless of their starting point: people with epilepsy have reported gaining greater understanding and/or acceptance of their relationship with the condition; friends and relatives have fed back that they have gained new insights into epilepsy and how it has affected/affects the lives of their loved ones; public feedback from visitors, audiences and participants shows evidence of new knowledge about epilepsy; and children and young people, the majority of whom had only the most basic awareness, have gained significant new knowledge about the condition.

⁴³ Audience member, 'Making for the Light'.

⁴⁴ Visitor to 'Illuminating the Self' at Vane Gallery.

⁴⁵ Student, Cardinal Hulme Catholic School.

⁴⁶ Fullwell group

⁴⁷ Listener to 'Art of Now: The Algorithms of Epilepsy', BBC Radio 4

When 84 people across the engagement programme were asked to rate the statement *“The exhibition/performance/event caused me to think about issues relating to epilepsy and other neurological disorders in new ways”* on a scale of 1 to 5 (where 1 is not at all and 5 is very much) the mean average score was 3.5

“I’ve gained a greater understanding of the diversity of ways in which epilepsy affects lives.”⁴⁸

The project has given a voice to people living with epilepsy. People with epilepsy have played a key role in the development and presentation of ‘Illuminating the Self’: by liaising with the team of scientists and creatives over the course of the project in an advisory capacity; as contributors to the development of the Operating Theatre film and performance work, as well as post-performance discussions; by contributing their testimonies to Susan Aldworth’s work for the Hatton Gallery, ‘Out of the Blue’; and as audiences for the project outputs. Comments and feedback from people with epilepsy or with connections to the condition shows the extent to which the project has affected and/or impacted on them.

“I just wanted to give my thanks for being able to participate in this project. I’m an artist with epilepsy... It was so exciting to actually talk about epilepsy. There was always something that was being stigmatised and sort of like in the background, like, I really resonate with what Susan said about the underwear because you’re always wearing it but it’s not a part of your exterior. So, on a personal level, this helped me start talking about my experience with epilepsy and I’m finding it to have a lot of value to others. I want to thank you for that empowerment.”⁴⁹

“Some of those who wrote their stories for the embroidery have told me that this was the first time they had talked about their epilepsy in public. And they found it liberating. This was a wonderful and unexpected outcome.”⁵⁰

“I think for some people with epilepsy who were involved or engaged, especially with the art, it gave them confidence that they are not alone, and for family members it helped give an appreciation of what their relatives are going through.”⁵¹

“For patients and families of people with epilepsy to see how much research and effort is going into finding better treatments was encouraging for them. I think certainly many people... have learnt for the first time about cutting-edge technologies.”⁵²

The cross collaboration between science and arts has enabled people to explore the scientific research being undertaken by CANDO in new and more accessible ways. The focus of epilepsy for the engagement programme has been an effective ‘hook’ to draw people into wider discussions about use of new technology to improve the lives of people with epilepsy and other neurological conditions. The collaboration with art and artists has further enabled this discussion by making science more accessible, both to a broader audience and in terms of supporting deeper understanding.

Visitors to the exhibitions and audiences for the performances have unanimously agreed that *“arts projects can influence our understanding of science.”*

⁴⁸ Audience member, ‘Making for the Light’

⁴⁹ Artist contributor to ‘Out of the Blue’.

⁵⁰ Susan Aldworth, Artist.

⁵¹ Michael White, CANDO project team.

⁵² Fiona Le Beau, CANDO research team.

When 84 people across the engagement programme were asked to rate the statement: *“The exhibition/performance/event improved my understanding of persons living with epilepsy”* on a scale of 1 to 5 (where 1 is not at all and 5 is very much) the mean average score was 3.3

“Makes the science more accessible but importantly helps to explore the emotional, ethical and philosophical research raised by scientists.”⁵³

“Combining art and technology together has always interested me. Really brings the project to life.”⁵⁴

“Absolutely, it can help to make theoretical concepts a lot easier to understand...”⁵⁵

“Yes, much more than reading a leaflet.”⁵⁶

“Artists can make abstract, mathematical, often clinical aspects of science more visual. They come with a different language – creates an extension to scientific language.”⁵⁷

“I think that art has an ability to engage people with topics that they might typically struggle with, so it was an honour to be one of the chosen artists to work as part of the CANDO team, knowing that my working style has the ability to help communicate these messages and engage with a wider audience.”⁵⁸

Discussion and debate took place across the programme: as part of the Operating Theatre performances; for the wider public through the ‘meet the scientist’; events and the exhibitions, supporting films and information; and with schools and community groups within workshops and activities. To ascertain thoughts and feedback, the question *“What do you think about the technology being developed by the (CANDO) project?”* was asked of visitors and participants as part of the evaluation process. There was overwhelming support and interest for new technology to make a difference to people living with epilepsy. The majority of responses were wholly supportive, using words like *‘Brilliant’*, *‘Mind-blowing’*, *‘Impressive’* and *‘Amazing’* to record their responses, with only a minority saying they were *‘unsure’* or *‘don’t know’*.

“A fantastic development. A true breakthrough.”⁵⁹

“Thank you for this opportunity and for the full and frank discussion. Some important neural, ethical and practical issues raised.”⁶⁰

“I think it’s great but there are some moral concerns about it.”⁶¹

“I thought all of the different opportunities were interesting.”⁶²

However, there was more concern about the potential wider use for brain implants over time for non-medical conditions, such as to enhance sporting or other abilities with, interestingly,

⁵³ Audience member, ‘Making for the Light’.

⁵⁴ Visitor to ‘Illuminating the Self’ at Vane Gallery.

⁵⁵ Visitor to ‘Illuminating the Self’ at Vane Gallery

⁵⁶ Audience member, ‘Making for the Light’

⁵⁷ Participant, Lifelong Learning workshop

⁵⁸ Melanie Kyles, Artist.

⁵⁹ Visitor to ‘Illuminating the Self’ at Vane Gallery.

⁶⁰ Audience member, ‘Making for the Light’.

⁶¹ Visitor to ‘Illuminating the Self’ at Vane Gallery.

⁶² Student workshop participant.

students taking part in the schools' workshops being more cautious about the wider implications of brain implants.

"I think it is good but will take up a lot of the world powers' time and focus and that is not easy to get. I believe it should only be available to those who medically need it."

"Keep searching for cures, but the sport, etc. technology is pointless and encourages laziness."

"It's good, but what if it is hacked?"

"It will be beneficial to people who really need it. However, it's scary to think that people could use it just to serve their own needs."

Different responses to the CANDO research from Susan Aldworth and Andrew Carnie have supported and informed this discussion: Susan's work has very much explored the human side of epilepsy and its impacts on people's lives, through the research and the practical making of 'Out of the Blue'; whilst Andrew wider exploration of the brain, the technology being developed by CANDO, and the ethics and implications of that technology.

"It's been very complementary to have Susan's work and more of the personal experience from the point of view of the patient, and then Andrew's work which is looking more at the technology and the implications of that technology."⁶³

The engagement programme has resulted in in-depth and authentic knowledge exchange between scientists, artists and others contributing to the activities. All project contributors across arts and science have fed back that the experience of working together and sharing knowledge and expertise has been valuable and positive.

"I had a few coffee chats with the artists and Operating Theatre, mainly at the beginning of the collaboration, as they were trying to understand the various aspects of the CANDO project. I work on the brain implant design and fabrication team, and the artists were interested in how we go about designing and producing the devices. The visual artists were especially interested in our design sketches and technical drawings, and it gave them ideas to incorporate into their work."⁶⁴

"The experience of working with the artists and Operating Theatre has been overwhelmingly positive. They have brought a fascinating discourse to the research and helped raise awareness of the wider implications... Working with them has also provided me with a different way of thinking about communicating and engaging with science and engineering"⁶⁵

"One of the main highlights has been the intense and many collaborations I made during the project which facilitated making 'Out of the Blue'... My collaboration and conversations with project scientists on many occasions in great depth, and the breadth of the disciplines involved in the CANDO project led to some fascinating research."⁶⁶

⁶³ Scientist, CANDO project.

⁶⁴ Scientist, CANDO project

⁶⁵ Michael White, CANDO project.

⁶⁶ Susan Aldworth, Artist.

Summary and Legacy

“I hope the long-term legacy is that people are more informed, which will be increasingly important as neurotechnology becomes more ubiquitous in our lives.”⁶⁷

The CANDO engagement programme has left a lasting impression on visitors and audiences, participants and professionals and a strong legacy for the future, including:

The project leaves an increased public awareness and understanding of epilepsy. Without doubt, the strongest legacy of the project is the enormous amount of increased public awareness and understanding of epilepsy and the wider scientific research being undertaken into the brain and implants. The exhibitions, performances, workshops and events directly engaged with over 8000 people of all ages and abilities, and the press, online and social media coverage, particularly the Radio 4 interview with Susan Aldworth, reached millions more. Visitor and audience feedback has been overwhelmingly positive in terms of enjoyment of what people have seen and done, but more importantly, the ways in which the programme has made them more aware of epilepsy, how many people are affected by the condition, the impacts it has on people’s lives, and the technologies being developed to help them.

The project has generated new audiences for science. The exhibitions, performances, workshops and events have engaged people in areas of science they knew little or nothing about prior to their engagement. Visitor comments clearly evidence the success of the programme in melding the science and art to generate new interest in and understanding of epilepsy and the neurotechnology being explored through the work of the CANDO project.

“Art, unlike medicine, can’t cure people, but it can raise awareness and open minds. I think we achieved this through the artworks.”⁶⁸

“Successful links between the concepts of art and science. Extremely thought provoking.”⁶⁹

The knowledge exchanged between scientists and artists over the course of the project will contribute to working practice on an ongoing basis. Shared learning and knowledge exchange has been at the heart of the CANDO engagement project, with the information and understanding shared between scientists, artists and performers forming the foundation of the works created. The learning on both sides has been considerable and leaves a strong contribution to future work and working practice across science and the arts.

“The engagement project has given us a lot of ideas that can feed into other epilepsy-related projects... I would like to develop an independent scientist career in epilepsy research in which I will work with sensitive human tissue. I will take what I have learned and channel this into

⁶⁷ Andrew Jackson, Professor of Neural Interfaces, Newcastle University.

⁶⁸ Susan Aldworth, Artist.

⁶⁹ Visitor to ‘Illuminating the Self’ at Vane Gallery.

future public engagement events I would like to hold with families and children suffering from early onset epilepsy.”⁷⁰

“I think the project has helped raise awareness and understanding of the arts by scientists by demonstrating how artworks can communicate complex science to the public and help with their understanding of a new technology or treatment, as well as understanding the research process.”⁷¹

The project has made a significant contribution to teaching and learning at all levels, which has the potential to extend well beyond the project lifespan:

- The workshops in schools introduced both students and teachers to scientific research and the new technologies being developed to treat epilepsy, as well as new practical arts skills they can continue to use in the future, both in and out of school. In addition, the online teaching resources produced by Operating Theatre to support the themes and topics explored in the ‘Deep Mind’ performance will remain available to teachers through the CANDO website.

“The work undertaken will contribute their GCSE coursework. Students were able to gain experience working with new materials and techniques and working with a practising artist. They gained insights into research being carried out into epilepsy which will hopefully give them a greater understanding into the work that research scientists undertake. They will be able to apply their knowledge of the brain functions to their GCSE science coursework.”⁷²

- The collaboration between Susan Aldworth and the Royal School of Needlework played a key role in the making of the ‘Out of the Blue’ installation and Artist’s Book and contributed to first-year students’ coursework. Feedback from participating students highlights the new awareness and learning they gained about epilepsy and the strong impact the project has had on them personally and in relation to their work.

“The words were incredibly powerful and moving; in fact, I cried the first time I read them. It was really important that they took centre stage...”

“I have very little personal experience of epilepsy and found this testimony very moving. I wanted to understand what having a seizure actually feels like and somehow to evoke this...”

The project has resulted in a strong body of artwork which reached a large and broad audience and has a life beyond the engagement programme. The messages conveyed by the exhibitions and performances were informed, accessible and clear, as evidenced by the evaluation feedback. The CANDO research themes will remain current and relevant for some time to come so there is scope to re-show works anywhere and reach even more people throughout the UK and beyond. For example, Andrew Carnie’s ‘Blue Matter’ is currently on

⁷⁰ Faye McLeod, Scientist, CANDO project.

⁷¹ Lucy Jenkins, Curator, ‘Illuminating the Self’.

⁷² Teacher, Cardinal Hulme School.

show as part of 'The World is in You' which runs until 16 January 2022 at Kunsthall Charlottenborg in Copenhagen.

"I think first and foremost we produced some really impressive, exciting and challenging pieces of art and theatre. I think these dealt sensitively and intelligently with some important areas of societal concern, and I think we raised awareness of epilepsy, how it can be treated, and some of the ethical issues presented by neurotechnology... I'm really hoping we can find a way to re-show some of the artwork once galleries start opening again..."⁷³

"Both artists created outstanding work that will have opportunities to be shown at other venues or exhibitions and continue to engage people with discussion of the CANDO project."⁷⁴

"The artwork and plays deserve another life, which will hopefully happen..."⁷⁵

The project leaves a significant bank of resources which have a lifespan beyond the project period. A wide range of resources were created to complement and/or support the 'Illuminating the Self' engagement programme, including: a large bank of photographs showing Susan Aldworth and Andrew Carnie's works in situ at The Hatton Gallery and Vane Gallery; films documenting the exhibitions and the artists' ideas, thoughts and working processes (<https://youtu.be/ndPbzHAhktM>); Susan Aldworth's Artist's Book, which presents the testimonies from people with epilepsy and/or those connected to them and the thoughts and responses of the people who embroidered the text onto the Victorian underwear; the Operating Theatre scripts, performances and the adapted and filmed 'Deep Mind' performance; and workshop formats and learning tools produced to support the formal learning activities in schools. Together, these all provide a valuable and ongoing bank of resources which have a long lifespan, as well as the potential, particularly with the digital works, to reach and be used by a broad range of people across a wide geographical area.

"The publication and film created about the project also provide a great legacy that means the project can be shared across the world digitally and with different types of audiences."⁷⁶

The project is a strong example of good practice in relation to a science/art delivery model which can be replicated by others and across other areas of science. Whilst cross-disciplinary science/art projects are not new, the CANDO project has been particularly successful in developing an authentic collaboration between artists and scientists that has long-term benefits for both areas of work.

"One of the main highlights has been the intense and many collaborations I made during the project, which facilitated the making of 'Out of the Blue'. Some of these have developed into long-term friendships and work collaborations."⁷⁷

"Hopefully, many researchers on the team have seen the value (and fun) of doing a large public engagement project in parallel to the science and so will consider such activities in the future."⁷⁸

⁷³ Andrew Jackson, Professor of Neural Interfaces, Newcastle University.

⁷⁴ Lucy Jenkins, Curator, 'Illuminating the Self'.

⁷⁵ Michael White, CANDO project.

⁷⁶ Lucy Jenkins, Curator, 'Illuminating the Self'.

⁷⁷ Susan Aldworth, Artist.

⁷⁸ Fiona Le Beau, CANDO research team.

Furthermore, there is clear evidence from the visitor feedback that the collaboration has successfully developed new public awareness and understanding, highlighting the strength of the model in disseminating research information to a broad and non-scientific audience. Visitor feedback suggests there is strong support for this delivery model – 86% of people completing feedback forms⁷⁹ said they agreed that *“arts projects can influence our understanding of science”*.

“(What I found more interesting about ‘Illuminating the Self’ was) the innovative collaborations making scientific research more accessible.”⁸⁰

“Knowledge and understanding help people to be listened to/informed to deepen their understanding of what the condition is and the need for more updated treatments.”⁸¹

“...Hopefully these types of interdisciplinary collaborations become more common. They work!”⁸²

⁷⁹ Sample size 91 forms.

⁸⁰ Visitor to ‘Illuminating the Self’ at Vane Gallery.

⁸¹ Audience member, ‘Making for the Light, Operating Theatre.

⁸² Enrique Escobedo-Cousin, Engineer, CANDO project.