Illuminating the Self: A Year On

Event Transcript

The discussion took place after a viewing of a documentary about the exhibition by Alan Fentiman. The film can be seen at [https:// youtu.be/ndPbzHAhktM](https://youtu.be/ndPbzHAhktM).

Lucy Jenkins: Great, well that was really wonderful to see that again and bring back the memories from a year ago, or just over a year ago, installing the exhibitions and really seeing the culmination of all that research and preparation.

If I can start with a question for Alan. As I think Fiona and Andy said towards the end of the film, there were two very different approaches that Susan and Andrew took and it was just to ask you, did you find it challenging to bring those two approaches together in a unified film?

Alan Fentiman: Oh, the short answer is yes.

Well, I mean it's really difficult, especially geographically but also financially in terms of trying to capture everything as it happens, and it was really interesting seeing how two artists approach this subject in a very different way. And with Andrew it was a very much slower process. Much more of a questioning approach and then Susan suddenly just went straight out the gate and she said "I've got this amazing idea" and I was just, I need to try to capture as much as I can. So in terms of editing it was quite difficult because there was an element that I missed.

Susan, you know, it would be interesting to hear your thoughts on this, where I would have loved to have been there to just sort of get captured that aspect of it. So yeah that was difficult, but I think everybody caught up in the end, and you know we've got two very different types of artwork. Does that answer your question?

Lucy Jenkins: Yes, thank you. I think you're absolutely right. They really do complement one another and explore the really varied nature of the project. The research that CANDO are doing and that lived experience of epilepsy.

And I think there is someone with their hand up. Is that Ushashi? Have you got a question?

Ushashi Basu: I've got two questions if that's okay.

Lucy Jenkins: Brilliant.

Ushashi Basu: So, my first question was that were the exhibition to open again and be open to the public what would you add to the collection?

Something that kind of addresses perhaps living in lockdown with epilepsy or something that addresses how difficult this past year has been for people with special needs and… Yeah, just what element would you add to the exhibition? For Susan and Andrew.

Andrew Carnie: I think that's quite a difficult question to answer, really. I'm kind of aware that I make work. It's driven from me, you know, in a sense, with this reflection on what's going on. So I think what's happened would have crept into it.

And, interestingly, I think that kind of notion of separation, of an audience, might have been really interesting to deal with that. That keeping apart might have been a really challenging part in a sense. I think in a broader sense just, you know, what would I have done a year later? I mean, you know, as soon as an exhibition goes up, in a way, you want to change it, you want to do something different. You know you reflect on it. It's a very complex thing dealing with spaces and time and all of these things. And you inevitably get things wrong.

What was really good there was how much went right, in a sense. I mean I think I alluded to buying equipment at one point. I bought whole sets of sound things, magnets and really I used all of them. Which was really satisfying in one way or another.

I don't know. Susan have you got ideas about the…

Susan Aldworth: Yeah, if the exhibition was to be restaged now, post lockdown, it would maybe be nice to go back to some of the people who wrote and some of the people who embroidered to see if we could add to the stories. You know this experience of the last year has been very strange and it's difficult to imagine.

I mean there were some technical problems with my exhibition when it didn't run smoothly all the time and I thought that was rather poetic because the glitches seem to me to reference the glitches in the brain of people living with epilepsy. And so, but I would like to have ironed those out. I'd like it to have run very smoothly so to have another chance to show it would be amazing. Whether we…

Mines quite, you know, the symmetry of it works very well. But if it's a different space, I could add more objects to it, and maybe bring in you know life. Life goes on, so the artwork can change as well.

Ushashi Basu: Right, thank you and my second question kind of just follows up on that. So this was the public engagement aspect of the CANDO project. I was wondering how the participatory experience is going to change when the exhibition happens again because we haven't been to a museum or an exhibition in a whole year and, like, how do you think people are going to interact with the exhibition a year later?

Andrew Carnie: What, this exhibition or any exhibition?

Ushashi Basu: This one.

Andrew Carnie: I mean I think it's all changed hasn't it? It's kind of really exciting about the notion of going back and things. I mean I had another exhibition in the middle of lockdown when things opened up and that was a very curious thing. It didn't work in the same way because the audience were, was reduced and very cautious about everything. And I think that's going to be one of the aspects about how people approach it now, after all this. You know I feel a lot quieter. I feel like I don't really want to go out that much, but we'll see.

Susan Aldworth: And the art world is in a strange flux. Funding is all over the place. You know artists aren't centre stage, quite understandably, during a pandemic. So if things do open up, I mean, you know I dream of going to exhibitions.

I'll run in and scream, I think. Maybe we should have a screaming session first. But you know, the world is a changed place. Hopefully for the better, but it's changed and I don't quite know what art exhibitions are going to look like after the pandemic for a while.

Ushashi Basu: Thank you so much.

Lucy Jenkins: I think one of the other things that came out in the film and that Andrew mentioned that this was a Wellcome trust funded project, both from the science and on the engagement side of things.

And Wellcome obviously have aims and objectives of helping public understanding of science. But with an art project, there are artistic aims and objectives and I'd be interested in hearing how Susan and Andrew felt, and Fiona and Andy's input really, how the whole project might have met those original aims.

Susan have you?

Susan Aldworth: Well, the aims of public engagement to the science are always for me complicated because an artist's role in this context is not to illustrate science. But it is to question.

And we were never asked to illustrate the science by our very imaginative team of scientists. They wanted us to take on board the ethical side, the ideas of hybridity. What happens to the notion of self if you put an implant in the brain? Are you the same person afterwards?

And we were both given the freedom to, through this funding, to explore the questions around implants in the brain during epilepsy in our own ways. For me, I wanted to look at the lived experience, because I didn't see how, for me, an exhibition can talk about epilepsy, if you didn't use the narratives of people really living with epilepsy as part of it.

And I think that the combination of the way we both worked on our own work, actually covered, you know, the public engagement as widely as, you know, as we possibly could. I think we took it… Well, I certainly took into account the aspects of what was happening in the brain during epilepsy. The lived experience of epilepsy. The stigma of it through the underwear. So things were, you know, brought out into the light that had been hidden under the surface.

And I think between us, we explored a whole gamut of things around what the scientists are doing with this radical new treatment of epilepsy. Andrew do you want to add to that?

Andrew Carnie: Again, it's a very difficult thing. I mean the first thing I'd actually like to do, I mean I kind of thank the Wellcome trust in the film. But I mean you know, Paul and Chris at Vane and everybody, all of the people, the Hatton, everybody. You know, it was an amazing effort from the scientist's teams and whatever. And the Hatton Gallery, and Vane, and then other people that were connected. We had such a good, positive response and I think that's really important to note.

In terms of the engagement I think it's very much a two way thing. I think it's something that goes on. I think that this occasion is very much part of it. I think the works will go on and be shown again which brings them in. I mean, I think that one of the things I've become really interested in the project, and I think it's part of, you know that kind of oeuvre of work that I've been doing over the last few years really is what happens and what changes our sense of self.

And this kind of working in this area does exactly that. I was very interested in some of the legal aspects of implanting something and I think some of the really interesting conversations we had with members of the law department at Newcastle about the implications of having a device in you, who owns it, who doesn't.

And terribly difficult to explore in a way. And I think that maybe you saw the one with the words on the fans. That was my attempt to do it. I took quite a lot of quotes and things from the documents of a conference called, what was it called? Cyborg, something like Cyborg 24 seven really or everyday cyborg. And this kind of notion of mixing us up really and the implications of that are enormous. And we are at this really big juncture with AI and implantation of devices and things and how we operate in the world with that. So that was my bit of the engagement. It happens and then there's a whole series of other events that happened.

So you know I've talked a couple of times at conferences since and that's been important just exploring those ideas. Exploring them with an audience. So it continues. It continues with our websites and all of these things that we're doing. And Michael, who's coordinated this today, has done a wonderful job of kind of forwarding everything really and keeps going that. And the theatre thing was really important. Operating Theatre. Their piece was very, very vital in it all. Of kind of this whole discourse that happened.

Lucy Jenkins: I don't know whether any of the members of the audience who saw the exhibition might have a comment on that. I know that… Marius' hand is up. I'm not sure…

Marius Kwint: Well, my question was. It's another question so I'm not going to follow…

Lucy Jenkins: Okay.

Marius Kwint: I haven't really prepared a response to that previous sequence but I really wanted to ask Fiona what she recounts of her experience of working with two artists on this project. Kind of the old chestnut in art science stuff is does the art inform the science as much as the science informs the art. So I just wondered what your perception of that process was and I see that you're a member of the impact committee at Newcastle and so on. So there's probably, you know, areas around public engagement and so on that you've thought about systematically.

Fiona LeBeau: Yeah, I mean, certainly working with Susan and Andrew. I mean when we set out to do this, I mean I suppose there are several things you want. You want to be able to kind of get the work that you're doing at the university out to a sort of wider audience.

But you also want to sort of have that whole process of engaging their way of thinking of things, because it is very different, as you're saying to a scientific viewpoint. So I think often Susan particularly focusing on the kind of the human story and Andrew focusing on the technology and the ethical issues, I mean it just sort of brought much more debate to the topic I think then we may have had without a public engagement project and communicating that. I mean what hasn't been sort of shown in the film but behind all of this Lucy and Michael have done a huge amount of work going out to schools, to endless kind of events and public engagement activities across a whole wide range of venues. So I think it has really created a kind of a dialogue between, kind of, a lot more people than would ever have happened without being involved in a project like this.

Don't know if that answers your question.

Marius Kwint: Yes, thank you.

Lucy Jenkins: Thank you, Fiona. Griselda.

Griselda Goldsbrough: Hi there. Can you hear me?

Hi, I saw the exhibition in Newcastle it's absolutely fantastic and I loved the video there and the idea of both artists talking about you can't stop noticing things which I thought was lovely. And this idea of lists and seeing the process. And also the ingredients. And I got a real sense as to the people that visited about this, Susan talked a little bit about physically breathing with the interaction.

And the same in Andrew's exhibition and I wondered if they would mind talking a little bit more about that sensory experience because we all really felt that on visiting the exhibition, and some people may not have been able to visit, and it was just absolutely amazing how that experience also lent itself very well to the science in both the human side and the technology side.

Susan Aldworth: Well the, I mean you're right, both of our installations and I can only speak for mine were very, very sensory. Mine was kinetic. It moved up and down in the algorithm of an epileptic brain, which you know, took a lot of fine tuning and working with a computer expert to get it to work.

And I think that the audience, I mean I remember watching them on the first night, the audience seemed to be completely engaged. So not only was there the stories of the people living with epilepsy, there was the artwork itself, which was the 100 embroidered items which were, had a full story on the front and one word on the back. So it worked both front and back. And then it had UV light, because a lot of the embroidery threads were in UV.

And so the story is suddenly sort of emerged from this extraordinary Victorian underwear which reacts particularly brilliantly to UV and I think I talked in the film about trying to get the pace of it to work like breathing so that you felt that these were human experiences. I wanted it to be, I wanted people to feel, to sense both the history of the costumes and also the history of the people through their own humanity really.

Andrew.

Andrew Carnie: Yeah, I've always wanted to make work that has a very kind of physical reaction really. I kind of want to use colour and all those sensations. I mean so, in a sense, the spaces were brought alive by the sensors kicking off things that happened, like the motors moving, rotating the lasers beams.

There was also a soundtrack which I think you heard a little bit in the film when Alan was filming in the studio. Of kind of, it's quite spooky in a way. It was kind of helicopters flying that had been mutated. There was a kind of sense, at times, of ominous, foreboding about things and a foreboding about change as much as there's positive things.

For years I've been following a heart transplant project and doing that. And again that brings up the same kind of questions about the advances that we make, and I think, possibly, the thing that I'm concerned about is the kind of back, the psychological backlash in a sense that we have, and the reaction and how actually everything's quite positive. But we do really need to do with, to deal with people's psychological wellbeing as we transform the world and we're not very good at that really. Of bringing that up. It's sometimes things can be a little bit gung ho in a sense, and we need to really think.

These are really important developments as we put these devices into people and how that moves forward.

But yeah, I mean the colour and the light, and you know I think I have a kind of threshold for being excited about things. I certainly wanted to bring that to the show really and be excited about it myself. And one of the things that's not maybe quite apparent is, like with the video, it falls on voile and so it's layered and it has this kind of strange mystic, mystical almost feel to it. It is about suspending belief. That's probably enough.

Lucy Jenkins: Thanks Andrew and Susan. I think we have a question from Shannon. Shannon McCarthy.

Shannon McCarthy: I just wanted to give my thanks for being able to participate in this project. I'm an artist with epilepsy and it was such a… It was. It was so exciting to actually talk about epilepsy.

There was always something that was being stigmatized 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. So I want to thank you for that empowerment.

Susan Aldworth: It's lovely to meet you at last. Hello!

Shannon McCarthy: Yes, nice to see you Susan.

Susan Aldworth: And thank you for your participation, it was so appreciated.

Shannon McCarthy: Thank you, it was honour.

Andrew Carnie: I think you bring up a very interesting issue about, I mean you know because it's a very common condition isn't it? You know in mild forms and some people don't even know they have it through their whole lives. And yet other people have it extraordinarily severely and it can be terrible and very difficult. But you know it's really interesting and it's very humbling in a way to make work when one doesn't have epilepsy about such a topic and then maybe hopefully feel it's been important.

You know I got kind of sensitive about what I was doing in a sense, because I knew I was, at the end of the day, kind of getting close to the line with the use of lights. I mean here we are, we're dealing with something with light in the brain and I was using it, but it's one of those things that could trigger epilepsy.

So it is humbling.

Shannon McCarthy: Thank you so much.

Lucy Jenkins: I think one of the questions that's been asked in the chat was around some of the ethical issues and you sort of touched on something there Andrew. Did, what the question somebody had asked was, did any of the original ideas that you both had change because of ethical concerns or considerations? I don't know whether that's something that impacted on your work Susan?

Susan Aldworth: Very much so. I mean I wanted to give voice to people living with epilepsy. But I, you know as soon as people… I had about 48 people who wrote their testimonies and then I realized that I don't have ownership over that. That I needed permission at every stage to show their words and I needed to make sure that people were happy with it, they were informed all the time.

So that was part of the sort of… But when Alan talks about missing some bits of the build up to my work because it happened so early on. It was the sort of huge administrative, ethical consent that I got from everybody. Because who owns… You know, an artist makes a piece of work, you use other people's stories, who owns that?

And I've never felt an ownership of people's stories. I felt that I wanted to present them but I needed to know that everybody was comfortable with it and they had the right… Everybody had the right at any stage, to pull their testimony out of the… You know I would never present work that didn't conform to those ethics. So I had, I have a studio assistant called Phil, Phil Alden, who handled all the ethics for me.

So, and we had to keep in constant touch with people. So there were 100 embroiderers, 106 embroiderers, 48 people sewing, people writing and a lot of other technical support. So the actual administration of my piece of work was so huge and I want to have a great Thank You to everyone who participated.

Which is why I'm. You know I need to say that this piece of work is my idea but it's through the generosity of so many spirits that I've managed to bring it together. And then not only on top of that, the embroiderers created 106 pieces of artwork because their sewing was monumentally surprising and brilliant. So the artwork grew with this huge body of people working towards the final show.

So, yeah, the ethics were hugely important and they still are. About ownership and my right to talk about other people's experience. You know all these things. And I'm sure Andrew had different ethical issues to deal with too.

Andrew Carnie: Yeah. I've kind of worked with a couple of technicians and whatever in certain roles. That was important. But it was, in a kind of way, a kind of sole activity of making the work. I mean I did, as I said, get a little conscious towards the end about what materials I was using and what effect they would have.

But, in a way, that's just a very difficult issue. I mean it's like, I felt as though as an artist, you have to have a voice and you have to keep to that voice in a way. And you have to kind of push the boundaries in a sense. So you know, and I've had that with a few kinds of works, historically, in the past, when I've worked in human dissecting rooms and use pieces and things like that. So I'm actually, kind of I guess, at the end of the day, feeling that the artwork was quite important, and that it should have its own jurisdiction and make it in the way that I needed to make it. And then see what the consequences are slightly afterwards. It is very difficult, though you know. And I'm very, very aware of what the issues are.

But sometimes you can get… You know, you can miss them in a way. There were some other ones that you can miss and they can kind of creep up. I mean I hadn't really thought that I would have too many problems with the lasers and, but that's just about, you know, how it's presented in the end. And in the end, that was about health and safety in a way. And then you have to put everything high. So it changed a bit, but yeah.

It, as I said, it's just humbling about kind of working with that areas of kind of disease and a condition. But the condition gives us such an insight into how everybody is and how our brains are.

Lucy Jenkins: And I think Andrew, some of the sort of ethical discussions or legal discussions that we had during the process that actually sort of almost came into, to the film itself didn't they? In terms of the ownership of any data that might be collected through the device.

Andrew Carnie: Yeah, I mean there's all sorts of elements that I wanted to explore and one of them is… I mean, you know a lot of the devices now are wireless and connected back to the doctors. Or you know you kind of input the data in some way. And then who owns it? Does the patient own it or does the corporation own it?

I mean, for me the very interesting thing is almost how corporations that make these things often almost didn't deny their ownership of them and there's expectation that the person that receives an implant owns it.

And it's kind of like them almost stepping back from it, from things going wrong. But I also know that the CANDO team were very aware of having concerns. And one of the concerns is obviously the optrode that goes into the brain is implanted, which is the thing that gives out the blue light and records any kind of incorrect activity and how that has to be isolated from the brain. And I was, I know that, with the team, there was a, that's a big concern really. The isolation of the device and how it lasts. So there's you know, for the project and the CANDO team there's a lot of time, like with Susan's work that goes into just concern, for people and for, you know, the ethics of it and how it works. Is that? That's right isn't it, Fiona?

Fiona LeBeau: Yes, I mean if Andy's still around on the call, he's probably better able to speak to the ethical aspects of it than I am, but yes. I mean obviously we are still a long way from this going into any patient.

But these are all matters that are very much in people's minds and having to be considered in the development of any new technology.

Lucy Jenkins: Great. Thank you everyone for their input on that question. One of the other questions I think simply was for Susan and what's happening to the garments now that the exhibitions have finished.

There were a lot of packing boxes.

Susan Aldworth: Well. They are now packed up thanks to Alison who came to help me with it, up in the studio upstairs.

There's two things I'd like to do. One is I'd love to stage it again. I'd love to stage it in a different space and to, I mean it will take a lot of funding sadly, but. And to get it working properly.

But secondly there's also, they are individually. I mean, I would also like to stage, if there's not so much money to stage, a non-kinetic version where the individual items of embroidery could be grouped together and staged together. So I have a few other exhibition ideas that are going on in my mind at the moment. I really don't feel it's been, for all the effort and all the work and all the thinking that went into it, I can't bear the fact it was only on the wall for so few weeks so one day.

Vicky McPhee: *unclear*

Lucy Jenkins: Vicki did you sorry?

Vicky McPhee: Sorry. I went to see it at the Hatton Gallery, Out of the Blue, Susan. And I thought it was magnificent. I was actually at an appointment at the RVI. I popped in afterwards, because I remember we had to see it, and it was, I thought was absolutely astounding.

Susan Aldworth: Thank you.

Andrew Carnie: Okay.

Susan Aldworth: It's nice to see you Vicki.

Lucy Jenkins: I think your input in the research process was really valuable, thank you Vicky.

Susan Aldworth: Yeah, absolutely.

Lucy Jenkins: Andrew, what about you, in terms of the work, post exhibition? I know you've had other exhibitions since but are you thinking about how you might use this or take this forward in another way?

Andrew Carnie: Yeah, I'm waiting for opportunities, though there's kind of something bubbling along at the minute about showing one of the pieces. So I'm kind of waiting for confirmation of that. It's kind of early days and actually the projection piece, so that would be good if it works. But again it's of a scale that makes it slightly difficult to go elsewhere.

I have everything back in the studio. It's quite a lot of stuff and I will probably cannibalize it into other pieces of work. I've gone on making some things. I got very interested in the weather balloons. And making work out of that side. I'm kind of in the middle of making another kind of projection piece with the balloons which I'm kind of interested in.

So it's still to go places. But as a reaction to all of that kind of mechanical things and I think that maybe Susan had the same problem. It's, you know, trusting mechanical stuff and getting it to work is always quite difficult. I did, in the main, keep going, but I turned back to drawing and painting quite a lot of things in this last year and just about building up energy to kind of go and make more physical things.

The one thing that I didn't use in the show was the magnets and I have another piece that's three quarters of the way through being made that I need to go and finish off with the magnet things, like electromagnets. So yeah it's always true with exhibitions. They're often very brief and then things come back. Then you don't know what to do with them.

Lucy Jenkins: And as we've said the work was shown across two venues. Two quite different venues. And, could either of you talk, or both of you talk about the challenges in making work for different venues.

Again, a bit about how it was how we were able to try and bring that together as a holistic exhibition.

Andrew Carnie: Yeah, shall I start Susan? I mean it was a bit of a challenge to make things work for both spaces and you know, in some ways, I was really pleased. You know, in some ways, that the big video went really well, I was really pleased how things came together at Vane. One of the things about the Vane space was that it was a squarer space. The width allowed me to do more things.

The Hatton space was quite thin in a way after I've got to work with the columns. And that was very nice. But I think there was quite a bit of constancy and some of the elements that I had in both spaces. So the fans with the words on were in both spaces so and I guess there was a lot of blue.

Which match them up, which link them, but they definitely kind of dealt with different elements. I was very concerned that those tubes and the Hatton. Particular ones dealt with certain kinds of things I felt about the work and the project. And then the other kind of works with the fans and the bigger pieces and the video and the balloons in Vane works in a different way about different topic. And in a way that, the Vane one with the sound piece, A Tale of Two, you know was much more interactive in a way, and led to a lot of stamping on the floor to activate it in a way. So that was quite interesting.

Susan Aldworth: I wanted the two shows to be very, very different. Both spaces worked really well for my work. The big back gallery in Hatton was the perfect shape for. In fact I think it's the only possible place it could have gone because we had to drill into the ceiling and do all sorts of jiggery-pokery to make it work. So I wanted… That piece of work was very much a collaborative statement of epilepsy. At Vane, I had a beautiful sort of square shaped room. That was just quiet, beautifully lit. And the cyanotypes I made which were, cyanotype is a form of cameraless photography where you can use natural forms. You coat a very thin paper with a cyanotype solution and it's developed by UV light and sunlight and because that references the blue light in the optogenetics and the science.

And I wanted them to just flutter in the wind very gently on the wall there. Alongside three portraits of people that I made some years ago for a show at the National Portrait Gallery of three people.

In a moment my portrait… I mean I'm not a portrait artist, but these are three portraits of people in a moment of epilepsy. One of the people was wanting to get pregnant, so I put her face in her womb. Another of the sitters was writing a book about The Magna Carta, so I put the Latin texts in amongst his EEG so I felt that was a very quiet contemplative space and they worked with each other and separately. And as Andrew has said, both Vane and Hatton were very generous with us, space and the support that they gave us and helped us stage, you know these remarkable four exhibitions. I mean gosh, we did a lot of work Andrew.

Andrew Carnie: Yes, yeah. I mean, I think, you know, for me again the split was, in a way, that kind of dealing with the legal bit kind of almost centred at Vane, with the large piece on the end wall and then the kind of balance and engagement of you know, with the big video piece was different at the Hatton. Yeah, it was good.

Lucy Jenkins: Thank you, Charlotte's asked a question on the chat. She's doing a dissertation around raising awareness of epilepsy, and I think that the kind of epilepsy she has and she's asked about how you created primary and secondary research about epilepsy. And I think this perhaps is a question that's perhaps Michael can come into as well about, not only did we have the exhibition's themselves and the work that Susan and Andrew had created. But there was a whole range of workshops and activity going alongside it. So there were public talks where Andrew and Susan both spoke to visitors at both venues. But there were workshops with other artists in schools, both the head of the project. Not everything that was planned, I think we had, Michael you'll remember this better than me, quite a lot planned for the Easter holidays and obviously.

Events overtook but there was a whole range of engagement activity that was about raising awareness of epilepsy. Michael I don't know whether you can sort of just add to that.

Michael White: Yes, so certainly we had planned events. I'll bring myself into a spotlight. We had a number of things planned for Easter, it was a good opportunity when kind of families and schools were off, to explore around the project and do things linked into the exhibition and the artwork. Which we'd had initial discussions with the Hatton gallery around different stuff.

And in terms of the kind of building preliminary epilepsy research, I think there's been surprise in going out and reaching groups of people willing to talk about it and wanting to help raise awareness.

For the CANDO project we have a patient advisory group, which was set up before I joined the project. Of not just people with epilepsy and Vicky was part of that, and Irene, you know who were interested in being a part of research, offering kind of a patient perspective and kind of public perspective.

And Susan's work she kind of contacted, I think, the Epilepsy Society and to try and get the word about trying to collect these testimonies. So collecting this kind of information it's the case of just going out there and trying and asking people. I think it'd be surprising, you'd be surprised how many people that will be kind of willing to and wanting to make that kind of offer of their advice and their story and help build awareness of the condition.

Andrew Carnie: I presume Charlotte you were thinking of primary sources of research and I suppose, for me, it was, this was the third project that I've done on epilepsy. In the very first one that I did, and it was based around work with the kind of scientists, the neuropsychologist Paul Brocks.

At that point, I did talk to patients and people that had epilepsy quite considerably. I think my remit on this one was more around other kinds of forms of research with the scientists.

It was almost entirely on that because I think that the work centred in a way around the optogenetics and the process and the legal aspects of that. So they were kind of like secondary sources in a way for kind of seeking information about what would lead in.

But really the kind of research I was doing is just always listening really, speaking. We had absolutely fascinating conversations with the team and whoever we wanted to speak to within the team. We'd kind of contact Michael and Michael would arrange for us to be up there, and to visit them and to and to go to their offices or to the labs and see all of the activity that was happening, you know. So it varied from kind of engineers through to psychologists and psychiatrists. The whole gamut really.

Susan Aldworth: Brain surgeons.

Andrew Carnie: Very interesting.

Susan Aldworth: I contacted, Charlotte, I contacted the Epilepsy Society who were very, very helpful. I also went on a visit there and met their scientists who are working on extraordinary things. So I was very lucky that they put out on their Instagram and Twitter that the project was happening and gave my contact details and you know 48 people got in contact and participated, which was amazing. I also worked very closely, not only with the Newcastle scientists, but with the London scientists at Imperial College who helped me with the computer and the mechanics of it all. And I consider that sort of primary research just because I had to learn, so much so quickly.

So, yeah there was a lot, it was a hugely research lead project, and then it transformed into an art project, which is what I like to do. Sort of pop the research in my head in one sense, and then go off and see where it takes me.

Lucy Jenkins: Thanks Susan. I think a question perhaps for Fiona would be what kind of impact do you think the engagement project is going to have on the way that the CANDO research project itself will continue to unfold.

Fiona LeBeau: Well, I think, certainly, you know a lot of the aspects in relation to the sort of ethics being able to kind of engage with people.

I mean there's no good coming up with a sort of technology and a device if people don't actually want it. So, I mean, there is the patient group as Michael's already mentioned that are involved all the way along through the CANDO project. So there were discussions with them.

I think overall it's really just I think probably everybody has learned to kind of just really talk about all the different aspects and think of many different components, to a large project like this. So I think it will certainly, has been a great help in that sort of dialogue, basically going through and we will kind of keep… You've got to just keep talking to patients. You've got to keep talking to everybody involved really.

Lucy Jenkins: Absolutely, and I think just reading the comments from the chat, that people have really appreciated and engaged very personally with the artworks that Susan and Andrew have made and the issues that have been raised, through them. So I think there's been, you know, a really powerful impact and… Sorry, just trying to catch one other question that I've noticed that somebody's asked. Did anybody spend time at the National Hospital for Neurology and Neurosurgery. I don't know whether? I'm not aware.

Andrew Carnie: No, not for this project. I have been there and worked with people there in the past.

Susan Aldworth: I have too in the past.

Andrew Carnie: Yeah, Susan the same. Not on this occasion. I mean we were spending as much time as. Well Susan spent time in London, but you know in Newcastle.

Lucy Jenkins: Absolutely. But, as I say, this are huge numbers of comments on the chat about how profoundly the work has impacted on people, and I think one of the things that one of the last comments that I've just seen was about how good the film is at exploring the artistic process, and I think that was wonderful. I found it really wonderful personally watching it again.

Because you really get to see that, most times when you see an exhibition you see the end product, and you don't get a sense of how that's developed often and, in this case over a long period of time and how I think as Susan comments in the film, that often what you end up with is not where you began.

So I think the film has been a great opportunity to show quite what a complex process, making artworks for an exhibition is and that collaboration between the artists and scientists and also for those who weren't able to actually get to see the exhibition in person.

A great opportunity to at least see some of that. I think we've got time for one last question, which I think was around collaboration, I mean it's very clear that this is a project has been about a collaboration between Andy and Fiona and the CANDO team of scientists and engineers and then artists, including the Operating Theatre group and Alan making the film and then Susan and Andrew making their artworks.

But I thought perhaps you could both finish by saying a little bit about the other collaborations that were part of making your work.

Andrew, would you be able to start?

Andrew Carnie: Um yeah, I mean I felt it was very collaborative in a sense, but you know back here in Winchester one of the difficulties obviously was it being, you know, away in Newcastle and we spent a lot of time up there. But that made it kind of difficult, so I was kind of working and centred in the Hampshire area and making contact with technical people and doing things from my own University at Southampton.

You know, and that worked to a sense. But I mean, you know… Collaboration has always been kind of… It's an interesting thing about how much things are collaborative or you know when, as I kind of working in that field of science art I do feel as though I'm kind of listening to people and then going away and making work in a sense. So it's kind of for me, it's kind of reduced, and I know that other people collaborate in lot stronger ways.

Susan I collaborated a lot on the prints which were made for global eye arts, you know, what about five or six years ago. That was a different process. This was a different kind of event really, where we made our own kind of work in the end.

Susan Aldworth: I've just been trying to think in my head all the people I collaborated on this and it's.

There are the wonderful embroideries. Thank you everyone. There was the people who wrote their testamonies, thank you and some people did both, wrote testimonies and embroidered. And there was the scientists in Newcastle, the scientists in Imperial College. There was Alan who did the computer. There was Will who made the structure. Then there was Phil who helped me organize everything, then there was someone called Alison. Alison Beadnell, one of the most wonderful sewers as I know who helped me design how to sew the things onto structures so they would hang. Then when my wonderful students from Central Saint Martins who came, Lewis and Rose and Lottie who came to help me sew them together.

And then there was, I made an artist book as well, which I haven't mentioned, because it wasn't in the film and that was put together by wonderful designers called Valley Walkley and edited by my dear friend Max Eilenberg. And photographs of all the beautiful embroidery was taken at the Royal School of Needlework. Thanks to Angie Wyman there.

Gosh. So I'm sure I've missed out. Lucy, thank you for… Collaborating with a curator, collaborating with the galleries. It was, it was about as much collaboration as anyone could do I think in three.

Fiona LeBeau: I agree. I would like to add to that…

Susan Aldworth: Michelle for ironing the underwear. You saw her with these sort of pair of crotchless knickers in the film. And she, also not only did she iron them, but she washed them because they were very old and she has magic. She understands Victorian underwear so she turned it into, from stained stuff to white stuff. And also down in Hastings there was a shop called Hawk and Dove who donated all the Victorian underwear for the project. So yeah. I think there might be a term over collaborating.

Fiona LeBeau: Well, I yeah I just like to add, actually, that you know, I think it was a hugely ambitious project and as the CANDO team, I know that we were really, really pleased with the work, and I mean the tragedy is simply that obviously that the exhibition wasn't on for as long as it could have been and we didn't get to do all the events that we had planned. But I mean the work that Susan and Andrew put in and Lucy and Michael has really been exceptional. So many people involved, and you know I just hope that we can get the work shown again elsewhere, really.

Lucy Jenkins: Absolutely, I think that's definitely something to aspire to. And Michael did you want to just say something about the film and where it's presented going forward?

Michael White: Right yes. So I'd just like to add in the thank yous, and there's lots of people as we've been saying there's so many people. Andy Jackson who is co-PI behind the project has been a major driver of the engagement. You've been quite busy this year so he hasn't been part of the discussion. But you've been fantastic kind of doing public talks and everything about the project. And also Hatton Gallery and Vane for their support and everything they did. Helping put us in touch with the school workshops and with other community groups and user groups.

The galleries help make it what it was. And also Wellcome who provided the funds to enable us to do all of it.

And the film, as I mentioned in the chat, is up on YouTube it'll be there available now, from now on, so you can go back and watch it again and share the link so everybody else can watch it and you should be able to embed it if you want to put in your own website or whatever.

The project website cando.ac.uk also has other resources with the kind of the essay that was in the booklet that we handed out at the exhibitions so you can read more about that.

And there are lots of photos by Colin Davison of the exhibition, if you want to explore those a bit further.

So yeah, so people can go and…

Andrew Carnie: There's worksheets for kids in lockdown isn't there as well?

Michael White: Worksheets, yes.

Lucy Jenkins: Oh, yes.

Michael White: They're not up there yet but we'll put those up. We can now include, able to include the link for the film in there as well. So you can kind of create your own kind of forest brain images on a similar to Andrew or your own, plan your own…

Susan Aldworth: nighty.

Michael White: Yeah, nighty from the testimonies.

But thank you to everybody for joining us this evening and for your kind comments and questions and it's been really, a really nice event to kind of look back and be proud about what we kind of, where everybody kind of working together, has created.

Andrew Carnie: Yeah. Big, big thank you to everyone. I think. Just had a thought of one final thing that I thought was great really is that when the project came about and the public engagement, I thought, Oh, you know I want to make artwork and how does this, how is this going to work as public engagement and then the fact that Andy Jackson came forward and made a fantastic statement about how it suited the whole project that they did launch it to the public in some kind of way and they wanted that feedback and they wanted that kind of presence was a really important moment.

Susan Aldworth: Yeah, thank you for the opportunities.

Andrew Carnie: Yeah the opportunity, yep.

Susan Aldworth: You know, CANDO and Wellcome and also to the Arts Council who funded my artist book. So yeah I feel very lucky to have had this project and worked with everybody on it, thank you.