Stroke through a lens: Exposing the challenges of establishing a visual arts project as a research engagement activity

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Abstract

To celebrate 20 years of an epidemiological study, the South London Stroke Register, we collaborated with student artists and stroke survivors to create an exhibition of visual arts displayed at a series of events in 2015–16.

This paper explores the expectations placed on researchers to engage with different publics, touching on current debates around institutional support and recognition. We critically reflect on the project process, identifying challenges and offering recommendations. We include the perspectives of the stroke survivors and the student artists, and examples of the artwork.

Keywords: research; public engagement; stroke; visual arts; critical reflection

Key messages

- Even relatively small projects using the arts to engage the public with science and research require significant time and financial resources.

- It is important to spend time building relationships between project partners to ensure that their sometimes diverse motivations and expectations are fully considered.

- Arts engagement projects are dynamic and may evolve in unexpected, challenging and rewarding ways.

Introduction

In 2015 the South London Stroke Register (SLSR), an ongoing epidemiological cohort study, reached its 20th anniversary year. Since 1995, the SLSR has been identifying and following up people who have had a stroke in a defined area of Lambeth and Southwark, two boroughs of South East London.

A stroke occurs suddenly, when the blood supply to the brain is stopped or restricted, causing brain damage and subsequent disability or death. Worldwide, stroke is a leading cause of disability (Feigin *et al.*, 2014). In England, stroke is one of the leading causes of death after heart disease and cancer, and is the largest cause of complex disability (Stroke Association, 2016). Historically, stroke has been seen as a disease of older people and up until relatively recently, a disease for which 'nothing can be done' (Hoffmann, 1974: 53). More recently, however, advances in clinical research

have led to significant improvements in acute care, and more people are surviving, albeit with multiple ongoing problems.

The SLSR was set up to collect accurate information about the number of people having strokes, the risk of stroke in the population and the long-term consequences and the quality of care provided, and has provided evidence informing policy and practice. People recruited to the SLSR provide information on their physical, cognitive and emotional status following their stroke, the types of care they receive, their ability to complete activities of daily living, their levels of social participation and their overall quality of life.

In 2005, a patient advisory group – the Stroke Research Patients and Family Group (SRPFG) (King's College London, 2016) – was established to enable patient and public involvement in the research. This group meets eight times a year and comprises about 35 stroke survivors (and family members), most of whom take part in SLSR research.

The SLSR is an enormous collection of data – nearly 6,000 first-ever strokes have been recorded, comprising 13,649,396 individual data items. The dataset is anonymized and the focus of investigation is on stroke in whole populations, and patterns and trends in disease and outcome. It is therefore easy to forget the individuals who generously allow researchers to turn their experiences into data.

In order to acknowledge the contribution of stroke survivors to the SLSR, we undertook a collaboration with members of our long-standing patient research advisory group, the SRPFG and BA Photography degree students at a local arts college. As researchers we had a wealth of experience in patient and public involvement (Fudge *et al.*, 2007; McKevitt *et al.*, 2010; McKevitt *et al.*, 2015) and science engagement, but this was our first foray into public engagement through art.

Aims for the paper

In this paper we explore the process of establishing a visual arts project within a research engagement climate at a higher education institution. We aim briefly to explore the expectations placed on researchers to engage with different publics and to ensure their research has impact, touching on current debates concerning institutional support and recognition. We review briefly the relevant literature and then critically reflect on the process we undertook, identifying the challenges and rewards of establishing such a project. We do this from the perspectives of the researchers involved, participating stroke survivors and the student artists commissioned to produce the visual arts project. We then reflect on the lessons learnt and offer recommendations for creative research engagement endeavours.

Engaging publics with research

Efforts to engage the public in science have a long history, and their rationales and practices have evolved over time (Bauer *et al.*, 2007). Early models of engagement were concerned with educating what was perceived as a scientifically illiterate population. The public engagement agenda has now shifted towards wider-reaching aims of inspiring, informing and collaborating, as well as educating (TNS-BMRB and PSI, 2015; Facer *et al.*, 2012).

For universities, which are publicly funded institutions, public engagement activities have been seen as integral to the role of ensuring knowledge dissemination (Moriarty, 2016). However, here too the purpose of public engagement is shifting;

it may be seen as a tool for raising institutional profiles, as well as for learning and sharing knowledge with different audience groups (Chikoore *et al.*, 2016; Watermeyer, 2011). Increasing marketization of research and higher education, requirements for research to be publicly accountable and demonstrate impact and the need for researchers to engage better with the end-users of their work have contributed to the current expectation for public engagement with research (Mahony and Stephansen, 2016; Holmwood, 2010; Facer *et al.*, 2012). A recent national survey suggests that over the past ten years the number of scientists participating in engagement activities has increased and public engagement activities are more likely to be supported, valued and recognized by research institutions and funders (TNS-BMRB and PSI, 2015).

However, ambivalent attitudes to engaging publics in research remain. Within academic departments, researchers themselves can dismiss public engagement and even regard it as career damaging, particularly for those early on in their career (Moriarty, 2016; Martinez-Conde, 2016; Chikoore *et al.*, 2016). A reward and recognition structure that encompasses and values researchers' work undertaken to engage publics is missing from research career metrics, which tend to focus on the actual research undertaken. Other obstacles preventing researchers from undertaking engagement include competing pressures on time, insufficient funding, lack of formal training for public engagement and difficulty in finding relevant opportunities to participate in public engagement activities or an inability to see the public relevance of their research (TNS-BMRB and PSI, 2015).

Using art to engage publics with science

It has been suggested that art–science collaborations can improve public understanding and appreciation of science, by making complex ideas accessible, allowing audiences to take a different view of the world and provoking and contesting some of the claims made within the scientific community (Ede, 2002; Ingham, 2013). In exploring avenues for our own engagement in science through the arts, we carried out a scoping review to investigate how other researchers have engaged with artists. Specifically we were interested in:

- the kinds of projects that had resulted from collaborations between scientists and artists
- the process of bringing together artists, researchers and, in the case of health-related research, patients or members of a community
- the lessons we could learn from existing projects to inform our own activity.

We searched Web of Science and Google Scholar for published peer-reviewed literature and used Internet searches for the grey literature. Our search terms included: science, research, art, collaboration and public engagement.

Our scoping exercise revealed substantial activity between science and art, but little attention to reflecting on the process of bringing researchers and artists together as part of public engagement in science. Much of this activity is described in the grey literature and on the Internet, with limited description of engagement projects in the peer-reviewed literature.

The arts–science engagement activities we found through our scoping exercise can be categorized into three groups: (1) artist-led projects; (2) collaborations between community groups, artists and researchers; and (3) charity-commissioned arts projects. Artist-led projects have included work by photographers, printmakers and sculptors, with the artists using artefacts from research or science, or discussion

with scientists, as their inspiration. Printmaker Susan Aldworth's exhibition 'Transient' was the result of working with clinical-research nurses who provided images of brains, which were incorporated into her art (Aldworth, 2013). Other notable projects include knitted neurons (ArtNeuro, 2015), the Aeolus project (Drumm *et al.*, 2015), 3D-printed deoxyribonucleic acid (DNA) structures (DNAted, 2015) and a palace made of human milk teeth (Palaces, 2013).

The grey literature revealed a number of collaborations between artists, community groups and researchers, with community groups taking an equal role in producing the art, often as part of an action research or educational component within the process (Arms, 2015; Artesaro, 2015). Orsin, a public health professor, used an art biennale in India to open up taboos about public health, and, in a similar vein to our approach, to acknowledge the people behind numerical, epidemiological data that form the majority of public health research: 'A lot of my work in public health research involves counting stuff and counting people, but my work is also about showing that the people we count, count. Everywhere is somewhere and everyone is someone' (Arms, 2015).

Charity commissioned arts projects formed a large part of the findings from our scoping exercise. These projects used the narratives and stories of people living with a condition, or in a particular situation, to raise public awareness, fundraise for the charity and make the link between charity-funded research and advocacy and improved lives for those concerned. Some of the examples from the charity sector corresponded more closely to our own approach than the above artist-led projects, as they raise awareness through telling the stories of people living with a particular condition or in a particular situation: for example, blindness (Macular Disease Foundation Australia, 2015), Alzheimer's disease (Alzheimer's Speaks, 2012), cardiac disease (Mullen, 2015), homelessness (Shelter, 2015) and poverty (Health Poverty Action, 2015).

While we came across numerous examples of using the arts to engage with science, we found few reflective papers charting the practicalities and challenges of using art to engage publics with science. A few exceptions are the Aeolus project (Drumm *et al.*, 2015), the Dharavi Biennale (Arms, 2015), Ede's (2002) reflection on why scientists and artists increasingly engage in each other's work and Ingham's reflection on a neuroscience exhibition, 'Between' (Ingham, 2013). However, these examples provided limited reflection on the practical challenges of such engagement, mainly focusing on the public impact of the exhibitions. Therefore, a number of questions remain about using art to engage publics in science and research. Arts–science projects require substantial funding, yet their impact is hard to measure and the value of that impact is debated (Wellcome Trust, 2012; Matthews, 2015), which raises a number of questions. Are arts–science collaborations concerned with informal learning or profile-raising for science institutions? Ingham (2013) raises the question of whether the usual evaluative approaches for public engagement (footfall, audience demographics, feedback surveys) are appropriate for artworks that are more site-specific, transient or performative. In terms of the practicalities of collaboration between artists and scientists, we still know remarkably little of the routine, everyday detail of engaging in collaborative work. As Callard points out, this is not a problem unique to public engagement, but is also apparent in other interdisciplinary settings (Callard *et al.*, 2015).

The scoping exercise resulted in few examples to inform the practical development of our project or to inspire ways in which to explore research participation through art. This paper therefore offers a novel perspective on practice in the arts–research engagement sphere, with its focus on the process and project management practices of implementing a research engagement project. In the following section we

discuss in more detail the inspiration for the visual arts project, how the collaboration with stroke survivors and student artists was established and the works of art created through the project.

The visual arts project

The project arose out of our work organizing an academic symposium marking 20 years of research in the SLSR. Our initial idea was to create a photographic exhibition featuring members of the SRPFG. The exhibition was to celebrate the people behind the anonymized register data, and to provide a 'human' element to an academic event, to which stroke survivors and the public, as well as researchers and clinicians, were being invited. From the outset we worked with members of the SRPFG to refine project aims, invite participation in the project and identify appropriate ways of working with the student artists. These discussions took place in regular SRPFG meetings but also in telephone and email conversations. In SRPFG meetings, members were largely enthusiastic about a creative arts project, but we contacted each member individually to give them the opportunity to privately declare their desired level of engagement in the project; 16 people registered their interest in taking part.

Meanwhile, we also contacted local arts colleges to identify opportunities to collaborate with photography students on the project. We decided on students taking their Bachelor of Arts degree in Photography at Camberwell College of Arts (University of the Arts London – UAL). This university was chosen because of its proximity to South East London, because the students were taking a community-based module, and because of the availability of a lecturer to act as project manager on behalf of the university.

We then organized a meeting with stroke survivors and students to agree a creative plan and strategy to produce the exhibition.

Box 1 shows the main stages in the process of developing the exhibition.

Ethical considerations, consent and contractual agreements

This project was developed in the context of patient and public involvement (PPI) activity. In the UK, ethics committee approval is not currently required for PPI; therefore, we did not seek ethics approval for this project (Hayes *et al.*, 2012). The researchers and SRPFG members have a long, ongoing relationship based on regular SRPFG meetings and other activities related to our research programme and raising public awareness of stroke. We discussed ways in which their images might be used, not only in the symposium exhibition but also in future formats, including the students' final-year projects and personal portfolios, and by the researchers' host institutions, a university and a hospital trust. They were content for images to be used as part of raising awareness about stroke and stroke research. Written consent for images to be used was provided using standard consent forms provided by both institutions.

We made contractual agreements with the student artists to address payment and licensing agreements as appropriate. Contracts were provided by the University of the Arts London, allowing us to own the licences to use images derived from this project for any future purposes.

Box 1: Process outline

The times in brackets indicate the approximate duration of each element of the project. This was not a strictly linear process; for example, seeking support and building the collaboration were done concurrently.

Conception and planning (6 months)
- Initial meeting with stroke survivors to gauge interest in principle. Second meeting to discuss participant involvement, communication preferences and logistics.
- Researcher discussions regarding potential outputs, creative or funding partners.

Seeking funding and institutional support (7 months)
- Applied to King's College London funding opportunities and charities (related to stroke, health, the arts and/or public engagement).
- Discussions with host institutions (King's College London (KCL), National Health Service (NHS), University of the Arts London) regarding support with promotion and exhibition space.
- Agreed financial and contractual obligations (expenses, materials and a project management fee).

Building the collaboration (4 months)
- Stroke survivor participants gave consent (verbal, then written), decided the extent of their involvement, submitted ideas for themes, the exhibition format and the title of the exhibition: 'Acceptance, patience, compassion, courage: Living with (in)visible disability after stroke'.
- Student artists introduced to stroke survivors; informal discussions on project during/after research advisory group meetings; and researchers facilitated 'matching' of student artists with stroke survivors.

Production of work and first exhibition (3 months)
- Student artists (individually/small group) met individual stroke survivors, as mutually convenient.
- Student artists with stroke survivors produced photograph series, handwritten pieces, short films and installations.

Exhibitions and community events (3 months)
- Exhibition and launch promoted via web/social media channels (SLSR20 blog, KCL and partners' Twitter accounts, KCL event web pages).
- Exhibition launched at KCL SLSR 20th Anniversary Event (200 visitors).
- Exhibition in gallery for 2 weeks.
- Exhibition displayed and discussed at two stroke community groups (Different Strokes Bellingham and the Stroke Group Lewisham).

The artwork

Both the stroke survivors and the student artists discussed the desire to present the reality of the stroke experience, and the resulting artwork documented aspects of life following a stroke, including pain, anxiety, communication difficulties and other hidden disabilities such as difficulties with using public transport and navigating busy urban areas. The student artists produced 24 photographs, but the media used broadened

out from solely photographic portraits, as we had initially envisaged it, to include six handwritten text images, three short films and an art installation.

The photographs were arranged into six series, accompanied by short descriptive texts written by the student artists. 'The Journey' is a series of five photographs of stroke survivors in their own homes (see Figures 1–3).

Figure 1: From the series 'The Journey'

Credit: Hedvig Larsson, 2015

Figure 2: From the series 'The Journey'

Credit: Hedvig Larsson, 2015
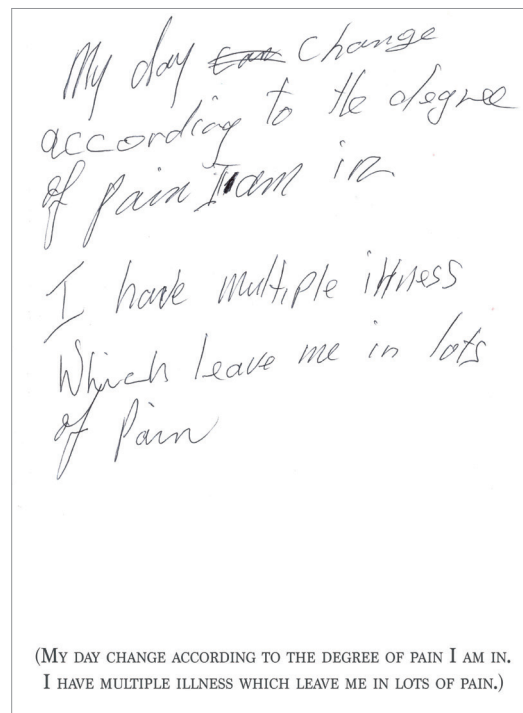
Figure 3: From the series 'The Journey'

Credit: Hedvig Larsson, 2015

The series 'The Great Wish' portrays one stroke survivor's home life and Swedish heritage, with images including her living room, family photographs and her dog (see Figures 8 and 9).
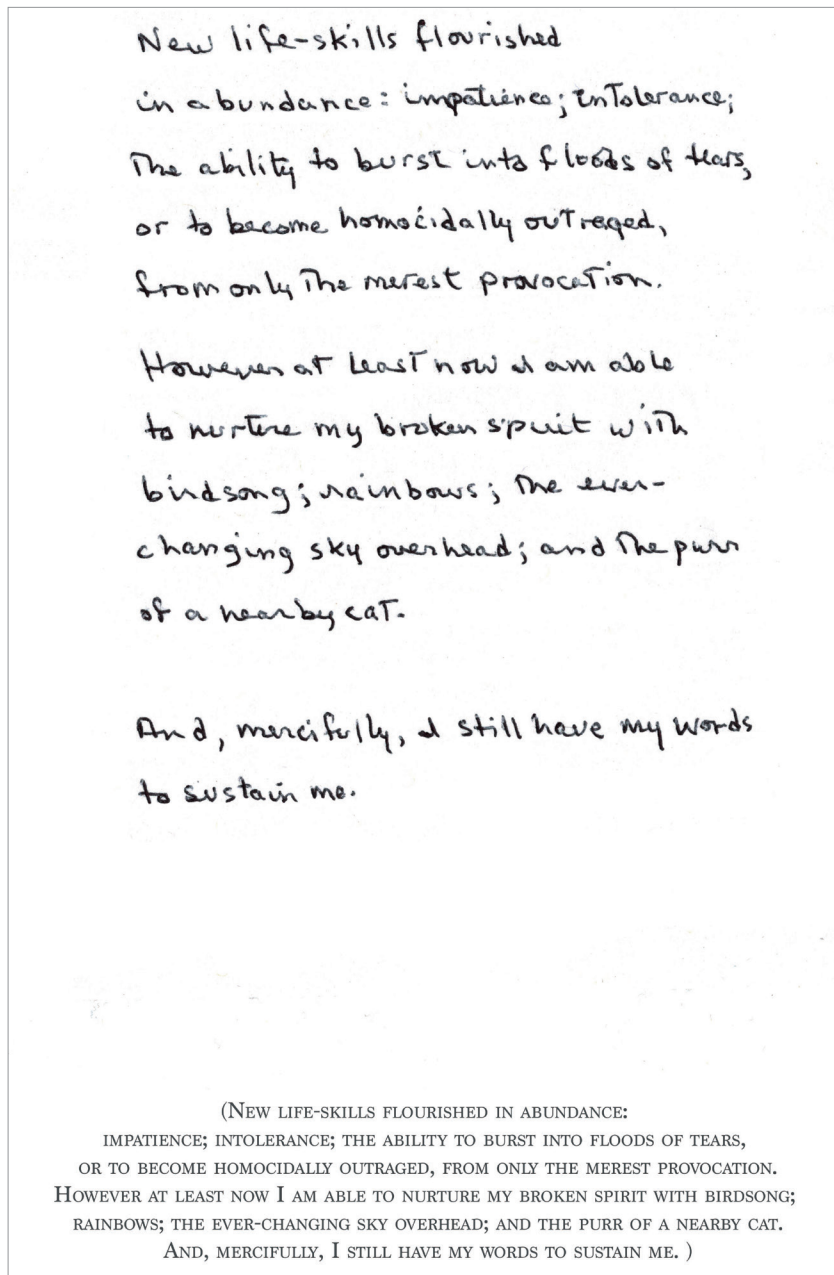
Another series, 'Different Strokes', shows a stroke survivor gesticulating as she describes her difficulties using public transport and reading maps since the stroke. A collection of handwritten texts reflect poignantly, poetically and humorously on the author's life after stroke (see Figures 4 and 5).

Figure 4: A handwritten image by a stroke survivor from the series 'Different Strokes'

(MY DAY CHANGE ACCORDING TO THE DEGREE OF PAIN I AM IN.
I HAVE MULTIPLE ILLNESS WHICH LEAVE ME IN LOTS OF PAIN.)

Credit: Emilija Milusauskaite, 2015

Figure 5: A handwritten image by a stroke survivor from the series 'Different Strokes'

(NEW LIFE-SKILLS FLOURISHED IN ABUNDANCE:
IMPATIENCE; INTOLERANCE; THE ABILITY TO BURST INTO FLOODS OF TEARS,
OR TO BECOME HOMOCIDALLY OUTRAGED, FROM ONLY THE MEREST PROVOCATION.
HOWEVER AT LEAST NOW I AM ABLE TO NURTURE MY BROKEN SPIRIT WITH BIRDSONG;
RAINBOWS; THE EVER-CHANGING SKY OVERHEAD; AND THE PURR OF A NEARBY CAT.
AND, MERCIFULLY, I STILL HAVE MY WORDS TO SUSTAIN ME.)

Credit: Emilija Milusauskaite, 2015

Three films feature a stroke survivor and their personal narrative (Castiglioni, 2015). In one, a survivor walks through a park while describing problems with directions following her stroke. The second features a stroke survivor in his own home. Affected by aphasia (a common communication disability after stroke), he struggles to talk about his family. The third film portrays a stroke survivor and his wife discussing the impact stroke has had on their relationships and working lives. The art installation was a boulder with a single balloon attached, suggesting the impact of stroke-related disability compared to a 'carefree' life without stroke.

Credit: Jenny Cook

The exhibition was launched at the SLSR20 research symposium, with 200 people attending. Subsequently, it has been shown at a 'Research in the Community' event attended by 50 people, presented and discussed with two community stroke groups and displayed at a commercial art gallery for two weeks (see Figure 6). We used institutional social media channels to promote the images and exhibition dates. The student artists presented the artwork at their college's end-of-year exhibition, and featured it on their personal web pages and online portfolios.

Strategies for critical reflection

We aimed to maximize the opportunity to learn from this experience, and so adopted a 'critical reflection' approach to our engagement (Fook, 2011). As coordinators of the project, we regularly reflected on how the project was progressing. For example, during our monthly project-planning meetings, we discussed and noted our successes and challenges, including institutional practices that helped or hindered the project. Six months after the initial stage of the project had been completed (with the first exhibition of the artwork), we conducted reflective group discussions, with the student artists (n=4) and with the stroke survivors (n=6). We also held individual conversations with two stroke survivors who were unable to attend the group discussion. In all discussions we reflected on initial perceptions of the project and its aims, reasons for participation, experience of the process and how the artwork materialized, impressions and impact of the finished artwork and thoughts on the project's ongoing development. With permission, we recorded all discussions. The critically reflective notes and transcripts, along with feedback from exhibition audiences and exhibition space managers, formed our data set for analysis. We undertook a thematic analysis, to identify the range of experiences among the participant groups and the learning that would inform the future development of the project.

Project planning and development: From conception to evaluation

In the following sections, we critically reflect on the process of establishing the visual arts project, including factors that facilitated and hindered the project.

Conceptual development

From the initial idea, the concept took some six months to develop. We adopted an iterative approach, seeking views and refining ideas through ongoing conversations involving all partners. As this was unchartered territory for both researchers and stroke survivors, it was initially difficult to talk about intangibles, such as what the resulting art might look like. Even once the student artists were involved they could not definitively say what the end product would be: the creative process was 'organic' and evolving, with the resulting artwork dependent on the interactions and discussions between student artists and stroke survivors.

The student artists attended two SRPFG meetings before beginning the project. Their evident enthusiasm seemed to help 'warm up' the stroke survivors to the project and give it momentum (see Figure 7). The student artists commented that these early exchanges had helped them understand that there were other aspects of stroke, beyond preconceived ideas about medical treatments and disability, which could be portrayed through their artwork. In reaction to this, the stroke survivors suggested that the project's objective might be to provide an alternative representation of stroke from the usual images in the media (particularly signs of acute stroke, such as facial droop and weak limbs, often seen in campaigns to raise awareness of stroke).

Figure 7: The student artists at a Stroke Research Patients and Family Group meeting

Credit: Jenny Cook

Funding applications

Identifying and securing funds for project expenses (such as travel, materials, exhibition space hire) was challenging. Our engagement project seemed too small to qualify for large grants from major funders. Most such funders require a cultural partner to collaborate with on the funding application, yet we were advised by our institutional engagement department that it would be hard to secure a cultural partner without having funds in place. We made five applications for small amounts of money, of which three were successful. This represents a disproportionately large amount of administrative work compared with the modest funds secured (approximately £2,000).

Finding artists to work on the project

As it had become apparent that funding would be hard to come by, we needed artists who were prepared to work on an expenses-only basis. We approached a number of art colleges (higher education institutions) in the vicinity to discuss our project ideas, with the hope that students might welcome the chance to be provided with subject material and gain experience from working to a commissioned brief. Additionally, a collaboration with a local college would help tie in the project to the area in South London from which the SLSR draws its research participants. Camberwell College of Arts responded positively and the course leader for the Batchelor of Arts in Photography identified six students who had experience in other visual arts, such as making short films and installations, as well as in photography. The exhibition would therefore be potentially more varied and novel than the simple, straightforward portrait photographs we had envisaged at the outset.

Working with local students had the benefit of bringing two generations together, lending the project further opportunities to engage with a younger audience in South East London. This enabled us to apply for further funding from a foundation with particular interest in giving back to the community and promoting well-being through the arts.

Stroke survivors who participated

The stroke survivors who agreed to work with the student artists to help devise, and potentially feature in, art pieces tended to be regular attenders and active contributors in SRPFG meetings. Some were keen to be involved as soon as the project was mentioned, and were happy to be portrayed in photographs. Others wanted to discuss it with their families first. A small number of participants, although intrigued by the concept, did not want to be identifiable in the resulting artwork. The student artists and the course leader gave reassurance that the visual representation did not have to be a standard portrait: stroke survivors could have parts of their body anonymously photographed, or an object representing their story might form the subject of the artwork. We encouraged the stroke survivors to be frank about how they would like to be featured or have their stories represented, and to make this clear to the student artist they worked with.

Project management and working relationships

Once we had engaged the student artists and stroke survivors, we had about seven months before the exhibition launch. For us this project was an extra task to be fitted in alongside our commitments to research, other engagement projects, teaching and organizing the academic symposium itself. These time pressures meant that we would not be able to oversee the student artists directly, so we agreed with their course

leader that he would have project management responsibility, including supervising the students' progress and ensuring that the deadline for handing over the finished work would be met. Communication between ourselves, the course leader and the students needed to be mostly by email, and this occasionally led to misunderstandings. We found it somewhat frustrating to be at this distance from the creative process, and would have preferred to be more involved, had time allowed.

These communication difficulties also meant that the necessary contractual agreements regarding delivery of the work, payment of expenses, copyright and so on were not sufficiently clear until a relatively late stage in the production process.

We encountered an additional administrative hurdle when it came to paying the agreed fees to the student artists and project manager, which we had assumed would be a straightforward process. Institutional processes made this surprisingly complex; in hindsight we should have discussed this with our respective institutions' finance departments before agreeing the form of payment.

Promotion and securing exhibition space

We were keen to ensure the work had a life beyond the research symposium for which it was created. To secure other exhibition spaces and support with promoting the project, we contacted a number of university and NHS Trust departments as well as small local commercial art galleries. We found that support (of a practical nature, at least) within the university for public engagement/arts projects was limited to larger scale projects that could promise greater impact. On enquiring about potential exhibition spaces, we usually found that these were booked up several months in advance and that many charged a fee beyond our budget. We and the stroke survivors were also keen to display the work on the stroke ward of one of the local hospitals, but were advised that infection control measures and policies prohibited artwork being installed within the ward. The multimedia nature of the completed artwork made it difficult to display it in its entirety; for example, the films required audiovisual equipment that was beyond our budget.

Critically reflecting on participant experiences

In this section we reflect on the experiences of the stroke survivors and student artists.

Motivation to participate in the project

We – researchers, stroke survivors and student artists – had in common an interest in participating in a novel engagement project, with the potential for personal development, and a desire to draw attention to the individual experience of life after stroke. The student artists were motivated by the opportunity to 'push the boundaries of [their] practice and explore something new' by working with older people whose life experiences were different to their own. Some had very personal reasons for wanting to collaborate in the project; for instance, one said that she was 'really interested in … personal trauma, you know overcoming things and so on … as a subject for my studies'.

For the stroke survivors, participating in an arts project with young people was very different to the usual research advisory group activities (for instance, critiquing research proposals, and interacting with academics and clinicians). For example, one explained her interest in taking part this way: 'Well anything that is different, broaden my horizons I could say. And to see what the younger generation are getting up to.'

The stroke survivors also wanted to inspire other survivors to move on with their lives: 'It makes people, the pictures and seeing them, they would be able to see "oh,

if I am having a stroke I can still move on and still do many things in life", that is what I was trying to portray.'

The researchers had additional motivations and objectives. In addition to our initial desire to tell the 'human story' behind our epidemiological research, we saw this as an opportunity to raise the profile of our research among a wider public.

Although the expressed motivations of the different groups involved were slightly different, they were not necessarily in conflict.

Expectations of the project and exhibition

In setting up our collaboration with the student artists, we emphasized that we would allow them to take the brief in a direction of their choice. We trusted that they would be more creative than us and we wanted them to be free to work with stroke survivors on a mutually interesting idea. Therefore, we did not have specific expectations beyond the production of visually appealing artwork. In our early conversations with the student artists, they seemed agreeable to this way of working.

In our retrospective discussions with student artists and stroke survivors, it was difficult to draw out what these groups' expectations had been, before and during the process of creating the work. However, stroke survivors expressed uncertainty regarding the project's purpose. For example, one said she was not sure about what the artist sought to convey in the photographs: 'I didn't really realize they were trying to portray stroke in its wider sense. I assumed they were trying to find people who didn't look too bad after a stroke so they could say to people "look, you don't have to look like death warmed up".' It might have been preferable to have clarified the expectations of the stroke survivors early on in the project, as we could have worked through potential misunderstandings. On the other hand, it was perhaps an inevitable part of the creative process that expectations and understanding of the aims of the project changed over time.

Experiences during the creative process

The stroke survivors and student artists had generally positive experiences of the process of creating the artworks: they enjoyed interacting with one another, and the stroke survivors gained a good impression of the students' interest in the project. However, one student artist told us that the stroke survivor with whom she had been working had admitted to her that discussing his own experiences could cause temporary anxiety for him.

We had tried to prepare the students to work with stroke survivors by giving them an introduction to stroke as a disease and to our stroke research programme and by offering advice on working with stroke survivors. Yet, it was an emotional experience for the students to see how some stroke survivors were affected by disability and isolation. One commented, 'I was really emotional after each meeting [with the stroke survivor], I think I cried on the bus home.' More positively, they felt they had helped to temporarily relieve loneliness and, through asking about stroke survivors' experiences, even provided a 'therapeutic' outlet. The student artists were concerned with achieving a sympathetic portrayal of the stroke survivors. They were aware that the subject matter was sensitive, requiring careful treatment in order to achieve a sympathetic portrayal of life after stroke. One said, 'I was worried about making them too exposed or to do it in the wrong way and that was really hard to get the right feeling to it.'

The student artists agreed that this project was a departure from their usual way of working in their undergraduate studies, in that normally they would 'do anything

[they] want'. They were interested in the challenge of offering stroke survivors a say in the creative process. One said:

> I was interested in the fact that what I would produce is not only a product that I would imagine but it would depend on someone else, someone else would have shaped it, it's not just me. Usually I do what I want to do, you know. There were some limits but also some plusses that these people gave to me.

The intention had been that the stroke survivors would contribute their own creative ideas, and the students were in principle prepared to allow this. However, one survivor suggested that his story, and therefore his contribution, was to some extent peripheral to the process of taking a carefully composed photograph:

> Well they humped in enough [photographic] equipment to sink a battleship and having unloaded all that lot they asked me a few questions … How long have you had a stroke, how it had affected me, how it affected relationships with other people, how about getting out. All the usual … kinds of things a social worker might ask. … And then it was a case of 'we need to plug this in' and then it was 'do you mind us taking photos'. Sit down, stand up. Nobody said 'look intelligent'. I sat here and then stood up by the window.

Perceptions of the artwork

While stroke survivor participants had praise for the exhibition overall, some thought that it was perhaps too positive about life after stroke, and did not offer an explicit portrayal of ill health or disability, or explain the need for mobility aids:

> I just looked like it could have been any woman sitting there, it didn't look as though I'd got anything wrong … or is that the whole idea? That even though you have had a stroke you don't look any different? Everyone assumes that they're going to look … lopsided, or not with it, vacant stare.

This response seemed to contradict the desire of the stroke survivors at the start of the project, that the exhibition should avoid stereotypical representation of people disabled by stroke. In fact, some of the handwritten reflections and the short films more explicitly portrayed the consequences of stroke that they experienced, and how they tried to overcome them. Yet in group discussions, the stroke survivors talked mostly about the photographs. There seemed to be a desire for a less subtle incorporation of the theme of disability in this project, which some stroke survivors felt the photographic work perhaps did not achieve.

One stroke survivor saw the photographs as showing a positive side of stroke and providing opportunities to talk about stroke to others who have not had this experience:

> … it's a big thing to talk about because people think it [having a stroke] is the end ... because people, when I tell them I've had a couple of strokes, they are horrified and they think you have absolutely gone out of your mind, but you don't.

The students did not provide detailed explanations of their creative ideas to display alongside the artwork, and there was no time between submission of the artwork and the exhibition launch to follow this up. Stroke survivors commented that this lack of
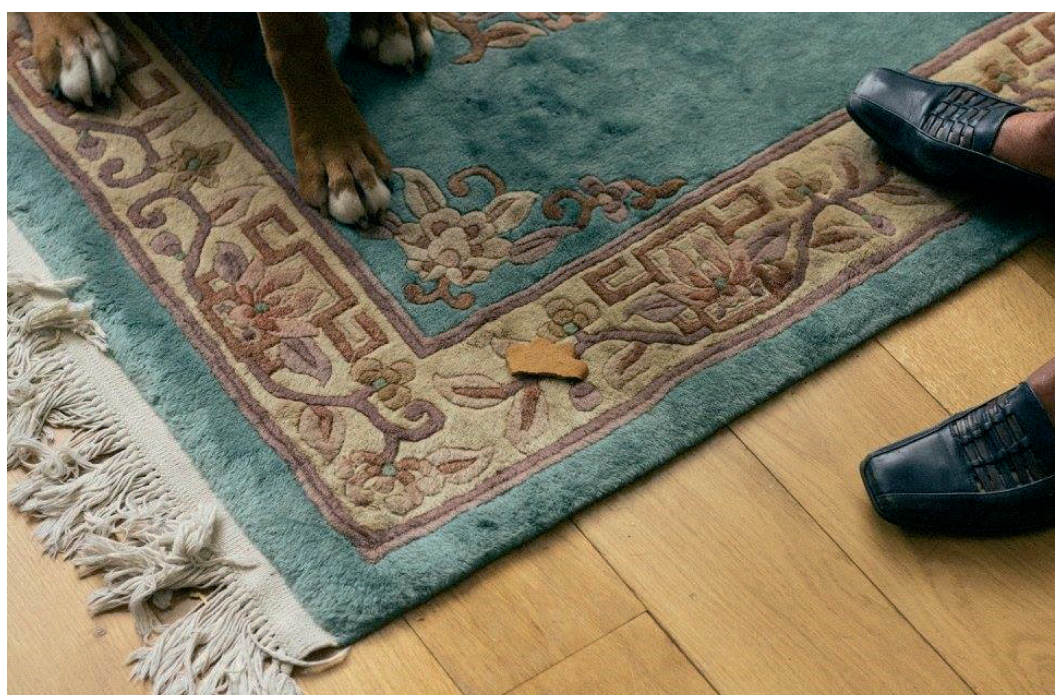
individual contextual information left viewers unclear about what the message of the artwork was.

Figure 8: Breaking the biscuit: A Swedish custom; from the series 'A Great Wish'

Credit: Halszka Staniewicz, 2015

Figure 9: Breaking the biscuit: A Swedish custom; from the series 'A Great Wish'

Credit: Halszka Staniewicz, 2015

We were not surprised to find that people interpreted the artwork in different ways. It may be argued that art is characterized by allowing multiple possible interpretations, rather than conveying a single 'message'. Had we tried to steer the students and participants towards explicitly portraying a theme, such as 'research participation', the result may have seemed rather contrived. One consequence of the work produced was this thought-provoking effect. For instance, one series of photographs, 'The Great Wish', shows Greta, originally from Sweden, first with a biscuit broken in her hand and then, in a second picture, with the broken biscuit pieces on the floor (see Figures 8 and 9). Before hearing the intended message of these images, guessed explanations from those viewing the photographs included that the biscuit represented a person being 'broken' physically or mentally by their stroke (a researcher) and the difficulty of picking something up off the floor when one's mobility has been affected by stroke (a stroke survivor). We expected to relate the images to stroke and disability, and this influenced our interpretation. However, Greta told us that it portrayed an old Swedish custom of granting a wish to the person who successfully broke the biscuit into three pieces – anyone can break a biscuit into four pieces.

As researchers we were delighted to see the stroke survivors, whom we most often encounter in formal group meetings, portrayed in their own settings. We were pleased with how uplifting several of the photographs in particular were. One of the researchers commented: 'The thing I really liked about the photos was that everybody, they didn't look like the stereotype of the stroke victim … I thought everyone looked strong and proud.' A visitor to the exhibition later emailed us to share their emotional reaction to it, also noting the sense of pride that one of the photographs evoked (see Figure 10):

> As someone who has never been in contact with a stroke patient, it is easy to underestimate the impact of a stroke on quality of life. The photo of Jawad really moved me, almost instantly I welled up and cried. He was stood so proudly in his suit! I was desperate to learn about his story.

Figure 10: Jawad; from the series 'The Journey'

Credit: Hedvig Larsson, 2015

The owner of a small commercial gallery in South London where the work was shown gave us his perspective: 'My impression of the project was … to raise awareness of a very worthy issue that affects every part of our society … But lacked any wow or focal point for the man or woman in the street.' He neatly summarizes the difficulty in generating impact from a modest arts project that would have benefited from greater professional advice on curation and promotion.

Discussion and conclusion

Using the arts as a means to engage the public with science is becoming increasingly popular, yet the literature lacks discussion concerning the process of how such projects evolve, the challenges they present or the impact of such collaborations. While this paper does not offer a formal evaluation, it provides a novel, critically reflective view on the process from participants' perspectives. The reflection raises three main discussion points concerning the practice and benefits of engaging publics in scientific research.

First, our experience raises a broad and recurrent question that has implications for public engagement activities, not just those taking an arts-based approach: what is public engagement for? Initially we set out with a simple aim – to celebrate in an interesting way the contribution of stroke survivors to our research. We then realized that our visual arts project could help promote the work that we do to a broader audience, and we have since used the artwork to help stimulate audience discussions and contextualize the numerical data our researchers have presented. Our experience reflects the definition of public engagement as promoted by the National Co-ordinating Centre for Public Engagement: that public engagement aims to share higher education research activity with the public, 'involving interaction and listening with the aim to generate mutual benefit' (NCCPE, 2016). However, our experience also resonates with the views of some commentators who have begun to question rationales for public engagement, which may primarily serve institutional concerns for raising profile and demonstrating return on research investment (Watermeyer, 2011; Watermeyer, 2015; Chikoore *et al.*, 2016).

This leads on to the second point that our experience raises: a mismatch between institutional expectations for researcher-driven public engagement and the resources allocated to it. We struggled to garner institutional support for our engagement project. This was apparently because our plans were modest and did not involve established artists, or cultural partners, with the potential to generate large-scale publicity for the benefit of the university. We were advised by our institution that our project's scope was too limited to attract a cultural partner, and, frustratingly, this seemed to close doors to other meaningful financial or promotional support.

If institutional public engagement strategies target their limited budgets to a few expensive, high-profile initiatives requiring cultural partners, this restricts the resources available for smaller projects that may have greater potential to engage local communities directly, with greater impact on knowledge production and interpretation from a number of perspectives. This adds further nuance to our question, what is public engagement for? Is it about raising the profiles of institutions or about engaging members of the local community in research that concerns them? Furthermore, strategies that focus on high-profile initiatives may overlook the need to create an infrastructure that supports and encourages more researchers to engage with their publics, with institutional support appropriate to the scope of their plans. We certainly experienced the pressures of doing public engagement alongside our other work commitments. As researchers' contracts are often short and career

recognition structures within universities still prioritize traditional academic outputs (grants, publications and teaching), researchers have to prioritize the core activities of their role. These factors may continue to persuade most researchers that public engagement is not for them (TNS-BMRB and PSI, 2015).

Our reflection highlights the practical and ethical challenges of working across research- and arts-based disciplines, as we encountered diverse and often competing priorities and approaches. This raises our third point, the challenge of art as a means of communication. There are inherent tensions in arts–research engagement activities, yet scant comment or acknowledgement of these tensions in the literature. Nor is there much advice about how to make these interdisciplinary collaborations work in practice. Epidemiological studies such as stroke registers are designed to capture information from many people and use statistical inferences to answer research questions. They are dispassionate, and not designed to communicate what having a stroke means or feels like. Art has the capability to do this in an engaging and emotive way, by, for instance, portraying how people adjust to life after stroke. We were pleased by the emotive responses our visual art project received from those taking part, as well as from those viewing the artworks. Art pieces are intrinsically more open to interpretation than the methods or findings of a scientific study (Ede, 2002). However, by the same token they are difficult to evaluate using standard measures favoured by institutions concerned with impact, such as feedback surveys and audience demographics (Parsons and Boydell, 2012; Watermeyer, 2015). Using art as a means to communicate research findings may therefore be problematic if there is a particular message to be disseminated. If, however, the value in engagement is to stimulate two-way discussion and challenge scientific assumptions, then the use of art to engage the public with science offers this potential.

Box 2: Planning an arts engagement project: Recommendations

- **Contractual.** Seek advice on any contracts, copyright or licensing agreements, agree expenses and how these will be paid to make sure that agreements are transparent to all parties.
- **Creative process.** Consider time for preparation and agreeing limits of the brief, including thinking ahead about how products will be displayed or disseminated.
- **Seek advice.** Where possible consult with professional exhibitors, curators or programme directors with experience in the relevant area.
- **Promotional.** Build relationships with potential partners as soon as possible after project inception, so as to create a mutually practicable timetable for promoting and advertising the project.
- **Funding and sustainability.** Consider where to approach for funding as early as possible, how the products will continue to have impact after initial launch and whether further funding will be needed.

Future research and implications for practice

Our experience was challenging but rewarding because of the lessons we learned through reflecting on the process (see Box 2). However, this has also highlighted further questions that are worth exploring systematically. These include further understanding of the value of public engagement for institutions, researchers, participants and publics, and the extent to which different, even conflicting values, may accrue for different stakeholders. Questions of how diverse types of impact – cultural, social,

economic – may be derived should also be explored. Our experience also leads us to argue that institutions need to review their strategies and structures to ensure that they harness the creativity and enthusiasm of as many researchers as possible, and to deliver a diverse and appropriate menu of public engagement activities.

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