

Case Study 3: A Pattern for Progress

Building a sustainable relationship with patient organisations

At a glance

Strategic Public Engagement Aim	Aim 3: To give patients a voice in our research and engagement activities that is valued and utilised (Primary) Aim 2: To connect to local under-served communities and empower them to access stem cell research (Secondary)
Dates	Workshops: February - March 2019 Patient Art Launch: 12 December 2019
Audience	MS patients and carers Artists Healthcare professionals
Reach	Workshops: 24 Patient Art Launch: 50
Location	Workshops: Littleport Leisure Centre Patient Art Launch: Jeffrey Cheah Biomedical Centre
Project lead	Harold Offeh, Artist Bob Bragger, MS Society Cambridge & District Branch
Researcher participation	Workshops: 6 Patient Art Launch: 14
Collaborators	Kate Welton, Ceramic artist Maeve Polkinhorn, Curator
Cost	£8,187.82

Project Aims

- To empower MS patients and carers to access contemporary research
- To build relationships and mutual understanding between researchers and patients
- To explore lived experiences of MS and patient voices through arts practice and co-creation
- To engage in dialogue in a non-clinical setting, contributing to the researchers' personal and professional development
- To start conversations that can inform future research questions
- To establish long-term partnerships with patient organisations

Summary

A Pattern for Progress, was initiated as a part of the artwork commission for the Jeffrey Cheah Biomedical Centre to bring new audiences on campus into contact with our research. The public engagement team facilitated the partnership between artist Harold Offeh, the local MS Society and stem cell researchers to explore their common interests and the ensure that patient perspectives were a visible and valued part of the fabric of our new building. The project had two phases;

Phase 1: Workshops

Led by Harold, a series of four workshops took place between February and March 2019, bringing together 20 Multiple Sclerosis (MS) patients, 1 Parkinson's patient, 3 carers, and 6 MS stem cell

researchers (Franklin Group) for facilitated ceramic sessions to explore experiences of living with and researching MS. The two-hour workshops were held in Littleport Leisure Centre, over 20 miles from the Institute, to ensure the project engaged patients in their local community, and supported their access needs.

Together, the group produced a series of individually designed and glazed tiles representing their understanding of the disease, with support from ceramist Kate Welton. These tiles were curated by Harold into a collective 'wallpaper' pattern of experiences with an accompanying film capturing the powerful reflections of participants, in their own voice. You can view the film here:

<https://www.stemcells.cam.ac.uk/about-us/jcbc/public-art-at-jcbc/art-commissions/harold-offeh>

The workshops created a 'safe space' for participants to build relationships and mutual understanding through a collective endeavour – art-making. Traditional hierarchies between researcher and patient were broken down, and personal exchanges allowed patients lived experiences to give depth and colour to scientific questions, as well as current research to be shared. The hands-on nature of the activities also highlighted the limitations that MS patients face in their daily lives.

Phase 2: Patient Art Launch

After months of development, the final artwork was installed as a flagship piece in our new public exhibition space in September 2019. The space, on the ground floor of our building, is publicly accessible all year round, and provides a 'hub' for us to engage visitors to the campus, including patients and healthcare workers. To celebrate the opening of the space, and acknowledge the contribution of the MS patient community, we hosted a bespoke launch, including minibus travel from Littleport. We used the opportunity showcase the impact a project of this nature can have, inviting researchers from other MS and Parkinson's research groups (Karadottir and Barker Group), as well as wider patient networks and MS healthcare workers. The afternoon was the first opportunity to screen the 30-minute 'centrepiece' film, which provided a moving insight into the groups journey together. The session was completed by short talks from the artist, MS Society and group leader, with a lively Q&A exploring the future of stem cell therapies. The screening was followed by informal networking over tea and coffee, providing a chance for conversations between patients and researchers, and to see the final artwork installed in situ, in the space.

The event allowed patients and carers the opportunity to find out more about the status of stem cell research in MS and Parkinson's disease, and see themselves as welcome contributors and visitors to our new building in the future. It also provided researchers with an opportunity to come out of the lab, and experience first hand the potential impact their research could make.

A Pattern for Progress will be on display at the Jeffrey Cheah Biomedical Centre until Sept 2020, with the film available online through Cambridge Betterment Society, MS Society and Institute channels.

Who did we reach?

The workshops engaged 24 patients and carers based in Littleport, who regularly participate in local MS Society initiatives, such as exercise classes. Most are disabled and not able to work.

In addition, more patients and healthcare professionals were able to attend the Patient Art Launch. The age range was between 16 – 82 years old, with over 50% of the participants over 50. Most attendees came from the South Cambridgeshire region, with 17% coming from beyond the CB

postcode. Around 80% of the participants had never visited a research facility before. 48% of the participants had taken part in the Phase 1 workshops with 52% coming to the event to find out more about MS research, support patients who took part in the workshop and to meet researchers.

Outcomes

For the public:

- 90% of participants at the art launch wanted to take part in a future workshop, with Bob Bragger (MS Society) reporting frequent queries from other patient groups who want to get involved and start their own collaborative arts projects with the Institute.
- At the launch 70% attendees mentioned talking to a researcher, with 40% saying this was the first time they'd been given the opportunity to speak with a scientist, highlighting the difficulty for members of patient communities in accessing research.
- For those who met a researcher for the first time, they were impressed to be listened to and that researchers were interested in the way that they coped with the disease.
- Participants felt that bringing the people involved in the workshops together to see the unveiling of the final art piece made them feel valued.
- All participants mentioned that it was easy to come to the launch event, because of arranged transportation.
- Overall, patients wanted to see and get involved in more art-based projects. They wanted to know how the research will have progressed in a year's time. They also valued having continued access to research in future.

Bob Bragger, MS Society: *'Prior to the event each of the people that made a tile stated that – 'they are not artistic', 'they are disabled how do I expect them to be able to participate'. Every single person designed, constructed and coloured a tile, yes with help, but they completed it themselves'*

'The project has been discussed at the regular group meeting since its conclusion and the December event was attended by all but 2 of the participants. To see their work on the wall and to speak with the young scientists meant a great deal to all, to see the film made of the project and to hear the words was, I believe, a powerful message to all of the people that work at the Wellcome MRC Stem Cell Institute regarding the importance of the research that they carry out'

'In terms of the difference the overall project has made to the MS Society Branch, we now understand more of how research is carried out and that we are not just a case file in a hospital filing cabinet. I firmly believe that by working with us and by meeting more people that suffer with the condition it gives some very clever people a view of why they are doing what they do and who they are doing it for'.

Workshop participant Jacqueline Tevlin, Carer; *'Very excited to be part of this particularly special, collaborative, art's project. Meeting all the participants at the first session illustrated our diversity; I was rather in awe of the clever researchers. Although they soon reassured us with their charm and good humour - no question about their research was off-limits; so this was a unique opportunity to ask and discover. The fun element of design broke down the barriers and soon we were all "playing" with form, line and colour - as if at primary school! As to the finished product of our artistic endeavours - I will be very happy to see the finished product and know that in some small way - I have made a contribution!'*

Workshop participant Aiden Tevlin, MS Patient: *'...it was useful for the researchers to see that we are real people with real lives, and for us to meet some of those who are doing the scientific research. The individuals are "keen and hungry" which is reassuring as progress understandably is slow for drug development. Money for research is hard raised and it is comforting that it is being used wisely. I hope that the art installation not only decorates the new neurosciences building but inspires a meaningful goal - in life one never knows what will happen for good or ill. We are all human and it is only by working together that achievement is richly attained.'*

MS Patient at Art Launch: *'I never realised that a research building could have an exhibition space and be open to the public. I love the building and thank you for organising the event.'*

MS Patient at Art Launch: *'I enjoyed hearing about the progress in research and meeting the people involved. As well as seeing the wall with our tiles.'*

Curator, Maeve Polkinhorn: *'It has been a fantastic project to have been involved in on the production side. Harold Offeh was very successful in bringing people together to share their experiences of MS. The resulting project is very moving and I hope it will be shown in many other galleries and different contexts in the future.'*

For researchers:

- 9 Postdocs, 4 PhD students and 1 PI took part across course of the workshops and launch.
- Feedback received from the researchers indicated the huge difference the project to how they understand the lived condition of MS and how the patients manage their disease.
- There was a clear desire to share existing and future research with the patient community.

Workshop participant, researcher: *'Even though I lived with two family members with MS, talking to other people always enlightens me on the various challenges faced, by the different types of people with the disease. As a researcher, I think it's extremely important to stay connected to the actual individual who is suffering the disease. Through the workshops, I have met so many different people, and learnt about so many different symptoms and experiences, which aren't really touched on or focused on in the research arena. I thought it was outstanding, I was very enlightened and met some wonderful people who have jobs and families, and at the same time they are struggling with the disease, but they're still staying happy with and optimistic and hopeful. For me that's the ultimate inspiration to go to the lab, and continue the work that we do to hopefully help these people one day.'*

Workshop participant, researcher: *'I have interacted with a lot of MS patients in other art outreach projects, but actually, this project was the first time we were on an equal footing, which was really humbling and really nice, because we all just spoke about our lives and the focus wasn't about just the MS, it was more about the human behind that. They didn't know if I was an artist or a scientist, which meant we had really normal conversations. I think this is unusual because often when you are a scientist you get put up on some sort of pedestal, and you are expected to take responsibility for all of science and to speak on behalf of all scientist. It was a really nice experience to be able to just 'be', and then to have this common physical thing that we were all working on, and it prompted some really odd conversations sometimes. I think it's easy to forget, as a scientist, how little people understand of the technicality. We can become highfalutin sometimes and forget that it's really complicated to %99 of the population, so we have to step down off that pedestal and explain it in real terms.'*

Workshop participant, researcher: *'It was really great seeing people with MS who are very determined and courageous. I learned so much about MS and also how we can help them, and how we can bring them into our research to motivate us, and also to give them more information. I really enjoyed seeing how enthusiastic they were, and how we communicated very openly and very genuinely. I enjoyed very much being 1-2-1 or being all together, chatting and telling our feelings and expectations.'*

Looking forward

The success of *A Pattern For Progress* has initiated a new wave of art collaborations with the MS Society across Cambridgeshire and East Anglia including a graffiti wall project in Peterborough, Huntingdon and Ely. Bob Bragger from the MS Society has become an integral part of the Institute's engagement network, speaking to researchers, funders and public engagement practitioners to share the learnings from the project. Bob has also joined our Institute Public Engagement Steering Committee to feed into future patient-led engagement approaches, and continues to connect us to other patient charities including local branches of Parkinson's UK and NHS Trusts.

Image gallery



Ceramics Workshops, Littleport

Patient's create personalised ceramic tiles depicting their experience of MS and hopes for research



Art Launch, December 2019

Artist Harold Offeh introduces the project. Researchers, patients and carers mix after the event



Art Launch, December 2019

MS Society participants pick out their tiles in the installed artwork. MS researchers and patients engage