



Our cancer journey: artistic expressions of living with cancer

Overview and context

Our cancer journey aimed to bring together patient representatives and LSHTM staff to produce creative expressions of the experiences and feelings of people diagnosed with cancer, not only during the time of their diagnoses, but also over the following months and years. As researchers normally accustomed to working with electronic health records and patient data, we wanted to connect directly with individuals affected by cancer to understand their experiences with the disease, and have the opportunity to share with them what we do, and how it involves them and their data, and why this is important.

We developed and delivered a creative workshop with local artists, and the resulting participant artwork has been exhibited publicly and at a conference.

Project Lead:

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Project Team:

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The basics

Who: Individuals affected by cancer

What: To bring together patient representatives and LSHTM staff

When: November 2018

Where: Newcastle, UK

How: One-day workshop

Funder: LSHTM Small Grants Scheme

By the numbers

Development time: Aug – Nov 2018

Project duration: 1 day

No. of participants: 8

LSHTM staff involved: 3

Other professional staff: 2

No. of volunteers: 0

Project budget: £1,236

Project aims

- To create an opportunity to bring together patient representatives and LSHTM staff who work with cancer patient data, to engage with each other and interact in a creative environment to stimulate dialogue and mutual understanding.
- To allow participants currently living with cancer to reflect on their diagnosis and attempt to understand how their body and feelings have changed over time, expressing this through their own individual pieces of art.
- To raise awareness that each person diagnosed with cancer goes through their own individual journey, and no two people deal with their diagnosis in the same way.
- To deliver an interesting and engaging scientific public engagement activity in the North East of England, which is regularly overlooked for such events.

The audience

Our cancer journey was targeted at individuals affected by cancer, including those currently living with cancer or with a previous diagnosis, and their carers, family members and friends. The workshop took place in a community space in Newcastle on 30 November 2018 and involved 8 participants: 7 patient representatives and 1 carer. We approached the

local Maggie's Centre in Newcastle, the Cancer Research UK Centre in Newcastle and the National Cancer Research Institute (NCRI) to recruit participants for the workshop.

We reached a wider public audience through exhibitions of the artworks at the Newcastle City Library & Community Hub (28 March – 3 April 2019) and Seacole Social at LSHTM (1 May – 15 August 2019). We also exhibited the artworks at two National Cancer Research Institute events, including their conference in November 2019 in Glasgow, enabling us to reach other researchers and clinicians. It is now permanently exhibited in the Non-communicable Disease Epidemiology (NCDE) corridor to bring patient experiences to the heart of our daily tasks and inspire other researchers to reach out to patients.

The project

We developed and delivered a creative workshop to engage with individuals affected by cancer, giving them a platform from which they could share their experience of cancer and the little talked about long-term physical and mental side effects, which are regularly researched at LSHTM.

The participants worked with local artists, Jayne Dent and Philippa Kelly, to produce mono-prints to represent their bodies and feelings at two different time periods: the time of their cancer diagnosis and the present day. Mono-printing is a technique that produces a single original print. It is a way of exploring expressive drawing in an unconventional way, as the individual must draw directly into the ink or on the back of a sheet of acetate to create the image, which will then be reversed often having picked up surprising textures and marks. The participants then produced a short blurb to explain and accompany their artwork.

Following the workshop, the participant's artwork and blurbs were exhibited locally at the Newcastle City Library & Community Hub to which the participant's family and friends were invited, and open invitations were made to members of Cancer Research UK centre, cancer clinical trials unit, national tissue bank, and local Macmillan cancer centres located in Newcastle. The artwork has subsequently been exhibited at Seacole Social at LSHTM and the National Cancer Research Institute Conference.

Collaboration and external partners

- **Jayne Dent:** an artist based in Newcastle. Jayne worked with us to plan and develop the workshop and resulting exhibition, and was the principal artistic facilitator of the workshop itself.
- **Philippa Kelly:** a fine art student at Northumbria University helped facilitate the workshop on the day.
- **Maggie's Centre Newcastle:** a hospital-based centre providing support for anyone affected by cancer. Maggie's distributed our electronic flyer to their networks and promoted the workshop through their social media channels.
- The **National Cancer Research Institute** and the **Cancer Research UK Centre in Newcastle** disseminated details of the workshop to their networks.

Key costs

Artists fee & workshop
delivery: £500

Exhibition materials &
catering: £324

Travel: £256

Workshop materials &
catering: £156

Before the project

Major planning and development tasks

Planning and development of the project was centred around three main areas: identifying a location for the workshop, recruitment of participants, and planning the schedule of the day. We benefited from both the local knowledge of the Artist facilitator and her experience of previous art therapy involvement, although this was the first time she had worked with those affected by cancer. We jointly developed a detailed plan for the workshop, but remained flexible in our organisation to accommodate participants' needs. This was later followed up with the planning and holding of the various exhibitions.

Main challenges

Participant recruitment: Recruitment of participants initially proved to be challenging. We started out by approaching larger, national cancer organisations to help advertise the workshop but found this generated limited impact. Once we approached local support organisation, Maggie's Centre Newcastle, which circulated details of the workshop through their social media channels, we were able to recruit a sufficient number of participants for the workshop.

Project outcomes

Our first and fourth aims were achieved at the workshop and we feel this event very much reached its overall aim of allowing us to engage with this particular group and stimulate dialogue and mutual understanding. All participants rated the workshop highly both in terms of enjoyment and the opportunity to reflect on their cancer diagnosis, which was the second aim of the project.

The unique nature of the art works produced and the stories behind each individual as recounted in their accompanying short texts worked well in an exhibition setting, enabling us to raise awareness of the individuality of a person's experience following a cancer diagnosis. Feedback we received at the exhibitions was overwhelmingly positive and supportive of both the participants and our aims.

The project also brought a human element to our work, which involves patient level data but no direct contact with patients/the public. The opportunity to talk to patient representatives about their experiences and their individual journeys was a valuable insight into living with the disease. It gave us a fresher look at research questions/proposals we are considering by reflecting and discussing the actual patient's journey and their interactions with the healthcare system.

What worked?

The individuals who signed-up for and came along to the workshop were a special group of people who, through their courage and openness, and their willingness to fully engage with the experience, made the event a unique experience for everyone involved. Having such a group at workshops is obviously not a given, but collaborating with Maggie's to recruit participants enabled us to reach people who were generally open to sharing in a workshop format. If we are able to put on future workshops, we would try our best to collaborate with Maggie's again.

The team brought together to plan and facilitate the project worked very well, and was also key to the success of the project. This was helped by having a long lead up time to allow proper planning of the event. The initial plan was to do the workshop a lot sooner, but we soon realised such a time frame would mean rushed planning.

What did not work?

The workshop was held in a community centre. Accessibility was an issue, but with the help of the staff there we overcame the challenges. With hindsight, we realise location is key as patients come with various needs and expectations. Accessing centres designed to host such workshops regularly would be ideal.

Feedback from participants

In the evaluation forms the participants were positive about their experience and that it had met their expectations. It was also very touching to hear how the workshop had helped some of the participants:

“The morning drawing exercises were brilliant at confidence building – I wouldn't have been able to do the prints without them. Being in the space, meeting other participants, being able to talk (and cry) freely, and being pushed to express feelings visually – all of this had a profound effect on me.”

“Coming together with strangers to share and learn something new was surprisingly calming a great way to cope with life's traumas!”


Future potential or plans

We would like to organise further workshops like this one to enable patients from other cities around the UK to participate and meet with researchers. Our aim is to bring together all the artwork from these workshops and exhibit them together at future conferences and events.

Advice for other researchers


- All the planning is essential, but also the ability to be flexible and read the mood on the day was a vital aspect that allowed our event to work well.
- The power of creative expression and the ability of art to act as both a form of release and the bringing together of people is second to none. Before the project, we did not quite realise the power that art had, but watching participants grow throughout the day, finding new ways of expressing their feelings, was extremely eye opening.
- From a research point of view, we learnt about the importance and value of connecting as people and what this can bring to our work. Informal conversations with participants throughout the day also allowed us to understand what is important to them and what they think should be researched.

Further information

 You can find out more about the project at the following links:


- [LSHTM Blog 'Their cancer journeys: artistic expressions of living with cancer'](#)


Contact

 For more information, please contact Public Engagement:
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