

Chapter 13

Quilts 4 Cancer: Quilting the Chemical Sciences for Pancreatic Cancer Patients



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Introduction

Pancreatic cancer has a 5-year survival rate after diagnosis of just 3.7% [1–3]. Pancreatic cancer is the 4th most aggressive cancer in the world, hard to diagnose, and is frequently discovered, at an advanced stage of development, during an emergency admission to hospital [4, 5]. Survival rates have remained stubbornly poor and there have been no major advancements in diagnosis, treatment, or prognosis in the past forty years. It is the fifth most common cause of cancer death in the UK [6] and the fourth most common in the US [7]. 80% of patients diagnosed with pancreatic cancer will die within a year of diagnosis. Chemotherapy is one method of treatment that frequently leaves patients feeling cold. This observation of patient experience became the inspiration for our project.

Every day, chemistry researchers across the United Kingdom (UK) and Ireland are working relentlessly to identify new technologies and treatments to battle this disease. However, the Royal Society of Chemistry's 'Public attitudes to chemistry' survey discovered that, when the public are asked to describe a chemist, they frequently describe those working in pharmacies [8]. This survey was the first national, in-depth study on how the UK public thinks and feels about chemistry, chemists, and chemicals [9]. It also revealed that people were interested in finding out more about chemistry, especially how it relates to their everyday life, although overall interest in and engagement with chemistry was low [10]. This is likely due to the

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Quilts 4 Cancer – Logic Model

Situation	Priorities	Aim	Quilts 4 Cancer: To bring together quilters and chemistry researchers to create research-inspired quilts for pancreatic cancer patients					
<p>Patients undergoing chemotherapy for pancreatic cancer are frequently cold during their treatments. General knowledge of pancreatic cancer signs and symptoms is low. Knowledge of chemistry research in UK and Irish Universities into new diagnostic and therapies for pancreatic cancer are also low.</p>	<p>• Provide quilts for pancreatic cancer patients to keep them warm during treatment</p> <p>• Provide a novel opportunity for chemistry researchers to share their work with the wider world</p> <p>• Provide quilters with a novel source of inspiration for their quilts, whilst also improving their knowledge of pancreatic cancer signs and symptoms</p>	<p>Inputs</p> <p>• Funding for consumables, events, and travel</p> <p>• Time (researchers)</p> <p>• Time (quilters)</p> <p>• Time (project leads)</p> <p>• Online platforms for hosting virtual info session</p> <p>• On site venues for meetings with quilters</p> <p>• Scheduling tools for digital content on social media</p>	Audience or participants			Outcomes - Impact		
			Short term learning	Intermediate Changing action	Long term Changing conditions			
			Assumptions To be checked!			External Factors		
<p>Monitoring</p> <p>Number of researchers involved, number of quilters involved, quilts made, number of attendees at events, where quilts are distributed, social media metrics</p>			<p>Assumptions To be checked!</p> <ul style="list-style-type: none"> • Researchers will want to participate in the project • Quilters will respond to the inspiration material • Quilters can afford to be involved in the project, from a financial or time perspective • Hospitals can accept quilts for vulnerable patient 			<p>External Factors</p> <ul style="list-style-type: none"> • Project reliant on receiving external funding • Reliant on sufficient material supplied by time-poor researchers • Quilters have time to get involved • Unknown circumstances 		
<p>Evaluation and monitoring</p>			<p>Evaluation</p> <p>Evaluation postcards for exhibition attendees, evaluation postcard for participants</p>					

Logic Model adapted and modified from UW Domension (2003). Program Development and Evaluation Logic Model. Available at: <http://www.uw.edu/ins/psaade/evaluation/pdf/LM03rev.pdf> (Retrieved 6/22/2012)

Fig. 13.1 Logic model for the Quilts 4 Cancer project [11]

finding that most people struggled to think of chemistry beyond their school days. This lack of an emotional connection to chemistry and knowledge of the chemists behind the research was something that we wanted to change through the delivery of our project

To plan the project, we used an outcomes-based approach called logic modelling. Logic modelling enables you to work backwards from what you are seeking to change (the outcomes) to identify the resources, activities, and audiences that will be needed to obtain your desired outcome(s). It also allows you to surface any assumptions that you may be making, alongside external factors that could affect the progress of the project. Evaluation and monitoring are embedded into the process. Please see Fig. 13.1 below for a summary of our logic model [11]. The logic model enabled us to plan our project systematically, whilst also leaving sufficient space for serendipitous outcomes.

Methodology

To successfully deliver the project, it was necessary to recruit two groups of participants: chemistry researchers working in Higher Education Institutions (HEIs) studying pancreatic cancer; and those with an interest in quilting.

Recruitment of Researchers

Our researchers were primarily recruited directly by our subject matter expert, Dr Hoskins. These researchers worked at five Higher Education Institutions (HEIs) across the UK and Ireland, namely University of Glasgow, Keele University, Robert Gordon University (RGU) Aberdeen, University of Strathclyde, and Ulster University, as well as ClinSpec Dx, a spinout from the University of Strathclyde, now known as DxCover Ltd. We also received permission from the Royal Society of Chemistry (RSC) and the charity Purple Rainbow to incorporate their logos into the project. All researchers were invited to provide a simple image based on their research, which was then used to create A4 summaries suitable for public consumption (Fig. 13.2).

These images were combined with information about the signs and symptoms of pancreatic cancer into a downloadable booklet that we distributed via our social media channels [19].

Recruitment of Quilters

Our original plan for the project involved Dr Hoskins delivering in person talks about the research and the project to quilting groups. However, the COVID-19 pandemic hit and prevented all on site events until the very end of the project. It became necessary to switch to a purely online format. We were heavily reliant on social media and word of mouth to spread the word about the project. We had a Facebook group (<https://www.facebook.com/Quilts4C>) and Instagram channel (<https://www.instagram.com/quilts4cancer/>), however we found that the most effective mechanism for reaching quilters was via our personal Tweets about the project. We also partnered with Fun Palaces Scotland to run an online Fun Palace in October 2020. Fun Palaces aim to spread the word that ‘*everyone an artist, everyone a scientist*’

Name of researcher(s)	Reference associated with their submitted image
Matthew Baker and Alexandra Sala	(12)
Bridgeen Callan	(13)
Lynn Dennany	(14)
Ross Forgan	(15)
Clare Hoskins	(16)
Clare Hoskins and Adeolu Oluwasanmi	(17)
Paul Kong Thoo Lin	(18)

Fig. 13.2 Sources for pancreatic cancer chemistry research inspired images.


[20]. To minimise barriers to involvement in our Fun Palace, we offered to provide free materials by post to those unable to make it to their local fabric stores or facing financial barriers to their involvement. Each pack contained sufficient fabric for a 12" square, as well as additional pieces of cotton fabric for creating applique designs.

Evaluation & Monitoring

To make evaluation as simple as possible, we designed two postcards for use at our events. One was based on the RSC 'Public attitudes towards chemistry' survey and consisted of a subset of the questions most relevant to our project [9]. This card was designed to be used before and after members of the public visited our exhibition to measure changes in attitudes (Fig. 13.3). It also ensured that pre- and post-visit answers were physically linked together. The data was plotted as individual data points before and after the visitors attended the exhibition. A two-tailed paired t-test was performed using GraphPad Prism version 8.0.0 for Windows (GraphPad Software, San Diego, California USA, www.graphpad.com) and individual values were plotted.

The second card was aimed at those who were directly involved in our project (researchers, quilters, longarm quilters, charities) who attended our final exhibition at the Technology and Innovation Centre, University of Strathclyde, Glasgow. It

a

Quilts for Cancer: Pre-event survey 

Please circle your response to each statement

	Strongly disagree	1	2	3	4	5	Strongly agree
I believe chemistry plays an important role in medicine	1	2	3	4	5		
I am aware of the signs & symptoms of pancreatic cancer	1	2	3	4	5		
I believe chemists can help pancreatic cancer patients	1	2	3	4	5		
I believe chemistry is unnatural	1	2	3	4	5		
I believe chemists make a valuable contribution to society	1	2	3	4	5		
I believe chemists are unapproachable	1	2	3	4	5		
I believe chemists are compassionate	1	2	3	4	5		
I believe that chemists don't care about patients	1	2	3	4	5		







    

Fig. 13.3 (a) Pre-survey for exhibition visitors (b) Post-survey for exhibition visitors

b

Quilts for Cancer: Post-event survey 

Please circle your response to each statement

	Strongly disagree	1	2	3	4	5	Strongly agree
I believe chemistry plays an important role in medicine		1	2	3	4	5	
I am aware of the signs & symptoms of pancreatic cancer		1	2	3	4	5	
I believe chemists can help pancreatic cancer patients		1	2	3	4	5	
I believe chemistry is unnatural		1	2	3	4	5	
I believe chemists make a valuable contribution to society		1	2	3	4	5	
I believe chemists are unapproachable		1	2	3	4	5	
I believe chemists are compassionate		1	2	3	4	5	
I believe that chemists don't care about patients		1	2	3	4	5	

Do you have any comments you'd like to share with us? _____














Fig. 13.3 (continued)

was designed to capture anonymous demographic information about those who took part as well as qualitative feedback on their experience during the project (Fig. 13.4).

Both evaluation cards are available for reuse online [19]. Visitors were at liberty to take part in our evaluation process and experienced no detriment should they decline to provide feedback. As no individually identifiable information was collected, ethical approval was not sought.

Submission of Quilts

Quilts were submitted by post or dropped off in person. These came in a variety of forms: completed quilts, including quilting and binding; quilt tops, without backing, quilting, or binding; and individual quilt blocks ready to be assembled into quilts. These quilts came from across the UK and Ireland. Those that were submitted as quilt blocks were assembled by Dr Ross into aesthetically pleasing quilt tops. These tops were then submitted to Dastardly Line, a micro enterprise in Glasgow who specialises in digital longarming (quilting tops, batting, and backing together on a large frame). Dastardly Line also created a bespoke digital quilting pattern based on the Royal Society of Chemistry logo. Once quilted, they were returned to Dr Ross who bound them and added Quilts 4 Cancer labels to the back.

A wee bit about you

Circle your answers

Age (years):

Gender: Non-binary Prefer not to say

How often do you go to science events (talks, festivals, trips) outside school/work?

Never Approx
 Rarely 1/year
 Sometimes 3/year
 Often 1/month
 Lots 1/week

Which of these best describes you?

Not usually interested in science
 Open to science; don't go out of my way to find it
 Interested in science; actively seek it out
 Work or study in science

Tell us what you think about Quilts 4 Cancer! Write a message, draw a picture, it's up to you

Fig. 13.4 Quilts 4 Cancer feedback cards for participants

Exhibitions

Although COVID-19 made in person visits impossible during lockdown, we experienced a narrow window of opportunity in late 2021 which allowed us to mount two exhibitions with the completed quilts. The first was at the Scottish Event Campus (SEC) in Glasgow as part of The Creative Craft Show in October 2021. The second and final exhibition was held in the Technology and Innovation Centre at the University of Strathclyde, Glasgow in November 2021. Quilts were mounted vertically on boards to enable visitors to examine the quilts at close range.

Results

Monitoring Impact of the Project

Using Dr Ross's Twitter statistics, content about Quilts 4 Cancer reached the timelines of 31,805 people from October → November 2021 and 1136 individuals were motivated to engage with the content (by liking, commenting, retweeting, or clicking on the content or user profile). In addition, those who liked the Facebook page grew from zero in October 2020 to 63 in November 2021 and on Instagram from 0 to 91 in the same timeframe. Twitter was a much more effective platform for communicating with our audience. The above numbers are extremely likely to be an underestimate of the overall reach of the project.

The two exhibitions, at The Creative Craft Show and at the University of Strathclyde involved the display of all the completed quilts in one place. The Creative Craft Show was relatively quiet due to the lingering impact of COVID-19, but we still managed to interact with more than 500 individuals over the course of the four days of the event. The University of Strathclyde event was restricted to those who had contributed to the overall success of the project, and we had 40 guests in attendance.

We also took part in the Fun Palaces weekend in 2020. We received one request from Perth and Kinross Library Service for 50 fabric packs to hand out to their users. We were also invited to record a Fun Palaces TV spot, which was shared on their Facebook page [21]; join Lesley Goodburn, the founder of the charity 'Purple Rainbow', on her podcast [22]; and invited to write a blog post for the Stitching Together Network [23]. Lauren Evans, Dr Hoskins's PhD student, also happened to be a Guide Leader out with Glasgow and so we also provided her and her Guides with an additional 50 fabric packs.

Completed Quilts

We received the equivalent of 16 quilts over the course of the project, more than we were expecting. These quilts can be seen in Fig. 13.5 below:

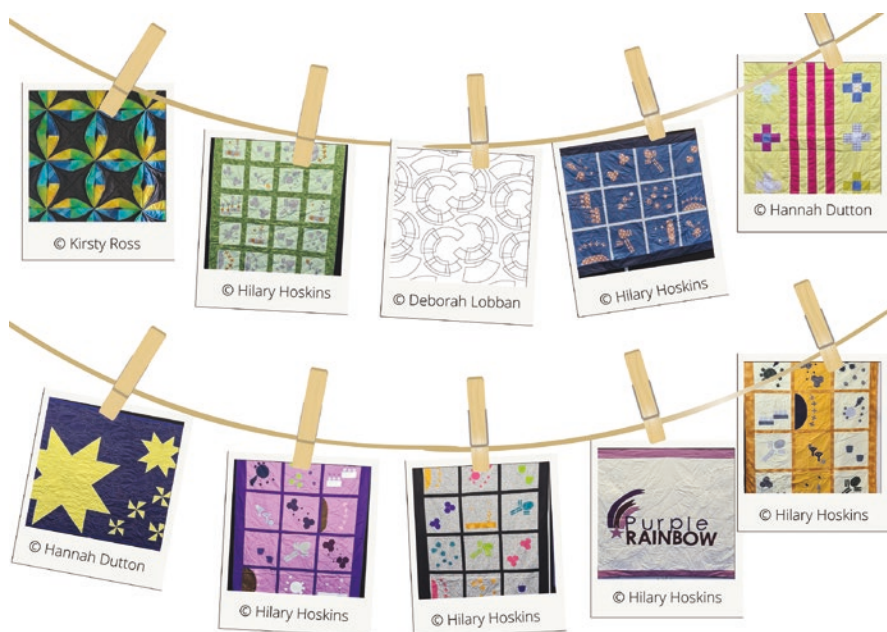


Fig. 13.5 Completed quilts submitted to the Quilts 4 Cancer project

We also benefited from support from the Chemistry Clinic staff and students to create informational posters that were printed on fabric and accompanied our exhibition. This provided our audiences with additional information about the signs and symptoms of pancreatic cancer.

Evaluation Results

At the Creative Craft Show, we kept a tally of those that we engaged with over the course of each day. This included those who stopped and looked but did not speak to us (aware); those who spoke briefly to us (interested); and those who engaged for an extended period and were willing to fill out our evaluation cards (engaged). Of the 500+ individuals, we interacted with at the event, 12.4% completed our evaluation card. 87% of those we interacted with were women. We received several unprompted qualitative comments from our visitors. These are summarised in Fig. 13.6 below.

In addition to the qualitative comments, we were absolutely delighted with the quantitative results from our feedback cards. As shown in Fig. 13.3a, b, we asked our visitors identical questions before and after they engaged with us and the exhibition. As shown in Fig. 13.7, there was a significant positive change in response to most questions when the pre- and post-responses were compared using a two-tailed paired *t*-test. Those questions with responses that did not change after the event were strongly negative questions (I believe chemistry is unnatural, I believe chemists are unapproachable). The respondents strongly disagreed with these statements before viewing the exhibition and continued to disagree afterwards.

Those who attended our final exhibition in the Technology and Innovation Centre were predominantly active participants in our project (i.e. funders, researchers



Fig. 13.6 Word cloud of qualitative comments from visitors

Finally, we offered the guide group the opportunity to design a badge for the Quilts 4 Cancer project. The winning design was made into a woven badge and presented to each Guide as a thank you for their involvement in the project.

Discussion

This project fully met our original aims and exceeded our expectations. Our objectives were to raise awareness of chemical research into pancreatic cancer; inspire quilters with that same research, as well as raising awareness of pancreatic cancer symptoms; and to keep patients with pancreatic cancer warm during their treatments with the resulting quilts.

We recruited 11 researchers who were able to provide 15 different images relating to their research. Those images were used by 33 quilters, from Girl Guides to retired women, to create quilts or individual quilt blocks. Our original goal was 6 quilts by the end of the project, so we were absolutely thrilled to collect 16! It demonstrates the kindness and willingness of our quilters who were very impressed by our project. We established Facebook and Instagram accounts to invite people to find out more and share the progress of the project. This resulted in individuals from across the UK getting involved in the project.

Our communication about the project was predominantly through online channels such as social media (Twitter, Facebook, Instagram), pre-recorded broadcasts (Fun Palaces TV), and podcasting (Purple Rainbow, RSC). We were featured in the local press (Glasgow Times) and institutional blog posts. On the downside, we were unaware that you are unable to gather social media data from your personal accounts that is more than 6 months old without paying external parties for that historical data. This is definitely a learning point for future projects!

Our original plan was to travel to in person quilting groups around the UK to talk about the project and our key messages about chemistry. The pandemic rapidly put paid to those plans! Our pivot to online delivery and communication successfully overcame this barrier and enabled us to reach our target audiences. We had not planned to engage with young people, as quilters tend to be working age and retired women, but involving a guide unit allowed us to reach an even younger audience. This was amazing and, based on their feedback, it may inspire the next generation of chemists. It is extremely common for a crafting related project such as this to be dominated by women and girls. It would be an interesting follow up to the project to investigate mechanisms to broaden the reach and involve more men, boys, and those who do not identify with binary genders in the project.

We released the quilt pattern inspirations in November 2020 during Pancreatic Cancer Awareness Month and used Facebook advertising to increase the impact of the launch. This allowed us to integrate our message into the narrative in social media. We brought all 16 quilts together during Pancreatic Cancer Awareness Month 2021 at the Technology and Innovation Centre as a bookend to the launch. We had attendees from Girl Guiding Scotland, the RSC, Cancer Research UK, Pancreatic

Cancer UK, Purple Rainbow as well as the scientific community, quilters, and pancreatic clinicians.

We worked closely with a micro enterprise to create a digital, edge to edge (E2E) quilt design based on the Royal Society of Chemistry logo that was used to quilt 6 out of the 16 quilts. We piloted creative evaluation methodologies, from online surveys to postcards and received highly detailed feedback and complementary feedback from our quilters and those who attended our exhibitions. We used a subset of questions from the RSC 'Attitudes towards chemistry' and saw statistically significant improvements in the scores in our post-event evaluation. These evaluation tools are now publicly available on Dr Ross's Figshare for others to use. The original data is available on request.

On a more personal note, it is hard to put into words the emotional impact that a project like this can have. We are giving hope to people who have had family members suffer, die, or who are currently undergoing treatment for pancreatic cancer. Meeting face-to-face meant that we heard how devastating the disease is to families, how they felt that nobody cared or was actively working towards a brighter future, and how they really valued our project. One week before our final exhibition, we received a Facebook message from a lady in Canada (her father is currently undergoing treatment for pancreatic cancer). She asked if she was eligible for a quilt as her father had lost so much weight and couldn't keep warm. This was very emotional for us and confirmed that our assumptions about quilts and treatment were accurate. We sent the lady the album of quilt pictures so he could pick his favourite, which just so happened to be the quilt that Dr Ross made! This quilt, along with a box of Scottish shortbread, was posted to him and we were delighted and moved when we subsequently received a video of her father receiving the quilt. The remaining quilts are being distributed via a Glasgow based pancreatic cancer surgeon and the Purple Rainbow organisation in Staffordshire, for those patients currently undergoing treatment or palliative care. Lastly, we would like to thank all who devoted time and energy to supporting our project as it would not have been possible without their help.

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