

**WE ARE
MACMILLAN.
CANCER SUPPORT**



Be cancer aware

Time to all talk about cancer

**A co-production project
Process Evaluation**



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1.0 Easy read executive summary



This document looks at the co-production of the 'Be cancer aware' peer education project.

Co-production means the public is involved at every stage of a process.

All members of the co-production team:

- are equal, working together
- sharing decision-making
- taking responsibility for actions and review progress



The Macmillan cancer learning disability project is part of the North East and Cumbria Learning Disability Network.

The Macmillan cancer learning disability project works to improve cancer services and experiences for people with a learning disability.

We try to include people with a learning disability, families and carers in all the work we do.



We decided to develop a cancer awareness training.

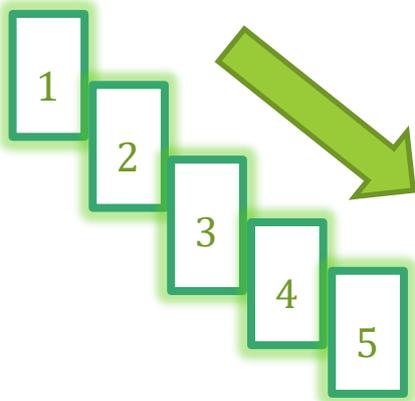
This document looks at the benefits and challenges of using co-production to develop the cancer awareness training.



The aim was to:
Work with a group of experts by experience and cancer experts to co-produce a cancer awareness course.

Train people with a learning disability to deliver the cancer awareness training.

Trainers deliver the cancer awareness training to people with a learning disability, family, carers and support staff.



The project was developed using 5 stages:

1. project set up
2. Development of training
3. Training of peer educators
4. Delivery of training
5. Evaluation



The report talks about some of the good things about co-production, such as making new friends.

The report talks about some of the challenges of the co-production work, such as finding the money for the project



Since we co-produced the Be cancer aware training we have been:

- Delivering the training to people with a learning disability, families and carers
- Telling others about the work at conferences
- Getting together for peer support sessions to talk about the training



In conclusion, we think co-producing the Be cancer aware training has been a great success.

We have all really enjoyed the work and are all proud to have been a part of it.

2.0 Introduction

The Macmillan cancer learning disability project has been working over the past two years to improve cancer services and experiences for people with a learning disability. We aim to include participation from people with a learning disability, families and carers in all the work we do.

As a part of this work we decided to develop cancer awareness training for people with a learning disability, families and carers. By upskilling this community, we hope to increase their knowledge and empower them to think and talk about their health and cancer.

We chose to develop the project using a co-production method. This means experts by experience would be involved at every stage alongside cancer experts who could advise on the accuracy of content and support development.

All members of the co-production team would;

- be equal, working together from the start to the end
- sharing decision-making
- taking responsibility for actions and reviewing progress

3.0 Aim

Our aim was to:

With a group of experts by experience and cancer experts co-produce a cancer awareness training course that people with a learning disability could use to educate other people with a learning disability, family, carers and support staff.

Through doing this we wanted to:

- Increase the knowledge of the co-production team
- Increase the skills and empower our peer educators to be able to share cancer messages in the learning disability community
- Increase the knowledge of the learning disability community and empower them to talk about their health and cancer
- Create a package that could be replicated by others

4.0 Methods

This project has been developed using 5 stages. The five stages are described below the table briefly describe the role of each stage and key points.

The process of co-production is easily replicated and adaptable to other topic areas. For the cancer work it was particularly important to have learning disability organisations on board who understood their role and they could support people with a learning disability to be involved. When training the peer educators, it was important the learning disability organisations had a key worker/s who would be a part of the Be cancer aware peer educator team continuing to work in a co-production model.

Stage 1 Project set up	<ul style="list-style-type: none">• Judge whether people think co-producing a cancer awareness peer education training course is a good idea and gain support from possible participating organisations• Identify people to support the co-production• Identifying and confirm funding for the project to ensure expert by experience could be reimbursed for their work.
Stage 2 Development of course	<ul style="list-style-type: none">• Expert by experience who are part of the co-production team ask peers what they wanted to know about cancer• 2 development days (1 week apart) designing the course and discussing delivery of content and facilitation packs.• Decision on course name - Be cancer aware - time to all talk about cancer• Testing of course content
Stage 3 Training peer educators	<ul style="list-style-type: none">• 5 organisations trained peer educators to deliver Be cancer aware• Introduction of the facilitation packs and final course content• Training in how to deliver the course content, including practice sessions and peer feedback• Set up peer support sessions and evaluation process
Stage 4 Delivery of 'Be cancer aware' courses	<ul style="list-style-type: none">• Commitment from each organisation to deliver 10 training courses over a 12-month period• Peer support sessions to support peer educators, gain feedback and offer additional training• Organisations use their contacts to arrange and deliver Be cancer aware sessions to the learning disability community across the North East and Cumbria
Stage 5 Evaluation	<ul style="list-style-type: none">• Evaluation of the process of co-production (this document)• Evaluation of the outcomes of training (ongoing)

5.0 Challenges and rewards of co-producing the *Be cancer aware*, peer education project

The below table describes some of the challenges and rewards of the co-production work, this is followed by personal statements from participants and some of the comments from the initial peer support session.

Stage	Challenges	Rewards
Stage 1 Project set up	<ul style="list-style-type: none"> • Getting the right people onboard • Funding for the project • Recognition a longer time frame may be needed • Acceptance from project lead that this is not their project or work but a group effort 	<ul style="list-style-type: none"> • Having the right people on board makes working together enjoyable and rewarding for all.
Stage 2 Development of course	<ul style="list-style-type: none"> • Having a balance between allowing people to think outside the box but still stay on track • Set clear time scale for consultation and development • Project lead to have time to pull work together into coherent package and check with co-production team 	<ul style="list-style-type: none"> • Opportunity to meet new people and make new friends • New and innovative ideas brought to the project • Pride in ownership of the project
Stage 3 Training peer educators	<ul style="list-style-type: none"> • Ensuring organisations and individuals understand the aims of the project and their commitments • Ensure trainers understand the parameters of the 'Be cancer aware' training and have clear set boundaries • Ensure peer support structure in place 	<ul style="list-style-type: none"> • Watching individuals grow in confidence • Empowerment • Sense of achievement and excitement
Stage 4 Delivery of 'Be cancer aware' courses	<ul style="list-style-type: none"> • Organisations identify groups to deliver training to sometimes difficult • Staying on script and knowing how to deal with difficult questions from an audience 	<ul style="list-style-type: none"> • Growth of individuals and teams • Seeing the impact of the training on audiences • Feeding into the development of the project through ongoing peer support sessions
Stage 5 Evaluation	<ul style="list-style-type: none"> • Allowing time to complete evaluation • Sharing learning 	<ul style="list-style-type: none"> • Having the team involved in sharing learning through presenting at conferences • Seeing the impact of co-production for project workers on confidence. • Seeing the increase in knowledge of participating audiences

5.1 Comments and feedback from co-production team

Here we have recorded some comment and feedback from individuals involved in the co-production project thinking about the challenges and rewards of working in this way. We have also included some comment from the peer educators first support session where we reflected on the co-production experience.

Julie Tucker – Macmillan cancer project manager, North East and Cumbria Learning Disability Network (project lead)

“For me doing the co-production has been incredibly rewarding. I started with an idea and nothing more. From that idea came an amazing group of people who took that idea and helped it grow. We worked together to understand what people with a learning disability want to know about cancer, took that understanding and developed our training. I am so proud of our end product which our 5 groups of peer educators are now using to deliver the training across the North East and Cumbria.”

“I think the hardest bit for me was finding the funding to ensure people can be reimbursed for the work. It was really important from the start that if we were asking for a commitment from individuals and organisation and are taking their involvement seriously we need to be able to offer to reimburse them for that time.”

Dr Katie Elliott - Primary Care Lead, Cancer Research UK GP, Northern Cancer Alliance, Macmillan GP, Learning Disability Network

“This was a fantastic piece of work to be involved in:”

“I think one of the challenges was holding back imposing professional/ ‘expert’ opinion about the content and structure and really embracing the co-production. Julie Tucker’s commitment to true co-production enabled the process, and the amount of work and outcomes achieved by the groups in the process was inspiring. I was absolutely enthused and engaged by the workshops. Thank you again”

Jo Mackintosh - Macmillan Engagement and Co Design Project Manager, Northern Cancer Alliance

“I have felt privileged to be part of this wonderful project. It is an example of best practice co-production that has involved all the participants working together to develop the content and structure of the programme and deliver the programme to their peers in the community. Another positive aspect of this project has been the opportunity to watch individuals grow in

confidence as they progressed through the development process, supported each other to become trainers and ultimately delivered the session out in their community.”

Lou – self advocate and peer educator for Be Cancer Aware

“It’s really good to find out from each other what we are doing and what all the other groups are doing as well. There’s a really good mix of people. I think it’s great that some people are working with their support workers on Be Cancer Aware. Some of the challenges are the time constraints – finding the time when we can all come together because everybody has other things to do”

Pam – self advocate and peer educator for Be Cancer Aware

“I met new friends. It was interesting to work together to make the course. I felt happy because I knew how far I could push myself. My confidence is a lot better now.

It was a teeny bit hard to understand everything when putting the course together. I need to be reminded in order to understand things properly”

On delivering the course..... “I felt alright doing the first session. The next session was more difficult because there weren’t as many people there. I’ve been able to help support others to go and get checked by their doctor. They went for a screening and got treatment”

Beverley – self advocate and peer educator for Be Cancer Aware

“I couldn’t believe I got up and presented. I was so nervous but I did it and everybody was really helping me. It felt good to know that I did it!”

Cathy Mellstrom – People First Cumbria, Support Worker and educator for Be Cancer Aware

“It has been a great piece of work to be involved with. There seems to be many ways that groups and organisations attempt co production but this was one of the best use of co-production principles that I have been involved with. Importantly, it is a great example that it can be done and it can work for people when it is co-produced from the very beginning. It was a pleasure to work alongside other groups with a shared objective and the width and breadth of their knowledge proved to be a key factor in the whole learning experience. The rewards therefore were noticeable not just for those involved in the project but for all who take part in the Be Cancer Aware course.”

Feedback from the peer educators support session

Discussion on co-producing the training

“Exciting to design the course, learnt so much, not embarrassed to talk (in the group)”

“Fun but sensitive, hard subject to talk to people about”

“Really good learning experience, we all put something in, shared experiences and bounced ideas off each other”

“Proud it’s my course, my work”

“We had lots of ideas, all our knowledge and ideas were shared to make the course”

“We were one big group, working as a team, sharing”

“Using people’s skills”

“We made friends, gained confidence through practicing delivering the training, everyone was given time and support to stand up and talk”

“We are all equal and all had our say”

“(We) need to share information not shield people from it”

6.0 Taking learning forward

Continued development of training – As with any course the product will adapt and develop over time. The peer support sessions will be an important element of this work gaining feedback from the individuals delivering the training and course participants.

Ensuring our peer educator continue to develop their skills and understanding of cancer will happen through additional training sessions, these are planned to link to the peer support sessions and will include topics identified by the peer educators plus updates on practice such as changes to the bowel screening programme.

Sharing learning – Sharing the learning of using co-production to create the be cancer aware training course is important to the team, they are incredibly proud of what they have created and the process they used.

As a team we have now presented this work at two conferences in the North East and Cumbria. In January four peer educators from two organisations and Julie Tucker presented at the North East and Cumbria Learning Disability Network cancer conference. In March

three peer educators and Julie presented at the Northern Cancer Alliance conference, The importance of public involvement.

During March, Julie with the support of one of the peer educator teams delivered an additional training programme to a sixth organisation in North Yorkshire so they can deliver the Be cancer aware training to their community.

Sharing the positive impact of using co-production is massively important and we will continue to use this methodology wherever possible. We are also keen to share our training course 'Be cancer aware', is has been co-produced by people with a learning disability for people with a learning disability and the more people we can reach and get talking about cancer the more successful the project will have been.

7.0 Conclusion and comments

This project was set up to develop cancer awareness training to be delivered by peer educators in the learning disability community using co-production.

The use of co-production for this project was the right methodology. The end product benefitted from the input of all involved producing a resource that individuals feel ownership of and are proud to be able to say I helped with that.

The benefits are much greater than just co-producing a product. The process used has been empowering. The work has been enjoyable and yet still focused, we have seen individuals grow in confidence, they have learnt new skills and can take these skills with them into other areas of their life.

Funding was obtained to train 5 organisations and for them to then deliver 10 Be Cancer Aware courses each. At the end of this funding I would like to think additional funding could be found to continue the work and maybe roll out the model to other areas to enable a greater awareness and understanding of cancer within the learning disability community.