

The Involvement of People Affected by Cancer in Greater Manchester Cancer Vanguard Innovation

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June 2018

Introduction

This purpose of this report is to share the learning from User Involvement and the co-production model within the GM Vanguard Programme.

Following completion of the 2 Year Vanguard programme, a User Involvement Share and Learn event was held. This was an opportunity for stakeholders to reflect on service user involvement in the Vanguard projects. It aimed to review the processes, outcomes and look at what had worked well and what could be improved from a user involvement perspective. It also helped to gain an understanding about the perception of user involvement from a healthcare professional perspective and identify the impact.

This report celebrates successes and outlines challenges and lessons learnt during the GMEC Vanguard Innovation programme. It also provides some 'Top Tips' which were co-produced through the Share and Learn Event by those involved in the Vanguard.

Background

The vision for Greater Manchester and East Cheshire Cancer (GMEC) Vanguard Innovation was for people affected by cancer and healthcare professionals to be equal partners in the co-design and improvement of cancer services.

Greater Manchester Cancer has an established User Involvement Programme supported by the Macmillan User Involvement Team. This was beneficial to the programme as it supported the participation of people affected by cancer within the Vanguard to begin quickly.

In Greater Manchester, we adopted the Macmillan model of co-production when implementing user involvement. This creates an equal and reciprocal relationship between teams of professionals and service users, working in partnership to achieve common goals. This approach has enabled innovation in cancer services in Greater Manchester to be co-produced by people affected by cancer.

CO-PRODUCTION

Delivering public services with people rather than to them. It requires an equal relationship between professionals, the people using the services, their families and their neighbours.

Nesta

What is Vanguard?

Definition: ‘A group of people leading the way in new developments or ideas: the experimental spirit of the modernist vanguard’

(www.oxforddictionaries.com/definition/english/vanguard)

NHS England: ‘Each vanguard site will take a lead on the development of new care models which will act as the blueprints for the NHS moving forward and the inspiration to the rest of the health and care system’

A single, National, two-year Cancer Vanguard programme (April 2016 – March 2018) set out to test cancer service innovation. If successful, projects could be scaled up in all cancer services and lead to radical improvements in cancer outcomes and patient experience.

From the outset, the programme aimed to put patients at the centre, so listening to and involving service users and carers at every level was a cornerstone of all the projects. This included involving people affected by cancer in making key decisions, ensuring that issues important to them were addressed.

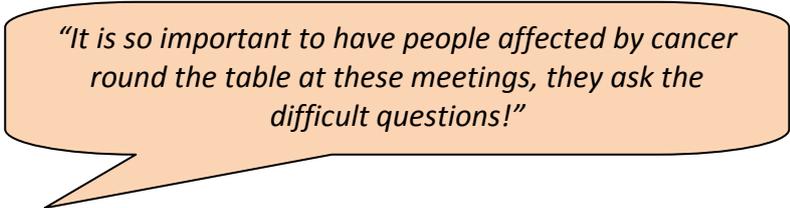
Seventeen projects were established in GMEC across seven work streams – Prevention, Early Diagnosis, Living with and Beyond Cancer, Medicines Optimisation, Commissioning and Finance, Cancer Intelligence, Optimal Timed Pathways. Appendix 1 shows the geographical spread of projects across GM and East Cheshire.

Range of User Involvement within the Vanguard Programme

Thirty three people affected by cancer have been directly involved with the Vanguard Innovation projects through involvement in programme board, steering group, projects boards and working groups. These service user representatives have all been part of the GM Macmillan User Involvement Programme which has given service user representatives access to a network of service users to gather wider views and opinions.

Involvement at a Strategic Level

As part of governance structure, the Vanguard Programme had a Strategic Oversight Group and a Programme Steering Group. The membership of both groups included two people affected by cancer. Involvement at these key governance groups meant people affected by cancer were instrumental in influencing the decision making and delivery of the entire programme.



“It is so important to have people affected by cancer round the table at these meetings, they ask the difficult questions!”

The Chair of the Vanguard Steering Group shared these reflections at the Share and Learn Event:

Reflections and Learning on User Involvement

- User involvement ensures valuable reality check
- Equal partnership working with service users / carers as well as clinicians is essential.
- Support for service users to feel able to challenge is important (e.g. preview of mtg papers)
- User involvement on decision making groups as well as projects is crucial.
- Mutual appreciation and understanding of the challenges facing the programme is important
- Significant potential for influencing national user involvement approaches

Cancer Education: Gateway C

This project was about educating GPs and primary care about cancer signs and symptoms. In the early days of the project, a focus group was held which aimed to gain an understanding of what patients felt was important in this work. Seven people affected by cancer attended, along with project and GP leads. As one of the first pieces of user involvement in the Vanguard programme, it served as a good starting point for how to people affected by cancer can get involved and start to influence and shape the project from the beginning.



Saeed Shakibai and Sue Coggins,
User Involvement representatives for
Gateway C Project

The first education module developed for Gateway C was about signs and symptoms of colorectal cancer. Through the user involvement in the project, this module was based on the actual experience of a service user who was involved in the Macmillan User Involvement Programme. When the first module was being filmed, a person affected by cancer attended

the filming. This was a key learning point for this project, as it became evident that this was not the right stage to involve the service user. Scripts had been finalised and there was little influence or opportunity to change things at this stage.

This resulted in much more robust engagement and discussions with service users at the earlier stage when future module scripts were being developed. For example, the project leads responsible for developing and writing the module scripts, met with the User Involvement Programme, Brain Central Nervous System 'Small Community' (which operates like a patient/carer reference group for the Pathway Board) to get their views on what was needed in a module on symptoms of Brain/CNS Cancers.

Following discussions with groups of service users, draft scripts would be shared back and forth, and service user feedback became an integral part of the development of each learning module.



People affected by cancer also:

- Co-designed interview questions that allowed the project to assess the patients experience of the GP making a two week wait referral
- Provided testimony about the importance of GP Education in identifying cancer symptoms at the Vanguard showcase event and as part of the project team
- Attended the Health Service Journal awards when the project was shortlisted for an award

New Diagnostic models - Faster Diagnosis

This project was piloting 'straight to test' appointments for Lung, Upper GI and Colorectal two week wait referrals. The Project Team worked closely with Bolton People Affected by Cancer and asked for help from service users to develop patient information to ensure it was clear and easy to understand. A number of service users worked with the project team to develop the patient information leaflets for the various tumour groups. Final drafts were then tested with a wider cohort of service users within the UI Programme and the group then refined the information based on the feedback.

Once the patient information leaflet was developed, it had to go through the local Trust governance structures. During this process, internal professional groups suggested changes

to the leaflets, however, the Project Team were able to demonstrate the robust process of design and testing with service users.

For the Colorectal 'straight to test' patients clear information was particularly important as effective preparation for the diagnostic colonoscopy was essential to the success of a faster diagnosis pathway. The Project reported 100% of patients had successfully used bowel preparation and had reported the instructions and information received was clear and easy to understand.

"it was wonderful to receive such valued support from the user group, it is so important to 'get it right' for our patients and I think I have met some amazing champions"

Clinical Nurse Lead

Patient Self-Referral

This project was in partnership with Manchester University. Due to the nature of the work, the Project Team were not familiar with user involvement and this was a new experience for them. The project developed a web based tool that estimated the risk of cancer. It then developed a partnership with a Community Pharmacy to undertake live testing of the tool. User involvement was an instrumental component of negotiations with the partners.



The service user representative, Tony, was able to articulate from the patients' perspective, the importance of early diagnosis in getting the most effective treatment and better outcomes. Having the patient voice involved at that stage made it real and helped introduce the concept, gain buy in and commitment from the partners.

Tony Bishop, User Involvement representative for Self-Referral project

The Project Manager, who was completely new to user involvement, recognised the value the service user perspective can bring to all aspects of the project. Through working with

service users on this project he acknowledged how it had changed his views and will influence his future practice. He highlighted the impact of having service user presence in such a key meeting:

“having the patient there offers something that feels more humanised than just having the technical experts. It enabled me to see a different perspective that perhaps I wouldn’t have seen previously.”

Project Manager

Developing Standards of Care

In this project, it was positive that user involvement was embedded in the structure from the start, with Terms of Reference for membership of the project group including people affected by cancer. This gave service user representatives a clear role and firm footing in the governance structure of the project. However, in reality, the planned structure for the project, including projects group meetings did not run as smoothly as hoped. Project Group meetings became irregular and were often cancelled on the last minute. This became frustrating for the service user representatives who had offered to join the project and planned time to attend the scheduled meetings and was a key learning point for the project. A lack of negotiation and communication when plans need to change created some negativity which had to be overcome for further engagement to be effective.

Despite this, views of service user representatives were fundamental in influencing the outcomes in this project. Through feedback from a focus group held with service users in the first few months, it was identified there was a gap relating to emotional and psychological support. People affected by cancer felt this was given little attention and it wasn’t identified as a standard of care. As a direct result, this was reviewed and was added as a standard for Person Centred Care.

Development of the standard was led by the service users. A task and finish group, supported by the User Involvement Manager worked in partnership to develop and co-produce the statements that would make up the standard for Emotional and Psychological support.

Through the Programme governance processes, in January 2017 it was decided this project would not continue. The work completed by the service users was handed over to the Psychological Support Pathway Board. They then included it in their work raising standards of emotional and psychological support to cancer patients across Greater Manchester. A key learning point in this project was ensuring that service users are involved in every aspect of

decision making so there is a shared understanding and clarity about decisions and rationales used.

Developing new Aftercare pathways (for Breast, Urology and Colorectal cancer patients).

Three task groups and an overarching project team made up this project. As well as a service user representative on the Project Team, a number of people affected by cancer were represented in all three task groups. The service user voice was pivotal in influencing the design of the new Aftercare pathways.



The involvement of a much wider group of people affected by cancer was facilitated through two co-produced stakeholder events for patients and carers. One focused on the elements of the suggested redesign and the second, in January 2018, reflected on what the testing of the new aftercare pathway had shown. The events were well attended and created energy and enthusiasm from service users and other stakeholders. They were an opportunity to bring together ideas and create solutions to challenges to support development of the pathways.



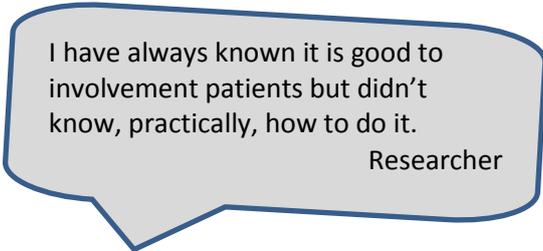
Each event was co-hosted by a person affected by cancer and included powerful patient and carer presentations about their experiences of Aftercare.

Enhanced Patient Decision Making

This project had early engagement with cancer clinics at The Christie and the Project Team recruited a current patient directly from a clinic to attend the project group. Initially, there was no dedicated support for this representative, however, they were later supported by the User Involvement Manager and joined the GM User Involvement Programme. They found this beneficial to have a wider network of other service users to link into and offer a more representative view when attending the project group meetings.

The focus of the project during the first year was to design an online tool to support patient decision making. Five people affected by cancer took part in one to one interviews. This data was then collated and used to co-design the content of the 'Goals of Care' tool. A focus group then reviewed the scenarios that formed part of the tool to test out their effectiveness from a service user perspective.

The User Involvement Programme Steering Group (UISG) invited the project team to attend their meeting in June 2017, to provide an update on the Enhanced Decision Making Project. They explained how people affected by cancer were working in partnership with professionals throughout the project and how beneficial it had been. They gave an example of where a service user was able to provide personal examples of why being supported to make informed decisions about treatment when having incurable cancer is so important. An important outcome of this work was the knowledge and experience gained by some of the professionals involved. Many of them had not worked with service users in this way before but they embraced the partnership working and co-production approach.



I have always known it is good to involvement patients but didn't know, practically, how to do it.

Researcher

Modelling a 7 day specialist palliative care service

This project was, essentially, a desktop, gap analysis of current palliative care services across Greater Manchester against the standard recommended by the Association of Palliative Medicine. One person affected by cancer who had experience of using palliative care services as a carer attended the project meetings. The role of the service user was to ensure the commissioning model for this service reflected the needs of people who will be using the service.

WE ARE MACMILLAN. CANCER SUPPORT

As a result of the scoping project a partnership with Macmillan has secured £1.8 million to pilot of the new model of service delivery.

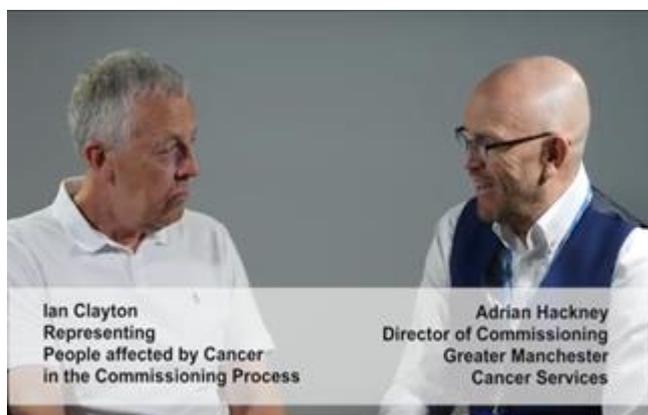
Having service user involvement during this early phase of the work ensured service users are part of the new pilot project established post Vanguard.

Part of the learning from the Vanguard Programme Governance structure from a user involvement perspective, was the lack of connectivity between service users involved in different parts of the programme. This has directly influenced the way user involvement has been structured within this new pilot programme of work where there are more representatives involved. A service user network has been established which allows the representatives involved to share their areas of work, gather feedback and ensure they are all aware of the wider programme of work.

Streamline the cancer commissioning process

This was a complex project that aimed to test out a model of cancer system architecture alongside the National Cancer Vanguard partners who tested other models. Due to the nature of this workstream, the User Involvement Team felt it would be helpful for service users who were involved in this work to have some working knowledge or background in this area of work. It was also important for them to have the appropriate support from professionals with the technical expertise to enable meaningful involvement.

The UI Team were able to match the skills and professional background of a service user to this project. It was also agreed that the Lead Commissioner for Cancer in GM would also provide direct support to the service user involved. This ensured he had the knowledge and information needed to be able to input effectively. The UI steering group were provided with regular feedback which provided an insight into the complexity of redesigning complex commissioning arrangements for cancer services.



As a result of his involvement in this project, Ian is now bringing a patient voice to commissioning discussions through his role as a User Representative on the GM Cancer Board. He is also sharing his knowledge with other service users to get more user representation within commissioning conversations.

Medicines Optimisation

This was a nationally delivered project overseen by a GM Project Manager and one project team with representation from all partners, The Christie, Royal Marsden and UCLH. Pharmacy partners were selected for the projects through an innovative process of 'Pharma Challenge'.

User involvement was initially planned to be at the project team level. However, this was a difficult expectation to fulfil because of the national remit of the project and the technical nature of some of the projects.

One of the Medicines Optimisation projects at the Christie, which piloted the mobile app, uMotif, (where patients could record their wellbeing between hospital appointments) when evaluated, showed some patient dissatisfaction with the tool. This was queried by service user representatives when the evaluation was presented to the Vanguard Steering group, however, it highlighted that the impact of user involvement in this project would have been better at the local project level. Opportunities were missed to identify, in this complex, national project, where people affected by cancer could have influenced the piloting of the tool at local level.

This has left a gap in the cancer services system understanding of the patients experience of this type of remote symptom monitoring and support.



The model of Pharma Challenge was repeated as an 'Industry Challenge' where health and technology organisations were asked to put forward ideas for Early Diagnosis. Learning from the process of pharma challenge, service user representation was included in the selection panel for Industry Challenge. This meant innovative approaches to early diagnosis were considered from the patients perspective and it demonstrated that user involvement can be effective at the important key decision points.

Cancer Intelligence Service

One strand of this work was to have a consistent patient experience tool for all cancer services in GM that would produce consistent, comparable and real time patient experience information.

An external provider was commissioned. The opportunities for people affected by cancer to be involved in selecting a provider were missed because the tender process took place early in the programme when the role of user involvement was not fully understood.

'I Want Great Care' (IWGC) were chosen as a provider and a nine people affected by cancer attended a focus group as part of the effort to demonstrate support for IWGC as a patient experience tool.

From a service user perspective there were a number of concerns about how IWGC could accurately capture the experience of cancer patients when that experience can involve attendance at a number of different hospitals. Also, through use of IWGC, patients were giving information to an organisation outside of the NHS and it was not clear in IWGC Terms and Conditions, how that information might be used in the future and whether, inadvertently, patients might make themselves identifiable.

Aside from a patient experience tool, another strand of this project was to bring together a range of sources of cancer performance data to form an intelligence dashboard showing comparable data from all providers in GM. It was also intended the dashboard would populate public facing infographic. Towards the end of the project term a group of people affected by cancer formed a focus group to advise on which of the data sources available would be relevant to patients and the public. The group made recommendations but unfortunately as the project came to an end the infographic was never produced.

Unfortunately within this project, the contribution from people affected by cancer had little impact. It is possible that the reliance on an external organisation to deliver a key part of this project, meant the value of user involvement was not recognised and this learning reinforces one of the underlying principle of user involvement - involve people from the start.

Key Messages and Learning from UI in the Vanguard

At the end of the Vanguard Programme, a workshop was held with key stakeholders who had been involved in the various projects to reflect on how user involvement had worked and what we could learn. The following key messages were distilled from the workshop:

Key Messages about User Involvement

1. There needs to be a system (infrastructure) to support meaningful involvement: training, one to one or group support, guidelines, terms and conditions.
2. Every complicated idea has a patient on the receiving end so no idea is too complicated, time just need to be taken to explain.
3. It is more efficient to involve people at the start, that way everyone learns together.
4. Not knowing everything can be a refreshing perspective.
5. Service Users perspective is just another kind of expertise.
6. Be clear about everyone's expectations: patient/carer and paid professionals. It'll change so it's ok to keep revisiting this.
7. Service Users as figure heads, appearing on publicity is ok, but it has to be more than this.
8. People live with the after effects of cancer for a long time, diagnosis and treatment might be years ago but it's still relevant.
9. Clear project leadership and purpose is required for there to be effective user involvement.
10. The value of the service users contribution may not be immediately apparent. Having an open mind and patience will reap rewards in time.

Appendix 1 Spread of Vanguard projects in Greater Manchester



