Macmillan User involvement Programme Greater Manchester Cancer 2016/17 Report

Introduction

This report highlights the key developments, successes and challenges within the Macmillan User Involvement Programme at Greater Manchester (GM) Cancer during the second year of funding from April 2016 to 31st March 2017.

During this time, the programme has moved on from the initial establishment of a structure and platform for the involvement of people affected by cancer, to actually affecting change within the system and playing a part in the development of cancer services with specific outcomes.

The Macmillan User Involvement Team (MUIT) has developed in this time to supporting not only the clinical pathway board work of GM Cancer but the GM Vanguard Innovation governance groups and workstreams. The focus over the last 12 months has been to:

- Strengthen and develop the user involvement structure co-produced during phase one of the programme.
- Continue to ensure representation of people affected by cancer at all levels throughout the system
- Developing an understanding of the user involvement model of co-production amongst all stakeholders
- Highlighting clear opportunities and outcomes from the involvement of people affected by cancer across the GM Cancer system

It is important to acknowledge the levels of commitment required from people affected by cancer in order to bring about the success of such a programme cannot be underestimated. Thank you to all the people affected by cancer on our programme that work so tenaciously alongside us to support the development of cancer services locally.

Within this report you will find a number of case studies which showcase the work that has been taking place and the outcomes of these. The capturing of case studies has been an objective over the past 12 months and will continue to be an important area to highlight success and challenges. Some of these case studies are in video form – please click on the blue links to see these.

Although this report takes a look back over the past 12 months, the Programme looks forward to continuing to strengthen work taking place during 2017 and beyond in order to support the implementation across all themes of the GM Cancer plan over the coming years.
The User Involvement Steering Group

Role: To monitor, evaluate and guide the Macmillan User Involvement Programme within Greater Manchester Cancer, with the support of the Macmillan User Involvement Team.

Current membership: 18 people affected by cancer living in Greater Manchester and East Cheshire with multiple links to cancer patient and carer groups across the region. Those that cannot attend regular meetings have the opportunity to feed into meetings remotely.

Work of the Steering Group has developed in responsibility and pace over the last 12 months. Activities have moved on from design and implementation of the programme, co-producing marketing and training materials in order to recruit and support people affected by cancer in their roles, to actively holding to account the user involvement work now taking place across GM Cancer within pathway boards and vanguard innovation workstreams. Service User Representatives (SURs) regularly provide updates to the steering group on activities, discussions and challenges at boards or workstreams, as well as providing a sounding board for advice and guidance.

The User Involvement Steering Group is now identified by GM Cancer as a key element in the accountability framework of clinical pathway boards. All board directors are expected to report to the steering group on progress and user involvement activity within their work. Most recently, the steering group have received presentations from and provided reports on key recommendations or actions that need to be taken back to the following Boards as well as Vanguard workstreams:

- Lung pathway Board
- Brain and Central Nervous System (CNS) Pathway Board
- Vanguard Innovation Project 11 workstream - self-referral

With the growing recognition and responsibility of the Steering Group, a clear reporting structure has been co-produced. This reporting structure identifies the opportunities for people affected by cancer to influence and support the design, development and implementation of services and innovation projects across Greater Manchester Cancer. It also highlights the Steering Group as the main ‘hub’ of the programme with all lines reporting into and out of the Steering Group.

The reporting structure can be seen on the following page.

The Steering Group now also have an agenda item at the GM Cancer Board so the views of the group and wider people affected by cancer can be fed in directly through the SURs.
MACMILLAN USER INVOLVEMENT REPORTING STRUCTURE

Greater Manchester Cancer Board

User Involvement Steering Group
- Membership of 20 PAbC with responsibility for monitoring, evaluating and guiding the UI Programme within Greater Manchester Cancer and Vanguard Innovation

Vanguard Innovation Workstreams
- 7 workstreams piloting new ways of delivering cancer services

User Involvement Steering Group
- Focus group (discussion group around a specific topic)
- Survey
- Task and Finish Group

Surveys feed updates from workstreams and governance groups to the Steering Group who can then comment and advise on actions required

Greater Manchester Pathway Boards
- Programme Board assures Macmillan Cancer Support and Greater Manchester Cancer that an effective approach to involving people affected by cancer (PAbC) is in place. 2 PAbC on Board.
- 2 SURs sit on the GM Cancer Board representing PAbC and reporting into and from the Steering Group

Complaints from PAbC about cancer services to be dealt with outside the system by contacting PALS

Groups & individuals affected by cancer in the community can feed views, comments and issues relating to cancer services into the system through the Service User Representatives supported by the Macmillan User Involvement Team. Actions on points raised will be fed back

Key:
- GM: Greater Manchester
- MUIT: Macmillan User Involvement Team
- SUR: Service User Representative
- PAbC: People Affected by Cancer
- PALS: Patient Advice & Liaison Service
Clinical Pathway Boards

A key objective over the past 12 months has been to ensure two people affected by cancer sit on all clinical pathway boards across Greater Manchester Cancer. This target has been achieved and in some cases surpassed, such as the Lung Pathway Board with 3 SURs and Brain and CNS with 5. All SURs are fully inducted and provided with on-going support by the MUIT.

However, a full and meaningful model of co-production points far beyond mere numbers of people affected by cancer being present at meetings but instead looks at how SURs work in partnership with professionals; how their views are listened to and actioned; and the value added to the system as a result of the involvement of people affected by cancer. The case studies below highlight just some examples of co-production in practice in the Greater Manchester Cancer Clinical Pathway Boards, and the outcomes of this…

<table>
<thead>
<tr>
<th>Case Study: Urology Pathway Board</th>
<th>Case Study: Brain and CNS Health and Wellbeing Event</th>
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<tr>
<td>Clinical Nurse Specialist (CNS) Helen and SUR Mike talk about the co-production of a gold standards framework for the follow up of prostate cancer patients and how this is being developed. <a href="#">Click here</a></td>
<td>Pathway Board Director Catherine McBain and SUR Mark Hodson talk about the design, implementation and evaluation of a health and wellbeing event for brain and CNS patients using the feedback from holistic needs assessments with patients and the views and support of the small community. <a href="#">Click here</a></td>
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**Outputs and Outcomes:**

- Focus group with prostate cancer patients and CNSs
- Gold standards of follow up care identified for prostate cancer patients
- Work linked with Vanguard workstream
- People affected by cancer actively influencing the design and development of services

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<tr>
<th>Case Study: Gynaecology Pathway Board</th>
<th>Case Study: Skin Pathway Board</th>
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<tr>
<td>Director of the Pathway Board and SUR Julie Holland discuss bringing in the patient perspective on a clinical board and how even when the smallest of things are listened to and valued, they can make a big impact. <a href="#">Click here</a></td>
<td>SUR Neil Cutler talks about his experiences of joining the skin Board 3 years ago before the MUIT were in place. Although honoured when asked to by his consultant to be involved with the Board he was unsure of his role or the value he was bringing to the discussions. Since supported by the MUIT, Neil has found his place on the Board. <a href="#">Click here</a></td>
</tr>
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**Outputs and Outcomes:**

- Review of wording within a referral document across Greater Manchester
- People affected by cancer are effectively involved, listened to and ideas actioned at the gynaecology Board

**Outputs and Outcomes:**

- Coproduction of a skin cancer survey to assess patient need of a skin cancer support group
- The views of people affected by skin cancer are being gathered to influence the development of services in GM
Representing the Wider Views of People Affected by Cancer

A key element of the User Involvement Programme at Greater Manchester Cancer, and one which sets it aside from others, is the commitment to ensuring the wider views of people affected by cancer are represented. SURs on boards and workstreams are aware of their responsibility to advocate on behalf of people affected by cancer as opposed to speaking from their own specific circumstances or representing their own views.

In order to facilitate this process a number of ‘small communities’ have been established. A small community is a group of people affected by a certain type of cancer or group of cancers. SURs take issues being discussed at board meetings to the small community, where their views are gathered and fed back to the board. The small communities can also ask SURs to raise issues they feel are important to people affected by cancer that are not currently being addressed on board agendas.

8 small communities have been established to strategically support the work of clinical pathway boards. The Living with and Beyond Cancer small community was one already established external to the programme but an agreement has been formed for issues from the Board to be taken to this group when required by the SURs. Although small communities are strategically linked to Pathway Boards, they are also used to link into and support Vanguard projects too; for example, the involvement of the psychological small community in the Vanguard Innovation around clinical standards. The following small communities are up and running and actively feeding in to projects:

- Brain and CNS
- Gynaecology
- Colorectal
- Psychological Support
- Living with and Beyond Cancer
- Breast
- Teenagers and Young Adults
- Head and Neck

Where no small community currently exists, SURs are supported by the MUIT to develop links with people affected by cancer in the wider community through existing support groups, individuals and voluntary sector organisations.

Case Study: Brain and CNS Pathway Board Small Community
Here, Director of the Brain and CNS Pathway Board and SUR Mark Hodson discuss the establishment of the small community. This case study highlights a best practice model whereby people affected by cancer elect who they would like to represent their views at Board level. Click here

Outcomes:
- Wider views of people affected by cancer are fed into the pathway board
- Board developments are co-produced with people affected by cancer

Case Study: Gynaecology Pathway Board Small Community
Director of the Pathway Board and SUR Julie Holland discuss the importance of representing the wider views of women affected by gynaecological cancers in supporting the development of services that effectively meet patient need. Click here

Outcomes:
- Wider views of people affected by cancer are fed into the pathway board
- Board developments are co-produced with people affected by cancer
Greater Manchester Vanguard Innovation

In August 2015 a full time User Involvement Manager was recruited to support the Vanguard Innovation work within Greater Manchester.

The established user involvement programme at GM Cancer allowed the participation of people affected by cancer within the Vanguard to begin quickly, utilising many of the resources that had already been coproduced through the programme and providing access to people affected by cancer who were fully inducted, supported and ready to engage with opportunities. This has been of particular benefit to the Vanguard Innovation work which has needed to get projects up and running quickly to test new ways of working within the two year funding period. Having an established resource has meant people affected by cancer have been available to support projects from as early on as possible, as a model of co-production would require.

A key aim was to ensure user involvement within all Vanguard Innovation workstreams and to have 2 SURs on both the Oversight and Steering Group. All of which have been achieved. The case studies below highlight just some examples of the activities and outcomes and challenges from involving people affected by cancer in the work of the Vanguard.

Case Study: Project 10 Enhanced Decision Making

PROJECT AIM: To support patients to make the right decisions for them when at the later stages of cancer treatment.

ACTIVITY:
- Interviews took place to gather the opinions of clinicians, patients and relatives of the current chemotherapy services for those people living with cancer in the palliative phase. People affected by cancer through the user involvement programme took part in the questionnaires.
- A further opportunity to be part of the project team was offered to people affected by cancer. The project team identified a current patient through their work with clinics, who wanted an opportunity to get involved in getting services to deliver the best care possible. The MUIT were able to then meet with the patient and ensure awareness of the support available from the MUIT and information about the structure the patient is feeding into. The MUIT were also able to link the patient in with the wider network of user involvement activity and support when attending project team meetings.

OUTCOME:
- People affected by cancer involved at all levels in the development of the project
- People affected by cancer have actively fed into a Goals of Care document which is now being piloted with patients at three cancer clinics.

Case Study: Finance and Commissioning Workstream

Here Adrian and Ian talk about the work taking place in the development of new cancer commissioning arrangements in GM and how people affected by cancer are feeding into this. Click here

Outcome:
- Commissioning review document that has been informed and underpinned by the patient experiences of ‘the fragmentation of services’.
Case Study: Project 9 Developing New Aftercare Pathways

PROJECT AIM: To transform cancer aftercare in GM, initially for early breast, colorectal and prostate cancer patients.

ACTIVITY: To co-produce an event at which a vision for the future of aftercare would be shared and feedback, learning and ideas from people affected by cancer gathered to inform and support the development of aftercare going forward.

A focus group took place to design the event, develop an outline agenda and discussion points for breakout sessions. People affected by cancer were clear about the need for the event to:

• ensure clarity for patients about when exactly aftercare begins. Support needs to prepare people for moving forward after cancer treatment and with the long term effects.
• include not just people who are approaching the end of treatment, but also those who are no longer on traditional follow up and still experiencing challenges with the late effects of treatment.
• include the opportunity for patients to voice their experience of aftercare. Following discussion it was agreed there should be patient experience from each of the cancer tumour areas (breast, colorectal, prostate).
• invite a person affected by cancer to co-chair the event alongside the workstream lead.

OUTCOME:
• An aftercare event took place successfully, shaped by patients working alongside clinicians and managers.
• Three people affected by cancer spoke about their experiences of breast, colorectal and prostate cancer aftercare which was identified as a highlight of the event.
• The event was co-chaired by a person affected by cancer and learning around how to facilitate the role for future events has been gathered.
• People affected by cancer shared their ideas for a holistic aftercare model based on the needs of patients and these are helping to shape the current development and implementation of aftercare models across GM.
Professional Training on Effective User Involvement

An objective over the last year has been the roll out of effective user involvement training for professionals – in particular targeting clinical Pathway Board Directors in the first stage and Pathway Board Managers.

The training was co-produced by a number of clinicians, people affected by cancer and the MUIT and people affected by cancer were not only involved in the design of the training but in the delivery of the sessions too. The training was also supported by a theatre group who depicted real life situations from information gathered from discussions with clinicians and people affected by cancer.

Three sessions were provided and directors were asked to book onto a training date. A letter also went out from the Medical Director to highlight that this training was not an optional extra but a requirement for all directors. Of the 20 directors invited to the training, all aside from eight directors attended and provided evaluation from the day.

This training will be amended following the feedback and rolled out more widely across GM Cancer and is a key objective for the coming 12 months up to March 2018.

Some feedback from the evaluation of Directors and managers that attended the day is highlighted below:

85% of attendees rated the training as either ‘very good’ or ‘excellent’
100% of attendees said they would use the knowledge and skills gained within the session
90% would recommend the training to a colleague

“Valuable to understand breadth of opportunities and what PAbC can bring”
“How PAbC are introduced to professionals and prepared for attending meetings is crucial”
“Useful to see the challenges of user involvement from a patient's perspective”
“Good insights into what user representatives feel are the benefits of user involvement”
“Very thought provoking session, very relevant and highlighted the importance of co-production between professionals and PAbC”
Recruitment

The on-going recruitment of people affected by cancer has been an important element of the programme.

- The MUIT were tasked with keeping the number of people affected by cancer on the user involvement database over 100. As of 31st March 2017, numbers are at a total of 125.
- The user involvement team are continually mindful of ensuring that the database represents a variety of people affected by cancer from different backgrounds and experience type that we can pull upon and offer opportunities of involvement to. This is a continuous process of monitoring and improvement of the representation of people affected by cancer on the programme and targeted recruitment is continually undertaken by the MUIT where needed.
- The MUIT have established links with a Black Asian Minority Ethnic (BAME) network that has recently been set up by the Black Health Authority. This has helped to widen professional contacts within a range of groups in GM.
- The MUIT team continue to attend, present and build links through Health & Wellbeing events, support groups and patient participation groups to raise awareness of the work of GM Cancer and the opportunities of involvement through the user involvement programme.

The charts below show the profile of the total number of people currently involved by gender, age, ethnic background, employment status, cancer type and geographic spread across the region.
**Cancer Type Experience**

- Urology: 15%
- Skin: 2%
- Sarcoma: 3%
- Oesophago-gastric: 4%
- Lung: 4%
- Hepato-Pancreato-Biliary: 10%
- Head & Neck: 11%
- Haematology: 9%
- Gynaecology: 11%
- Colorectal: 16%
- Breast: 13%
- Brain & CNS: 13%

**Profile by Postcode**

- Oldham: 8%
- Rochdale: 3%
- Tameside: 5%
- Trafford: 5%
- Wigan: 11%
- Bolton: 7%
- Stockport: 13%
- Salford: 9%
- Bury: 10%
- East Cheshire: 11%
- Central Manchester: 18%

**Profile by Ethnicity**

- White/British: 87%
- BAME: 13%

**BAME Profile**

- Mixed: 15%
- Asian/British: 12%
- Black/British: 19%
- Chinese/Other ethnicity: 6%
Challenges

- A small number of clinical pathway boards have faced varying challenges with leadership and attendance of members at meetings which has resulted in a lack of activity within certain cancer areas at Pathway Board level. This can be a challenge for the engagement of people affected by cancer who believe passionately about the importance of certain issues and who want to share their ideas and support to improve services for patients and carers. It is also challenging for people affected by cancer to see activity and development of services across a whole cancer system but certain areas and key cancer types that relate to them being left behind. People affected by cancer on the user involvement programme have voiced support for the cancer plan and the accountability this will provide for all boards going forward.

- Integrating a model of user involvement where people affected by cancer work alongside professionals in an equal partnership to develop services is something that requires system change. Although examples of best practice exist across GM Cancer for the involvement of service users, there is still some way to go until full system-wide meaningful engagement is in practice.

The MUIT have not yet had the opportunity to provide effective service user involvement training for professionals more widely than the Pathway Board Directors. In the co-produced MUIT communication plan for 2017/18, the roll out of this training to Vanguard leads, project managers as well as commissioning teams and wider pathway members has been identified and funding to support this activity secured. It is hoped this will continue to consolidate understanding around how and when people affected by cancer can effectively support the design, implementation and delivery of improved cancer services, according to the co-production model of involvement upheld by GM Cancer.

- An objective set for this period was to identify one suitable Pathway Board to participate in a pilot to ascertain the feasibility of having a Board to be co-chaired by a person affected by cancer. Further to this, to identify development needs to the chosen pathway board members and to co-produce a bespoke training programme for all involved. This objective has not been achieved and was agreed at the user involvement programme board that this would be deferred until next year.

Although this objective presents an exciting opportunity for a new level of partnership working between people affected by cancer and professionals, with staffing levels in the user involvement team down from 4 to two members, capacity to develop this piece of work effectively
was a challenge. Also it was agreed that due to some uncertainty around potential changes with pathway board directors, this may be better left to a later date.

- Ensuring the wider views of people affected by cancer are continually fed into the programme is a continuing challenge, in particular, that these views are representative and reflect the current experiences of patients and carers currently in the system. This is a challenge we are managing, however, it is one to continually be mindful of as this takes a considerable amount of resource and capacity to facilitate the process successfully.

A document has been co-produced to support this process and identify the activities within the programme to support sustainability and constant inclusion of new people affected by cancer who are keen to share their experiences and skills to support the programme. For example, a key activity to support this is establishing a term of office for all SURs at board levels so that opportunities are opened up to new members and a process by which people affected by cancer select who they feel is best placed to represent them and advocate on their behalf.

- Recognition and understanding of how people affected by cancer can bring so much more to the table than their experiences of being a patient or carer, but that they have a variety of experiences and skills beyond this which can be utilised to support the system as a whole.

**Case Study: An Untapped Resource**

Julie talks about the professional skills she is providing in supporting of an educational day for professionals…

[Click here](#)
Sharing Best Practice

Sharing resources and learning more widely than the GM Cancer has been an activity of the MUIT so that other professionals and patients can benefit from the effective involvement of patients and carers in the design, development and implementation of services. Some examples of the wider networking and information sharing are highlighted below:

- Sharing of information on the establishment of the user involvement structure, current reporting structure and outcomes at a meeting with Sharon Cavanagh at London Cancer

- Presenting to the Scottish geographical team of Macmillan Cancer Support around the GM Cancer User Involvement Programme and how this is working locally. People affected by cancer were also involved in the presentation of information and this was identified as a key highlight of the day. An invitation has been extended to attend the Macmillan Conference in Scotland in October to present more widely on the user involvement work at GM Cancer.

- Presenting at the National Macmillan Voices Conference about the user involvement programme, in particular around the involvement work in the GM Vanguard Innovation work and shared best practice with people affected by cancer on how to make steps to getting involved with cancer alliances.

- Involvement and supporting user involvement activity and set up at local hospital trust level. For example, work is happening currently to share information and best practice on setting up a steering group at Salford Royal Foundation Trust to support the development of cancer services and health and wellbeing events at the Trust.

- Identified in the communication plan for the coming year is the continued development of resources and accessibility of these around the effective involvement of people affected by cancer using a model of co-production that can continue to be shared more widely, benefiting not only other projects within GM but nationally too.