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MACMILLAN CANCER SUPPORT

MANCHESTER MACMILLAN SUPPORTIVE AND PALLIATIVE CARE PROGRAMME

USER INVOLVEMENT REPORT

2019-2021

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Macmillan User Involvement Facilitator
January 2019 until January 2021
Mid project report – Year 1 and 2

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ACKNOWLEDGEMENTS

Thanks go to every service user who has contributed to this work in the last 2 years for sharing their personal and very sensitive experience to make a difference to palliative and end of life care in Manchester. The commitment and hard work of the Service User Subgroup to this point has been incredible. I look forward to continuing this work with service users to the end of the programme.

INTRODUCTIONS

The purpose of this report is to share the work and outcomes of the user involvement component of the Manchester Macmillan Supportive and Palliative Care Programme (MMSPCP) during the first two years.

MANCHESTER MACMILLAN SUPPORTIVE AND PALLIATIVE CARE PROGRAMME

In 2013 Macmillan identified palliative care as an issue in Manchester, and in particular North Manchester which was a national outlier in providing choice for preferred place to die. As part of the Macmillan Cancer Improvement Project, Macmillan funded a 2-year pilot in North Manchester to provide a consultant led community palliative care service. Following the success of this project, the service was funded recurrently by local commissioners.

In 2017, commissioners and Macmillan acknowledged, the success of the North Manchester pilot had created an inequality of service provision for community palliative care across the city. In 2018, Macmillan came together with key partners in Manchester to develop and fund the MMSPCP over 4 years. This aimed to replicate the North Manchester model across the rest of the city, transforming local services to provide a citywide integrated community palliative care service.

USER INVOLVEMENT

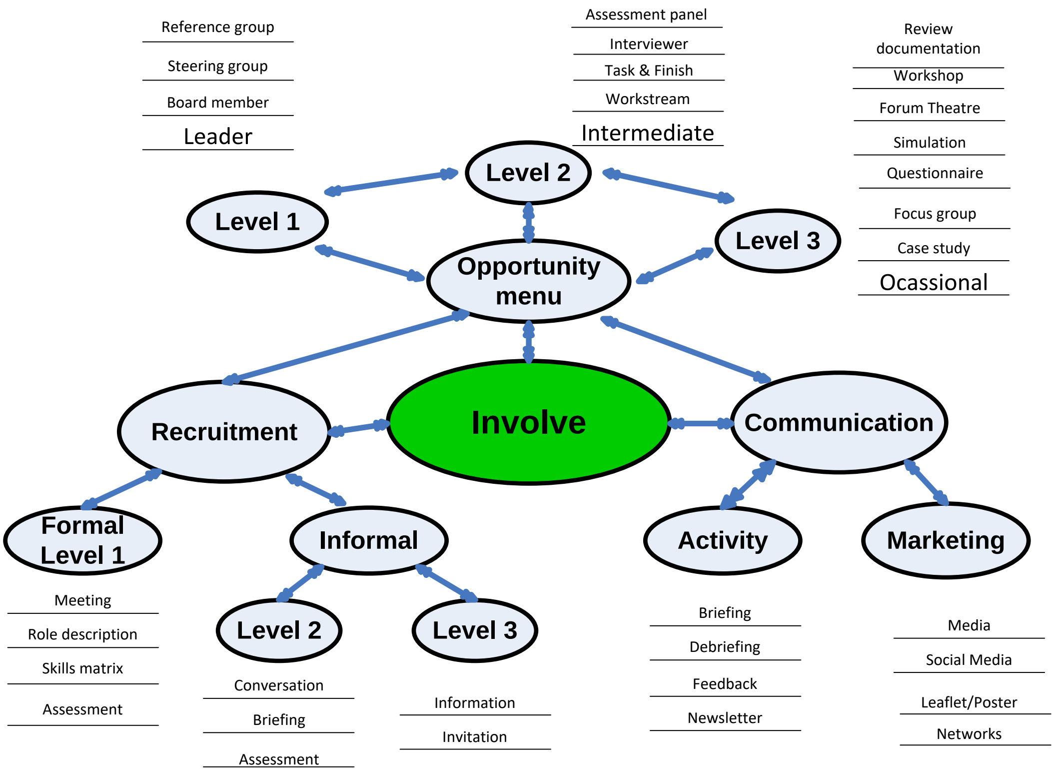
From the initial discussions about the citywide programme, user involvement has been a golden thread, and this was supported by Macmillan's Head of Engagement. The first involvement opportunity used co-production methodology to engage with 2 service users and supported them to participate in a Macmillan internal End of Life Care workshop. Their participation in this workshop kick started their involvement in this programme and they became part of the steering group as an equal member.

Due to the size and scale of this programme, Macmillan funded a Programme Management Team, which included a full time User Involvement Facilitator. The interview process was co-produced with 5 service users, the Macmillan Engagement lead and Head of Engagement from MHCC (Manchester Health and Care Commissioning. The Macmillan User Involvement Facilitator was appointed and came into post in January 2019.

USER INVOLVEMENT AND CO-PRODUCTION MODEL

The co-production model used was locally co-produced and consists of a set of principles and framework supporting a menu of meaningful opportunities. This model has continued to be used throughout the programme delivered by the user involvement facilitator.

User Involvement is the active involvement of patients and carers in how cancer services are commissioned, delivered and evaluated. Co-production is an equal and reciprocal relationship between a group of professionals and service users who have agreed to work in partnership to achieve a common goal. This is the model which user involvement throughout the programme was based on.



Remembering our friend and colleague Linda Hill

At this point we would like to acknowledge our colleague Linda Hill who sadly passed away in September 2020. Linda was instrumental in setting the foundations for the user involvement agenda in the MMSPCP as well as many other programmes of work. Linda recruited people with lived experience and had formed a small group of representatives having started coproducing pieces of work to complement the programme.

USER INVOLVEMENT STRATEGY

The involvement of people living with/affected by cancer and other life-limiting conditions has been key to the development and delivery of the programme and has been a golden thread throughout it. Effective and meaningful user involvement is essential to ensure that the programme delivers a high-quality service that is accessible and inclusive and that meets the needs of those who will use it.

The User Involvement Strategy was developed at the start of the programme. It outlines the Manchester Macmillan Supportive and Palliative Care Programme

(MMSPCP) approach to involving people affected by cancer and other life - limiting conditions. The strategy was co-produced with 6 people living with/affected by cancer who all played a key part in setting the direction for user involvement within the programme.

This document was part of the formal programme governance and was signed off by the Programme Board in February 2019.

CONSENT AND CONFIDENTIALITY

Service users within this programme were asked for their consent in relation to the experience they shared with the Macmillan User Involvement Facilitator. Consent is an important aspect of the user involvement process. Individuals involved in the programme need to know that they give permission and consent to use the information they share in different ways and the extent of those circumstances.

In the formal induction process when a service user is recruited a confidentiality and consent form is signed.

At other times in the programme there has been a need for more specific consent. An example of this is media footage, this is another level of involvement by way of the audience receiving this information being potentially wider.

Confidentiality is an important part of this relationship both for the service user and the organisations, there is therefore an agreement around confidentiality which is signed by the service user.

All service users who have been actively involved within the programme have given consent for the information included in this report to be documented.

This is with an understanding that this will be shared widely with stakeholders inside and outside of the programme.

Other people who have been involved have all agreed that their stories/quotes can be used but will be anonymised.

Consent and confidentiality are always discussed as part of a formal induction and this continues to be review as different involvement opportunities arise.

USER INVOLVEMENT SUB GROUP

When the programme was in set-up phase, the User Involvement subgroup was established as a key component within the governance structure. The subgroup is chaired by the User Involvement Facilitator and formally reports to the programme Steering Group on a monthly basis.

There was an active recruitment campaign across the city to promote the programme and the opportunity to be part of the subgroup. Due to the nature of palliative care, this has been a sensitive area to engage people in. Often, patients who are receiving palliative care may be too poorly to attend meetings or to be actively involved on a regular basis.

In the initial months of the programme, the User Involvement Facilitator supported those who had already been involved and recruited a number of new representatives who showed an interest in being involved as a regular member of the subgroup. The group became established and is made up of 13 people who have been formally recruited and inducted into the programme as active Service User Representatives.

A Terms of Reference statement was developed by the group which linked to the wider governance structure of the programme. This was important to set the scene, establish the subgroup as an equal component within the programme and manage expectations of both those involved and the other groups. Many of the service users who had been recruited to the user involvement subgroup had no experience of this kind of opportunity. The Terms of Reference gave the group structure and a clear remit which was a supportive framework for those new to this type of involvement.

The subgroup is used as a platform for two-way communication. Many of the members also sit on the other programme groups as User Representatives and use the subgroup as the feedback process to keep everyone updated on what is happening across the programme.
User Involvement Subgroup June 2019
(Left to right Ann, Alison, Gaynor, Patrick, Tom and David)

RECRUITMENT OF SERVICE USERS

When recruiting to the user involvement subgroup, the User Involvement Facilitator started engaging with health professionals and community groups to identify people who may be interested in being involved. It was important to think about the diverse representation within the group to allow maximum impact on the programme. This also included other life-limiting health conditions not just cancer.

Understanding the circumstances of individuals was key as they had to be people with the relevant experience. It was also crucial that people had time to share and be heard in relation to their own stories, background and experiences. In addition, palliative care is not always fully understood as this is a complex area which cuts across all disease groups and can affect anyone. So, ensuring that potential representatives fully understood the nature of the service and the type of content and information that would be shared with them during involvement was also key.

The small group of service users who were involved from the start worked with the User Involvement Facilitator to support promotion of the programme and the opportunities presented. An important part of this process was the co-production of a poster and information sheet for health professionals and community workers to pass on to potential service users.

MEET THE SERVICE USER REPRESENTATIVES

Here are some of our Service User Representatives who have been an active part of the programme and user involvement subgroup over the last 2 years. There are some other people who are also involved on a regular basis but they did not wish to be featured in this report. Some chose to work remotely with the programme or on an ad hoc basis.

TOM

I am a 58 year old gay man living in North Manchester who cared for my partner Ian. Ian had prostate cancer and was diagnosed two and a half years before he passed away in March 2015. The first year of his diagnosis he lived well and as a couple myself and Ian lived for the here and now travelling around England and Ireland. As time went on Ian started to become weaker and tended to sleep a lot more, this progressed, and I found myself as a full-time carer for Ian. Ian did manage to see his first granddaughter be born which was a total joy for him.

GAYNOR

I am Gaynor, I am a 53 year old woman living in South Manchester who cared for my husband David. David had cancer of the duodenum which however presented as liver cancer and progressed ultimately into lymphoma. David died in November 2014.
I cared for David right up to the end of his life working hard to get the care he needed at the right time.
I have two daughters and a stepson who I continue to support with their bereavement.

ANN B

I am Ann a 67 year old woman who lives in South Manchester. I looked after my aunt for three and a half years, she had vascular dementia. I started recognising signs that she was reaching the end of her life around three months before she died. There was nothing specifically clinical that I could put my finger on that this was the case other than her losing weight, not eating as much, sleeping more during the day and not engaging as much.

LEILA

I am Leila I am a 32 year old woman living in the city of Manchester. I was 13 when I was diagnosed with Leukaemia and was 17 when I relapsed and had a bone marrow transplant. I continue to live with long-term late effects as a result of treatment I had for cancer. From a young age I have seen many friends pass away and with this realised younger people have different needs at end of life. As I have got older my support for friends at the end of life and their parents/carers has been more involved and this is where my experience can make a difference.

ANN A

I am Ann. I am a 72 year old retired Jewish lady living in North Manchester. I was diagnosed with colorectal cancer in 2012. I had surgery and treatment for my cancer, this experience had a huge impact on me. I will always be grateful to the NHS staff who cared for me and being involved in this programme is a way of my giving back. I have always had an interest in end of life care and have experienced losing close family. I believe that this service should reflect the large diverse community of Manchester.

PATRICK

My name is Patrick. I am a 70 year old man living in the city of Salford. At the age of 64 I was diagnosed with prostate cancer and had radical surgery in November 2014. In January 2015 I was told that the cancer had spread to my lymph nodes and I started to receive hormone manipulation treatment (HMT) in the form of Zoladex implants. In 2018 I discovered that it was also in my left hip and pelvis. Since then in addition to the Zoladex I have been receiving Enzalutomide, another HMT. Although these treatments are palliative rather than curative, I am grateful for the last six years and hoping for more.

ALISON

I am Alison. I became involved following the death of my husband, aged 57, a mountaineer, fit and active, destroyed by a grade 4 glioblastoma in just 20 weeks. During that time I experienced the worst and very best of care...the worst in hospital, the eye-wateringly brilliant in the community. The difference was nothing to do with physical skills and knowledge. It had everything to do with ethos, patient-centred care and honesty. This experience will never date, in the way 100 years on, we still learn from the first world war, about trauma and resilience

TONY

My name is Stephen (Tony) Wright, I am a 58 year old Jamaican living in Manchester, I have worked in the community for over 40 years supporting BME and disadvantaged community residents to access public services. I have developed various innovative projects to enhance quality of life and wellbeing, sitting on various committees and wellbeing focus groups. As a cancer champion I joined the Macmillan User Involvement Group as a service user representative to help develop the new service.

JOHN

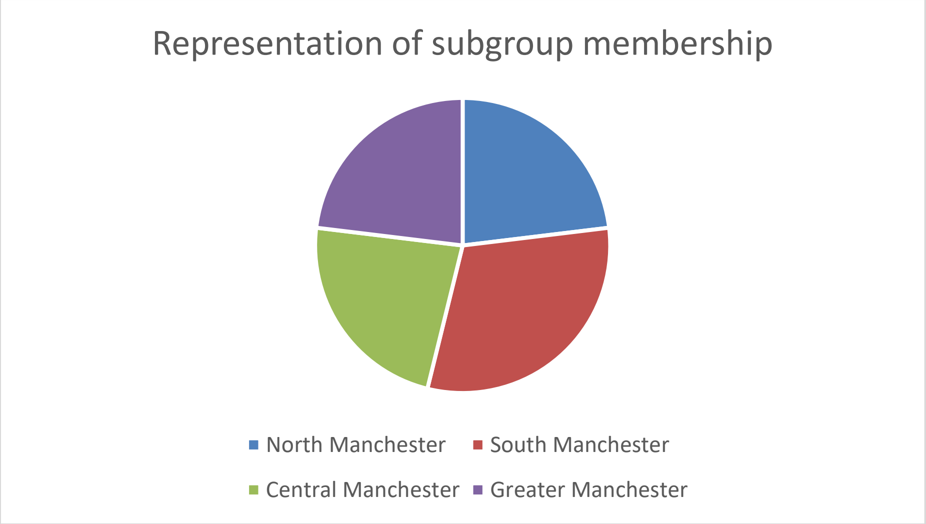
Remembering our friend John Lancaster

We would like to acknowledge our friend and colleague John Lancaster who sadly passed away in June 2020. John had been involved in the programme from its inception, supporting development of the user involvement strategy and he was an active part of the subgroup. John was passionate about helping to improve services and he brought a wealth of experience and knowledge to the work with the programme. John lived in the city of Manchester and his end of life care was provided by the new citywide service.

BEING REPRESENTATIVE OF THE MANCHESTER POPULATION

The user involvement subgroup is diverse and consists of 10 carers, 3 patients, 1 friend. There are 4 service users from South Manchester, 3 from North Manchester, 4 from Central Manchester and 3 from Greater Manchester. The lived experience of the people involved varies with different cancer types and different other life-limiting conditions.

''The group is diverse... different backgrounds, ethnic and social, religions, sexuality. It is the most diverse group I have been part of.''
- Service User Representative



When the user involvement subgroup was being established, the need to be representative of the city of Manchester population was at the forefront of the recruitment. The other aspect of consideration for recruitment was that palliative care affects all cancer types and other life-limiting conditions.
It was identified that there are also three distinct experience groups which are equally important to be represented:

- Patients who are in the last 12 months of life
- Carers who are currently looking after their loved one who is in the last 12 months of life
- Carers who have lost loved ones looking back on their experience retrospectively.

Recruiting user representatives for this area of work has been a huge challenge.

This is such a sensitive time for people to reflect on, or indeed be involved as a patient who may be receiving palliative care. The work of the Macmillan User Involvement Facilitator was crucial in ensuring not only were people engaged, but also fully understood the programme, the service and the type of content and involvement that was involved.

One way in which the representation was addressed was through recruiting people to the subgroup who also had links to other community groups, charities, support groups or associations. This allowed for a wider voice to be heard and Macmillan service user representatives could tap into their wider networks to bring back views and feedback from the wider community.

The Macmillan User Involvement Facilitator had a key role to play in developing relationships with the community networks. Through proactively engaging we were able to make contact with community groups to reach a wider voice of people around palliative and end of life experience. This enabled a wider voice and views to be reached whilst increasing awareness of the new service within the communities.

In the first year of the programme (before the pandemic), the Macmillan User Involvement Facilitator, with the support of the service user representatives, carried out a range of engagement work to gather the views of the local community. Examples of some of this work include:

- LGBT Foundation – Focus group
- Greater Manchester Youth Network – Focus group
- Yellow Bird Group (BAME) – Workshop
- African and Caribbean Care Group – Focus group
- Motor Neurone Disease Branch Group – Talking to patients and carers and a day shadowing a nurse
- Wai Yin Society – Presentation to community, then hearing from patients and carers

All of the findings from the engagement work have been fed into the programme via the Macmillan User Involvement Facilitator or the service users themselves when appropriate opportunities arose. This work has been documented separately also.

Interesting quote:

''Attitudes of clinicians need to improve in our experience, particularly in breaking bad news and better training in sensitive conversations. It feels like most clinicians are coming from highly privileged backgrounds and haven't a clue about the real world'' – Service User Representative

THE ROLE OF THE MACMILLAN USER INVOLVEMENT FACILITATOR

Macmillan has a well-established model of co-production within the user involvement landscape. This approach and ethos has been adopted within this programme of work and was the foundation of all activities. This programme of work was a major transformation of a citywide service. It involved working with some very established staff groups, some of which were new to the concept of user involvement and co-production.

Initially, there was some resistance about having service users involved in certain aspects of the programme, especially when it came to involvement in the more operational components of the service. The Macmillan User Involvement Facilitator had a key role to play in educating the health professionals about UI and co-production.

A proactive approach was taken to seek opportunities and work with health professionals across the service to champion user involvement. This was both on a one to one basis and through established groups or meetings that the PMO Team were involved in. By taking time to explain the benefits of user involvement and co-production and outline the structure and level of support that was available through the Macmillan User Involvement Facilitator role, gradually resistance was reduced.

''I didn't feel at all uncomfortable and this is the first time I have ever interviewed with a service user representative.
I think it was helpful as he was objective and contributed very effectively when making the final decision about the appointment. Involving a Service User in the recruitment process was very positive after my initial resistance about how this would work.''
Sharon Royle – Business Intelligence Manager

It took time for the PMO Team to establish relationships with the operational team and to understand the operational aspects of this complex programme. As the groups became more established and work plans were developed, the Macmillan User Involvement Facilitator identified opportunities of involvement. This required hard work and resilience to promote user involvement throughout the programme as this was a new way of working for many health professionals.

It was important for the Macmillan User Involvement Facilitator to ensure that the service users involved were fully supported with effective preparation and debriefs. However, it was equally important that the Macmillan User Involvement Facilitator worked with the health professionals, to prepare them for service users to be involved in a meaningful way. This included listening to their concerns and anxieties about the process, providing assurance and discussing how user involvement could be included in the various aspects of the work.

Over time, as service users became involved in the different workstreams throughout the programme, attending meetings and engaging in conversations around the table with health professionals, it started to become the norm. Due to the nature of palliative care, sometimes there are very sensitive discussions that take place in the meetings. This was often an area of concern for the health professionals and the Macmillan User Involvement Facilitator played a key role in ensuring everyone was able to be open and honest about these anxieties.

With support from the Macmillan User Involvement Facilitator the service user representatives gradually became more confident with asserting their voice and feeling equal when contributing to discussions. Gradually we were embedding the user involvement agenda throughout MMSPCP.

A quote from one of our service managers highlights the journey some professionals have been on with user involvement:

''At the start of the recruitment journey, discussions were had regarding service user involvement and a service user being on the interview panel. To say the least I was very sceptical!!! How I was so wrong''

''It is a pleasure meeting on regular occasions with the service users, they are extremely warm and welcoming, they help develop and change the future of palliative care'' Claire Rathmill Service Manager Central Hub

"Working in collaboration with the Service User Involvement group to develop and improve end of life care is so valuable. Members of the group share their lived experiences which enables us to tailor service improvements and staff training to meet different people's needs." – Joanne Williams Service Manager

The Macmillan User Involvement Facilitator attends all programme meetings supporting service user representatives, being the voice and advocate for patient experience and equality and diversity. From listening to many personal stories and working closely with patients, carers and friends there are inevitably times when it is appropriate to include experience and knowledge within discussions to support decisions and influence change.

Another aspect of this role was to be present within programme meetings and discussions to identify opportunities for service users to be involved. This is something to be on the lookout for as it will not always occur to health professionals to include service users in the work.

REPRESENTATIVES ON MEETINGS

Initially the most obvious opportunity for user involvement within the programme was ensuring representation on the programme meetings.
Ideally, at least two service user representatives are selected for each meeting, this allows flexibility and provides peer support.

There are several aspects to consider when selecting service user representatives to attend meetings including availability, commitment required, not duplicating the same people on different meetings, confidence levels and level of understanding within the area of work. A role description for service user representatives is provided and the Macmillan User Involvement Facilitator will work through this with everyone nominated to represent subgroup at the meetings.

There was user involvement on all the programme groups with the exception of the Evaluation Subgroup. As this group became established it was initially very technical, driven by data requirements and IT system work which would have been very difficult for service users to comment on and contribute to. The Macmillan User Involvement Facilitator attended these meetings to ensure the user perspective was always considered where necessary and to provide feedback to the Service User Subgroup. As the programme has moved into the latter stages of evaluation there are three service user representatives who attend the Evaluation Subgroup as there is now a significant role and value that can be added.

Service users who have been representatives on programme meetings and working groups bring a personal experience around end of life and palliative care. However, their role is to represent a wider voice in meetings and by sharing a collective experience sometimes they changed the dynamics of conversations with health professionals. They regularly offer constructive challenge or ask questions which help ensure everything is done in the best interest of the patient and their family.

An example of service user contribution was in a steering group meeting where education was being discussed for service staff. The service user at the meeting asked this question:

'Once a staff member has attended training or education, how is this managed and monitored in the delivery of care and support to the patients? i.e. how are we monitoring performance of staff?'

This influenced the work of the education group and has been discussed more widely within the service manager's role in managing staff performance.

COVID

In March 2020, the global Covid-19 pandemic began and soon afterwards the MMSPCP was paused as the NHS reorganised and diverted staff across the system. The PMO Team continued to support the operational teams delivering community palliative care as a Covid-19 end of life community workstream was developed to lead end of life plans.

As the national lockdown began, a number of our service users were in high risk groups and advised to shield. The importance of keeping in touch with the service users and offering support during such a difficult and uncertain time soon became apparent. The members of the group had acquired a huge level of understanding about the programme and the strategic aims of what we needed to achieve, therefore it was important to keep members engaged and involved for when the programme resumed.

As a result of the changes, which included everyone home working, we quickly adapted to new ways of working and started to learn how effective the virtual world could be. Many of our service users were keen and happy to learn how to use virtual platforms for meetings and to keep in touch.

Throughout the pandemic, all meetings have remained virtual and the service users met with the Macmillan User Involvement Facilitator on a weekly basis for catch ups. This developed into a supportive and social forum, purely optional to attend and a regular group of 6 or 7 people joined each week. This was done on an informal basis as a source of support and engagement with the user involvement group.

As weeks went on, the group decided a small task would be assigned each week for completion and presentation on the Thursday virtual meeting. The tasks differed each week and for some, this became the highlight of their week!
The overall theme of the meeting was supportive and sensitive and it became a great source of peer support as people started to feel the impact of the isolation during national lockdown. There were many smiles, lots of laughter and on occasions some tears and high emotions as people faced the challenges. The group became a very trusted and supportive space where members could be open and know they were received with love and understanding.

''It has given me a new group of friends and connection with others especially during the pandemic. To me the user involvement group is like a small extension of family'' – Service User Representative

A booklet has been developed and given to all members of the group who were involved during this time to serve as a memory of this very unusual time.

In between these weekly meetings the Macmillan User involvement Facilitator continued to contact service users on a one to one basis to discuss any concerns, offer support and generally check in. These conversations sometimes triggered a variety of emotions and difficult conversations.

As the programme resumed, the formal meetings restarted in the virtual world. By this time, many of the service users were very confident using Microsoft Teams and were not daunted by engaging in the virtual programme meetings and made full use of the functionality to be included.

CASE STUDIES

One way of gathering the experience of service users is to collect case studies or patient stories as they are often referred to. Collecting case studies is a powerful way to understand peoples experience of a service. There are many forms this can take, for this programme, this usually has been captured by the Macmillan User Involvement Facilitator's discussion with the patient or carer.

During the programme the Macmillan User Involvement Facilitator has captured 17 case studies which have been collated to showcase different aspects of the service. Some case studies were specifically generated for media and communication, some were to showcase specific staff roles and others were around equality and diversity. All case studies collected for this programme are from people who have lived experience around palliative and end of life care.

The user involvement group have reviewed all the case studies and discussed them from a service user perspective. The case studies have been used to identify key themes to support the development of the service, identifying things that are important to patients and carers.

Themes identified from programme case studies:

- **Joined-up care is essential** for all involved, the patient has their needs met and carers have stress lifted through not having to follow things up

  "I was selfish, I was fighting for my husband to live, being very honest, but it was because I loved him so much and could not come to terms with him never being there. Nurses need to work with families in a more collaborative way rather than

just stating how it is.''

- **Communication is key** – building relationships between health professionals and patients and their carers is essential to providing the best care. The trust built allows more honest conversations.
  ''You know what you have told me but you don't know what I have heard'' Carer for son who passed away.

- **Timely referrals into the service** – this is essential to allow the relationships to be built as in the point above.
- There is a lack of awareness around bereavement support to be accessed by loved ones after their loss.
  ''Once your loved one has passed away you are dropped from a great height and your life becomes empty. Nobody is there then'' (Smithy's bereavement group)

  ''I needed support after my husband's death but I was treated so badly as I am from Romania, if it wasn't for the help of the Macmillan information team, it could have been very different.'' - Carer for her husband

- **Psychological support** is needed for patients and their carer's as these are some of the most difficult times of their lives on both parts, the patient facing their mortality and the carer watching their loved one progress with their condition aware of what is happening.
  ''She became mentally and physically depleted. She saw a counsellor on a private basis.'' Carer for husband.

- **Expertise in particular diagnosis** – there needs to be more collaborative working with specialist nurses to ensure the correct level of care and support is delivered. This is for health professionals but also for care providers.
- **Good information** and support is needed up to the patient's passing away but it is essential for people to know what to do after someone dies at home.
- The **service needs to be better promoted** as in many of the case studies it was clear that there were opportunities missed for referrals.
- **Carers** need to be included in as much care and support for the patient as they wish to be **- A carer is a key worker with all the responsibility and none of the authority'' (carer for late aunt with Dementia)**
- **Managing expectations of patient and carer -** progression of illness and when the end is near
  ''Honest conversations (I know a doctor who calls them courageous conversations because it takes courage on both sides) are difficult to have and difficult to monitor, but it is

essential to the success of the programme''

HOW SERVICE USER REPRESENTATIVES HAVE USED THE CASE STUDIES TO INFUENCE DEVELOPMENTS

Case studies have been instrumental particularly in understanding gaps and areas for improvement. They have given our service user representatives the understanding of other experiences so they can represent the wider voice of patients and carers to support service improvements.

All of the themes identified have been highlighted during the programme and within different sections of this report it has been documented as to how the themes are being worked on/addressed.

LEAFLET DESIGN

One of the main aims of the programme was to roll out a citywide model of care, it was important to ensure that all literature given to patients and their families was consistent across the city. Through their collective experience, the Service User Involvement Subgroup identified the need for a range of information leaflets that would be beneficial to support patients and families through end of life care. A leaflet task and finish group was set up to develop a suite of leaflets for the citywide service that created consistency throughout the service.

The Service User Involvement Subgroup held a workshop to gather views and perspectives on what the suite of leaflets needed to consider, and these were then used by representatives to inform the work in the task and finish group.

Visual – How a service leaflet should look	**Format – What formats should be available**
• It should reflect the diversity of Manchester and its neighbourhoods • It should feature real people • It should feature real Manchester places (north, central and south Manchester) • Minimum font size 12 and written in plain English • No acronyms or use of technical terms	• A5 leaflet - For patients - For unpaid carers - For children and young people • Animation with sub-titles • Audio content and available in different languages • Website page • Short videos with sub-titles • Live Chat with community team via website

- Include how to contact the service - Telephone - Email - Website - Post - An explanation of what is palliative care - An explanation of what an advance statement is - What does the service offer - Include operating time of the services and what happens during out of hours - How to raise a concern or make a complaint - Include how there is access to interpreters or translated information	- Skype - Translated information - Face to face - Use of social media to share information/resources and hold online discussion forums

All leaflets for the MMSPCP have been co-produced. The service leaflet is in use on a citywide basis and other leaflets are going through the process for sign off and print. The leaflets developed and co-produced will all be used for education purposes as well as distributed to patients and carers. This service user involvement ensures the recipient has been considered and therefore the leaflet should be clear and sensitive with the right level of information needed, all based on real life experience.

COMMUINICATION - TOUCHPOINT WEEKS

The programme's Communication Plan identified a series of touch point weeks which aimed to promote the service and focus on different elements each time. The service users were able to influence the topics covered, one of which was equality and diversity. This had been a topic of conversation many times within the UI subgroup as this is an area the group were passionate about and wanted to influence.

The service users were able to use the programme structure and their representation at the communications subgroup meeting to put forward a proposal for one of the touchpoint weeks. The representatives highlighted the importance of showcasing some of the good work which they knew had been done. They reinforced the need to reach out to the community of Manchester to improve accessibility to the service.

Stakeholder engagement was always an agenda item on the communication subgroup and work was constantly being done to review ways we could engage with the wider community to improve referrals into the service. All this work incorporated equality and diversity.

Here are some of the comments that were tweeted during the equality and diversity touchpoint week from our service users who are willing to put their views out there for such an important message. The outcome of this was the @PalliativeMcr twitter handle gained new followers which is key to awareness of the service.

"Life priorities for everyone are different and it's important to support these needs. To allow proper care and support the voice of a young service user is crucial." Service User Representative.

"The information is improving. You do see more diversity in the leaflets and booklets. When you see someone who looks like you, you relate to it better. You want to take notice and read it." Can Survive Service User

"To be able to give my partner a kiss and hug at the moment he slipped away meant so much in my arms, it was our final goodbye to each other, after years of a loving relationship". Remember many gay older men were brought up when being gay was not accepted to show their love openly, unlike today and still carry these social scars.'' – Service User Representative

LESBIAN GAY BISEXUAL AND TRANSGENDER EDUCATION FOR HEALTH PROFESSIONALS

The role of the Macmillan User Involvement Facilitator was also to encourage a range of involvement to gather wider views. To enable this to happen, a key role was to work with local community groups with the intention of reaching a more diverse voice. This work was done collaboratively in partnership with existing community organisations. This improved networking and relationships to promote the programme and the service offer to various communities.

An example of this was a piece of work done with the LGBT Foundation, in September 2019 a focus group was held. The aim was to seek views and opinions about end of life and palliative care from people who identified within this community.

The 2-hour focus group generated rich narrative and all participants contributed to the discussion. They were keen to share their own experiences in order to make a difference moving forward:

- Be aware of making **assumptions** about an individual's sexuality - Every member of the group described a particular experience where an assumption had been made by a health professional that they were heterosexual
- **Communication** and building trust is key to successful care '' Hear what's not being said''
  ''Don't take for granted the fact you talk about these palliative and end of life care situations every day. Each patient/carer who you are dealing with will be hearing things for the very first time.''
- **Family dynamics** in gay men – ''Estranged family come out of the woodwork when there is a life-limiting diagnosis and not always is the patient's partner acknowledged. This is so tough on the partner. ''
- **Culture** - "Death is more of a taboo in LGBT communities - it's not sexy and that's a big deal for gay men!"

Following the success of the focus group, some participants requested to reconvene to discuss developing a 'visual' which would capture the key themes that came from the focus group. They felt it was important to portray some of the feelings and emotions around being a gay older man and the importance of gaining trust with health professionals to allow an open conversation about sexuality.

After agreeing a plan together, one member of the group met a number of times with the Macmillan User Involvement Facilitator to start the design of this piece of work. It was decided a cartoon-type visual would be commissioned by an artist to capture the key messages in this format.

User involvement and patient experience is at the heart of the **Manchester Macmillan Supportive and Palliative Care Programme** (MMSPCP). The programme is engaging service users and carers to share experience and use this to support the development and improvement of the service. To reach more diverse voices and gather views and feedback relating to palliative care a focus group attended by 4 gay men took place in partnership with the **LGBT foundation**. This group shared their real experience and provided feedback which has been key to develop this visual to support health professionals to understand the specific needs of older gay men at end of life.

Please see the link below which is a clip of one member of the group who was instrumental in pulling this piece of work together. He explains in his own words.

https://youtu.be/2ih66VHQ534

This piece of work has been shared widely through the programme groups and with the operational teams. It created some valuable discussions in a number of forums and has now been taken by the Service Education Lead to be incorporated into one of the palliative care modules for staff training and development.

All service staff and wider stakeholders will be able to access the palliative care modules and this will now form part of their induction and education packages. This is an excellent example of how service user involvement can truly influence service delivery.

''Advanced communication training is not enough. How will the service monitor progress? '' – Service User Representative

MEDIA CAMPAIGNS

As the MMSPCP has developed there have been a number of opportunities for service users to be involved in media and press coverage.

Personal stories come across to members of the public as emotional and therefore very powerful and attract attention for these reasons. This is what heightens awareness when real people with real stories are involved. However, it can also be very emotional for service users to share their experience and in some cases relive something that was very distressing or painful.

Therefore, this can be challenging, especially in such a sensitive area as palliative care. The Macmillan User Involvement Facilitator role is very important in supporting this work. It is essential to ensure that service users fully understand what the role is, how this may be used. It is essential that they have the right support, time to plan with someone they trust and also time to reflect and debrief afterwards.

On occasions if stories are being used by the media, they are not always presented in the way that it is intended. A particular example of learning from this was when one of our service users agreed to be interviewed for media coverage. Despite the journalist being briefed thoroughly, when they introduced him, they used different words to what had been discussed, stating he had just been told his condition was ‘terminal’, whereas he had used the terminology of ‘treatable but not curable’.

Members of his family watched the interview on the local news and afterwards he had several phone calls. This left our service user disappointed as his family had been worried by this and thought his situation had changed.

There have been three occasions during the programme where service users have been involved in media coverage

1. Angela Jones, on North West Tonight, shared her experience of end of life care as a carer for her husband in North Manchester. This coverage was aired in July 2019 and showcased the exceptional care and support they received as a family from the Macmillan Supportive and Palliative Care team. This piece was on BBC North West and reporter Jill Dunnigan interviewed Angela with the support of her family.

   Here is the link to the footage:

   BBC NWT news report Macmillan end of life #5.2m investment - YouTube

2. Patrick Fahy was interviewed by Jill Dunnigan to do a piece on BBC North West to launch the Macmillan investment into the service. Patrick shared his view on the importance of the financial Macmillan investment as a patient with an incurable diagnosis. The new model of care funded by Macmillan was showcased as a gold standard service to palliative and end of life care. The power of real life experience is important for successful communication of the message.

3. Suad Ibrahim – Suad was featured on Granada news sharing her experience of losing her father and the tremendous bespoke care and support he got from the Manchester Macmillan Supportive and Palliative Care Service. This was featured by Granada news on 22nd December 2020.

Suad and her father Mohammed Omar who passed away in September 2020

In all these examples the service users involved were supported by the Macmillan User Involvement Facilitator ensuring there was contact before and after each event. Managing expectations of service users who are involved in opportunities such as this is very important. As this coverage reaches such a wide audience it is important for them to be comfortable with what they are sharing and understand the wider impact of this for the future.

Points taken back to the programme for consideration from these examples:

- One of the learning points from Angela sharing her experience was how important it was for members of the public to know about the service and how important it was to be referred into the service in a timely way.
- A significant aspect of Suad’s story was that the team respected the culture and religion of the family and ensured this was a priority with the care and support given.

These points have influenced practice and showcased the need for continued improvement to work around stakeholder engagement and equality and diversity.

STAFF RECRUITMENT AND INTERVIEW PANELS

One of the early opportunities identified by the Macmillan User Involvement Facilitator was to work with the service managers to develop a process for service users to be part of the recruitment and selection of programme staff.

Initially, this was an area where there was some resistance to this idea as staff had not experienced this before. The Macmillan User Involvement Facilitator worked with managers to explore concerns and develop trust so that a process for involving service users as equal panel members could be developed. It was also important to recognise that managers needed support to test this out and develop confidence.

At first it was decided that the candidates would be interviewed by the panel of health professionals and then separately meet the service user, who was supported by the Macmillan User Involvement Facilitator. The service user representative asked questions which had been co-produced by the wider service user subgroup. The interview panel and the service users then reconvened for discussion and a decision. This process worked extremely well and gave confidence to the Service Managers that this could work well moving forward.

“At the start of the recruitment journey, discussions were had regarding service user involvement and a service user being on the interview panel. To say the least I was very sceptical!!! How I was so wrong. I thoroughly enjoyed the service user being involved when

interviewing candidates, getting a different aspect from my clinical view as a Clinical Nurse Specialist. The service users had had previous experience of interviewing in their own role and brought knowledge and skill with them that was so valuable'' Claire Rathmill Service Manager Central Hub

From the success of this approach, it was agreed to move to a process where the service user representative would sit on the panel alongside health professionals and conduct the interviews together. There was still an anxiety from professionals that interviews need to be conducted in a certain way, ensuring guidelines are followed to guarantee a fair and equitable process for candidates.

To support this process, it was agreed that service users who wished to be involved in recruitment panels would undergo recruitment and selection training. A training package was commissioned from ACAS which is a reputable training provider in this area. Training was tailored to meet the learning needs of service users and provide the basic principles and good practice for recruitment and selection. Six of the active service user representatives attended this training.

Once this new process was established, Service Managers would contact the Macmillan User Involvement Facilitator to arrange interview panels with a service user representative as an equal member of the panel.

During Covid there was no recruitment taking place but towards the end of 2020 a number of roles went out to advert. At this point, due to Covid restrictions, service users were not meeting face to face and therefore could not sit on interview panels. To ensure service users continued to be involved in the process, it was decided that the service users would co-produce a question to ask during the interviews:

How would you adapt your communication skills to meet the needs of the patient bearing in mind the diverse population of Manchester and can you give us an example of when you may have demonstrated this?

''In more recent times because of COVID during the recruitment process of new staff, service users haven't been on the panel due to the service users shielding. However, I still valued that input and asked for questions that they would want to ask on the interview panel.'' Claire Rathmill Service Manager Central Hub

Claire also fed back to the user involvement group, this question was powerful and to the point and worked well when asking candidates during the interview process. This question will continue to be asked in interviews until it is safe for the service users to attend face to face once again. This aspect of co-production is sustainable and will be a continued legacy of the programme.

A DAY IN THE LIFE OF......

To the group of service users involved in the work of the programme a lot of involvement opportunities presented themselves as strategic and remote from the operational service. Service users understood the model of care and the core objectives of the programme implementation, but they were detached from the day to day running and function of the service.

Through discussions the Macmillan User Involvement Facilitator identified that service users had a desire to fully understand the running of the service and what this looked like on the front line. They wanted to understand how their involvement had made an impact on the service as well as seeing the reality of the new model of care in practice.

It was put to the group that they should share ideas around how this could be demonstrated. There were suggestions of shadowing staff within the service however this was not possible due to Covid and social distancing and also the confidentiality of patients and their relatives needing to be respected. After some thought it was decided that a series of virtual meeting would be arranged and staff members from each discipline would attend to describe their role to the group of service users.

The Macmillan User Involvement Facilitator started to work with the hubs to identify a range of staff in the various roles who would be willing to do short presentations. As these were conducted through a virtual platform, they were recorded so that the programme now has a suite of video clips showcasing the roles within the service.

The service users found this very informative and this helped them to visualise what they had been contributing to at they had been contributing to for at least 12 months. The presentations focused on questions for the practitioners around the following topics:

- Your role and a description of it
- How your role fits with the overall community palliative and supportive service
- At what point are patients referred to you
- Some real case studies of your patients
- Just bringing your role to life in the best way possible
- Any changes to your role and delivery to patient as a result of the programme
- How you work your hours/rotas etc

- Why do we need specialist roles in a palliative service (this was aimed more at the therapist roles)

''I don't think that until you work closely in a multidisciplinary team that you really understand and value the expertise of all the team members. The point about picking up on a comment from a district nurse and following it through highlighted this. If it's missed by one person it may be picked up by another and the fact that anyone in the team can refer to a colleague opens up opportunities.'' – Service User Representative

MACMILLAN COFFEE MORNING

During the pandemic it was clear that the Macmillan coffee morning was going to take a different format. The Communications subgroup started to work on creating a new version of the famous coffee morning. Service user representatives were involved in this work from inception through discussions on the communication subgroup.
The representatives brought this back for a wider conversation with this User Involvement Subgroup. The group generated lots of ideas such as a drive-through coffee and cake collection, and showing videos promoting Manchester-based organisations holding their own socially- distanced coffee mornings on Twitter.

The idea of a virtual coffee morning was raised with participants grabbing a drink, a cake or biscuit and coming together to promote our programme of work. This idea picked up momentum, through the involvement of the service users in the Communications subgroup and this was developed into a one-hour virtual Macmillan coffee morning to help promote Macmillan and the service.

Lynda Thomas, Chief Executive of Macmillan Cancer Support joined the Coffee Morning event.

1st Picture Lynda Thomas, CEO Macmillan and Suad and her sister (Service Users)
2nd Picture Gaynor (Service User) and Suad and her sister (Service Users)

BEREAVEMENT

The MMSPCP is a service to care for and support patients and their families in the last 12 months of life. As the citywide model developed, the issue of bereavement support came up on many occasions and the historic practices amoung the three hubs differed. With the influence of the Service User Subgroup, a task and finish group was set up to develop guidelines for bereavement to ensure consistency across the city.

A virtual focus group was set up with the service users to discuss the bereavement agenda and what would help a carer/friend/family member after the death of a loved one. These were the points raised by the group:

- **A phone call to the family from the Macmillan team when a death has occurred, made by the member of staff who has most knowledge of the circumstances of the patient and carers. Knowledge of the situation is so important.**
- **A card should be sent offering condolences, within the first 6 weeks after death.**
- **At the point of sending a card there should be a list included of bereavement support services across the city for loved ones to access**
- **Remember at this point the focus is on the person/s left behind including children**
- **12 months is a significant milestone in the bereavement journey and the acknowledgement of this time is helpful and significant to the carer.**

When hearing service users' experience around palliative and end of life care almost always the bereavement aspect of the experience is highlighted. Many carers express the lack of support after the death of their loved one, this was noted in the review of the case studies.

As a result of this work, a set of guidelines has been drafted for the service to address many of these points and ensure a consistent approach across the hubs.

It has also been agreed that the service will send a card to the relative/carers at the 12 month anniversary.

''The 12 month anniversary is a significant time in your grief''

The User Involvement group have designed a card which is currently in draft format.

SERVICE USER PERSONAL DEVELOPMENT

All service users who have contributed to this programme of work did so with their own motivation. Some to 'give something back' and others to develop personal skills with a view to future paid employment. The Macmillan User Involvement Facilitator has ensured that the motivation of all the individuals has been heard and expectations managed as to how we can develop individuals personally. This is key to the success of the user involvement agenda, service users should get something back from their involvement and the motivation for this should be identified at the induction stage of the process.

A number of training courses have been sourced specifically for service users to support the programme such as a recruitment and selection course delivered by ACAS and health and wellbeing courses to support self-care and personal wellbeing.

Some general things people have said they have gained from being involved are:

- **Growth in confidence**
- **IT skills**
- **A sense of purpose**
- **Feeling part of a community**
- **Greater understanding of health services**

''At first, I felt a little overwhelmed in meetings but with more understanding I have grown in confidence. I feel I can communicate better'' – Service User Representative

GAPS IDENTIFIED

Throughout the programme to date, there have been many ways in which service users have helped identify areas for improvement and change. However, there are still areas of work which have not been addressed within the programme and which have been highlighted by the Service User Subgroup:

1 - Psychological support – every case study mentions the overwhelming aspect of stress, anxiety, fatigue and uncertainty. This is for patients and their carers/family. There are some people who can have low-level intervention and the MMSPCS staff are able to support these cases however many patients feel this on a more intense level and therefore need specific psychological intervention. It is felt this support should be specific to palliative and end of life care as this is different to other areas affecting mental health.

''He would cover the mirror in the bathroom before having a shower as he couldn't look at the weight he had lost''

Service users have also expressed the need for the same kind of support for staff within the MMSPCS teams. The staff are dealing with cases which are more complex, supporting people to live and die well in their own homes and sometimes staff are exposed to difficult circumstances. The importance of looking after the wellbeing of staff to ensure they can continue to provide an excellent service needs to be acknowledged.

2 - **Bereavement support –** This is another area which is mentioned by many carers sharing their experience of losing a loved one. There seems to be very little bereavement support in the city of Manchester. If this is not the case, and there are bereavement support services, people are not aware of them and are therefore not sure where to access them.

The MMSPCS are currently looking at their bereavement offer after a patient has passed away. As the service is commissioned to care and support patients and their families in the last 12 months of life there is a connection with bereavement support, however, the staff within the service are specialist in their field and bereavement then becomes a different area of care.

There has to be a point in the service where the team signpost the carer/family to relevant support to grieve.

Many carers feel like they have been dropped, a repeated quote:

''Once your loved one has passed away you are dropped from a great height and your life becomes empty. Nobody is there then''

This is a familiar phrase you hear from carers.

The service users in the user involvement group are keen to see this area develop as the right support, at the right time, is key for people to move forward.

SUMMARY

This report demonstrates the significant influence and input patients and carers with lived experience bring to improving services and changing practice.

Service user involvement has been the golden thread that has run throughout the programme, their input has been invaluable. Our service users have worked as equal partners alongside health and care professionals supporting all aspects of the work strategically and operationally.

The key to successful user involvement is to manage expectations of service users. This is done by enabling service users to fully understand all aspects of work including finance, staff capacity and overall logistics of running a service.

The key to designing and improving health services that truly meet the needs of patients is to ensure effective and meaningful user involvement.

HEALTH PROFESSIONAL REFLECTIONS

''It has been a pleasure and a privilege working with our service user representatives throughout this programme. Palliative and end of life care is a sensitive area of work and nationally we are still trying to encourage the population to talk about death and dying. Many of the people working with us have lived experience of caring for a loved one at the end of life and some have been receiving palliative care themselves. I am in awe of how strong and selfless they are in giving their time and commitment helping us improve the service to meet the needs of patients and their families. They have done many practical things to support the programme, helping with media and engagement sessions, designing promotional material, including patient facing information leaflets and supporting staff interviews. However, some of the strongest impact of their involvement has been through their presence and input into all our

programme meetings. They have developed an excellent understanding of the programme and are equal partners with health professionals around the table. They have listened, and worked through, sometimes very sensitive topics alongside health professionals with a solution-focused mindset, always offering valuable contributions. Having service users involved in every aspect of the programme has not only influenced the direction, it has educated health professionals in the value of authentic user involvement and co-production which will be a legacy of the user involvement in this programme. I would like to give my personal sincere thanks to all the service users who have supported us throughout the programme, user involvement has been a golden thread and your input has been invaluable'' – Sarah Haworth Programme Manager

''Here's a shout out to user involvement. I mean meaningful user involvement is everything when designing services'' - Lynda Thomas Chief Executive Macmillan

''In my view service user involvement has been critical to the development of the Macmillan Service Model. The insight and constructive challenge provided by the group has been consistently sustained over the last 3 years, providing much-needed continuity and oversight. The nature of the service user involvement and co-production has been. in my experience, of the highest quality and has offered a level of validity reflecting the values of the service. In summary, this has been the most positive contribution to community development work I have experienced to date and is due in a very large part to the support offered to our service users by our Service User Facilitator. Her expertise in this field has been invaluable and her approach has been both nurturing and empowering. The impact of the Service User Group on the success of the Programme cannot be underestimated.'' - Sue Ware, MLCO Adult Palliative and End of Life Care Lead

RECOMMENDATIONS

This report reflects year 1 and year 2 of the MMSPCP. The Macmillan User Involvement Facilitator is in post until December 2021 and in the final months of this role the following will happen:

- A plan will be put in place to sustain the user involvement agenda within the MMSPCP
- Specific one to one support will be given to service users to ensure their involvement within the programme has met their needs
- We will work with the user involvement group to develop a case study template for future collection of case studies

- We will continue to support the development of the bereavement process for the service.
- We will develop a user involvement legacy video