



What does a successful and effective Cancer User Involvement Programme look like and how can it be more diverse and work for everybody?

Executive Summary

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Introduction

The Greater Manchester Cancer Alliance is one of 21 Cancer Alliances across England. The Alliance aims to improve the lives of people affected by cancer in all 10 localities in Greater Manchester via its Cancer User Involvement (UI) Programme. This is an important programme within the Alliance, which is long-established and ensures the voice and needs of people affected by cancer in Greater Manchester – including patients, their carers, friends and family – are at the front and centre of the Alliance’s work. To ensure the programme delivers the greatest benefit for people affected by cancer in Greater Manchester, there was a need to understand how effective and meaningful the Cancer UI programme currently was and if and where improvements might be made. Mustard Research were commissioned to conduct a programme of independent research and review.

Research objective

The purpose of this research was to build on the many existing strengths of the Cancer UI Programme, whilst also looking forward to the future to ensure that it becomes a programme that ‘works for everyone’ and ultimately achieves better outcomes for people affected by cancer.

Methodology - What we did

We conducted a programme of research between June and August 2022, using various methods to ensure that the provision of feedback was accessible. **The total time Mustard Research spent engaging with Current Members, Potential Members (people affected by cancer in Greater Manchester who are not currently members of the programme) and Stakeholders** (anyone who is part of the Cancer UI Programme as part of their professional career) **was 137 hours**. Engagement included **qualitative research (telephone depth interviews, focus groups and an online community) with 68 participants and a quantitative online survey, with 138 participants**.

Sample profile – who took part

In total, 206 people took part in this research project. Quotas were set to ensure that a diverse range of opinions were collected and that the views of those typically under-represented in the current Cancer UI Programmes were heard. We engaged with people aged 16 and above (39% aged 44 and under and 61% aged 45 or above), a mix of genders (63% female, 36% male and 1% Non-Binary) and socio-demographic classifications (69% UK social grade ABC1, 27% C2DE and 4% preferred not to say).

Participants mostly resided in Greater Manchester (97%), although we had a minority from the North East, South East, South West and the Midlands. In terms of ethnicity, 80% of participants were White, 10% were Asian / Asian British, 6% had Mixed / Multiple ethnic backgrounds and 4% were Black / African / Caribbean / Black British. The ethnicity breakdown of participants broadly mirrors that of the 2011 Greater Manchester Census (2021 Census results are yet to be published in full).

This information can be made available in alternative formats, such as large print, and may be available in alternative languages, upon request. Please contact 07815474014 or email mc.userinvolvement@nhs.net.



Over the years there has been many successes with the Cancer UI programme and participants were able to vocalise a number of strengths. This includes the opportunity to collaborate, co-design and co-produce content, services, pathways, treatment information etc. and ultimately improve the experiences of people affected by cancer. A current member had this to say: *“I am a strong advocate for anything cancer-related. I like to take up positive opportunities that give me a chance to use my voice to create more positive experiences for individuals on their cancer journey in whichever capacity is available.”*

Whilst there are many successes to celebrate, a lot has changed since the creation of the programme, including the scope of the Alliance’s work in addition to new ways of working following the COVID-19 pandemic. There is also limited awareness of the programme, meaning it can be difficult to get new people involved to address gaps in representation (particularly when it comes to diversity in ethnicity, sexual orientation, socio-demographics, age and cancer type). *“I am part of a support group, but the only person in the group who has been involved with the UI Programme. I would therefore try to represent the other members but I can't see anyone getting involved because whenever I mention the programme, I am met with confused or ‘glazed eyes’ looks, because the purpose of the programme can be very confusing and distant.” (Current Member)*

There is a need to re-focus on the core objective of the programme and plan for the future: *“In order to get more people involved, it needs to be simple, accessible and enjoyable or worthwhile, (e.g. paid, or more opportunities arising from taking part or really seeing the changes coming to life). So much time is wasted thinking about wording, formalities. The panels are not diverse because the groups are not accessible. Too academic, too formal, too confusing, spending so long talking ideas round in circles. Most people I spoke to don't even know these groups exist and they find it confusing.”*

The evaluation identified four main insight streams (some of which naturally interlink):

Design: Potential Members and some new Current Members lack an understanding of what the programme is and how they can get involved. Some of those currently involved, feel the programme has lacked consistency, structure and a lack of focus in recent years. Now is the time to take a blank sheet of paper approach to review and rebuild the programme from the foundations up.

Delivery: There is a lack of consistency in Current Members knowledge and involvement with the programme. There was evidence of people wanting to be more involved but not knowing how. There needs to be more structure in the delivery of the programme. It is key to ensure the expectations of those involved are managed and the Cancer UI Programme is delivered in a consistent way so everyone is treated equally.

Relationships: There are a lot of good things happening across Greater Manchester, but these are often happening independently. The Cancer UI Programme has to get out into the communities proactively, rather than expecting people to come to the programme. More work and effort needs to go into forming and nurturing relationships to truly bring everyone together.

Communication: There is a desire for improvements to communications and in particular in relation to sharing knowledge / best practice. Wider communication improvements (ensuring content is pitched at the right literacy level, having a clearer purpose etc.) should assist in raising awareness and member acquisition. Ongoing communication improvements should assist in getting Current Members more engaged.



Recommendations and actions

Thank you so much to everyone that has been involved in the Cancer UI Programmes evaluation. We are so appreciative of everybody giving up their time and providing us with open and honest feedback. This has all been taken on board and has highlighted a need to build on the current strengths and make some improvements:

Design

- Refresh the Cancer UI programme (including a new mission and values, that are simple and easy to understand)
- Create a formalised induction and review process for new and Current Members. As part of this, ask Current Members to sign a revised volunteer agreement (with clearly defined roles, tenure, behaviour charter, etc.)
- As part of the induction process, and throughout their time with the programme, help build the confidence of Potential Members and new Current Members.

Delivery

- Rebrand the Cancer UI Programme (an accessible and appropriate name for the programme and for volunteers)
- Review all content / website materials – with a focus on literacy
- Continue to do hybrid meetings and have a range of meeting days / times (to improve accessibility)
- Offer technical support / devices to those on lower incomes
- Create a central location for all programme documents, including a menu of options for how people can easily get involved.

Relationship

- Focus on strengthening relationships across a wide range of Stakeholders and organisations
- Create a cross board group to discuss broader themes across all cancer care
- Utilise existing organisations and projects to help create a bigger positive impact on the lives of people affected by cancer
- Proactively conduct (ongoing) community outreach work to forge new relationships in under represented communities and cancer types
- Create more 'focus' for important meetings by having separate social events so people can still meet and get to know each other.

Communication

- Raise awareness of the Cancer UI Programme, using a variety of channels
- Share appropriate knowledge across pathway boards, hospitals, alliances, etc.
- Share programme successes more widely to evidence successes
- Consider whether programme content could be translated into common languages used across Greater Manchester.

Implementing these changes should result in a **more effective and productive Cancer User involvement Programme, that is more representative of the Greater Manchester population as a whole and most importantly works for everybody.**

The full report is now online:



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