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

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"We can not become what we want by remaining what we are."

Max De Pree (American businessman and writer)

Contents

Background and methodology

Objectives

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 is a need to understand how effective and meaningful the Cancer UI programme currently is and if and where improvements might be made. With that aim in mind, Mustard was commissioned to conduct a programme of independent research and review.

Specific objectives of this research and engagement activity included:

o   Conduct a fair, transparent and accessible review programme that collects data, information and feedback from a range of stakeholders relevant to the user involvement programme and ensures that all those who wish to contribute have their voice heard;

o   Collate data, information and feedback in order to produce a feedback report suitable for the public and the Greater Manchester Cancer Alliance Team, including where appropriate, recommendations from this data that should inform the new programme;

o   This process should inform and enable us to produce a programme that continues to be suitable, effective and meaningful for both users and healthcare professionals in the post-COVID period, which lends itself to productive engagement and involvement to improve overall outcomes and experiences for service users.

Ultimately, this research will need to answer the following question: What does a successful and effective Cancer User Involvement Programme look like and how can it be more diverse and work for everybody?

Methodology

In total we had 68 people take part in the qualitative research phase (telephone depths, focus groups and an online community) and 138 in the quantitative phase (online survey). Across all methods, the total time Mustard 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.

Teams / Telephone Depths

- 19 x depth interviews (via Teams or telephone)
- 6 x Current Members
- 3 x Potential Members
- 10 x Stakeholders
- Each depth interview lasted 1 hour
- All interviews moderated by Mustard
- Interviews followed a discussion guide designed by Mustard and approved by GMC.
- Depths took place between 7th June and 28th July 2022

Focus Groups

- 4 x in-person groups held at Mustard HQ and 2 x online via Zoom
- Groups sizes ranged from 4 to 6
- 30 participants in total:
- 14 x Current Members
- 6 x Potential Members
- 10 x Stakeholders
- Each group lasted 1.5 hours
- All groups moderated by Mustard
- Sessions followed a discussion guide designed by Mustard and approved by GMC
- Focus groups took place between 14th June and 7th July 2022

Online Community

- 10 day online community with 8 different discussion themes
- 9 x Current Members
- 10 x Potential Members
- Average time commitment across the 10 days was 2.5 hours per person
- The community was moderated by Mustard
- Discussion guide designed by Mustard and approved by GMC
- The online community was live between 29th June and 7th July 2022

Online Survey
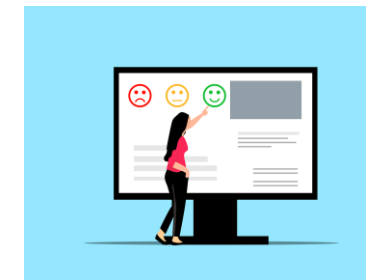
- An online survey was scripted in the industry-leading survey software ConfirmIT
- Total sample size = n=138
- Mustard utilised an online panel partner to achieve n=51 Potential Member survey completions
- GMC promoted the survey via the weekly newsletter, social media and individual invites to achieve n=88 completions
- Average survey length was 11 minutes
- Questionnaire designed by Mustard and approved by GMC
- The survey was live from 15th July to 1st August 2022

All research was conducted under the [Market Research Society code of conduct](#)

Online survey confidence intervals

The confidence intervals (based on a 95% confidence interval – meaning that if we were to conduct the same research again with a similar population, 95% would respond within the ranges below) for the completion rates by key sub-groups are:

	Number of respondents	Confidence Interval (based on 95% confidence levels). Results accurate to...
Total (all respondents)	138	+/-5.0% to +/-8.3%
Involvement		
Current Members	45	+/-8.8% to +/-14.6%
Stakeholders	60	+/-7.6% to +/-12.7%
Potential Members	51	+/-8.2% to +/-13.7%

Note: Respondents could have more than one role as part of the Cancer User Involvement Programme – this means the total number of different involvement types does not add up to the total number of respondents.

Research context

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. Whilst reading this report it is important to consider the following context:

Representation

Cancer can affect anyone and whilst we haven't been able to engage with every 'type' of person cancer affects, we have been able to consult with a wide range of people that are currently involved with the Cancer UI Programme and also people that could be Potential Members (people who have been affected by cancer and have shown some interest in sharing their views of cancer with others).

Valuing the time and input of our users

There were so many different people involved in the project.

We really respect and appreciate everybody that has been involved and given up their time to share their views and opinions, more so as we know you all have other commitments too.

The research team has balanced as many needs as possible and has always had 'what is best for the overall Cancer UI Programme' in the back of our minds when conducting our analysis.
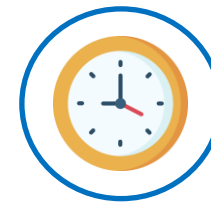
Competition for time

For many, time is precious and we're leading increasingly busy and fast paced lifestyles. The comment below sums up how the views are of people affected by cancer are in demand (not just by the Cancer UI Programme):

"I think it's also very competitive world with many organisations, charities, fighting for engaging with service users. We're just one of many people looking to engage this group of people and wanting to hear from them and use their expertise."
(Stakeholder)

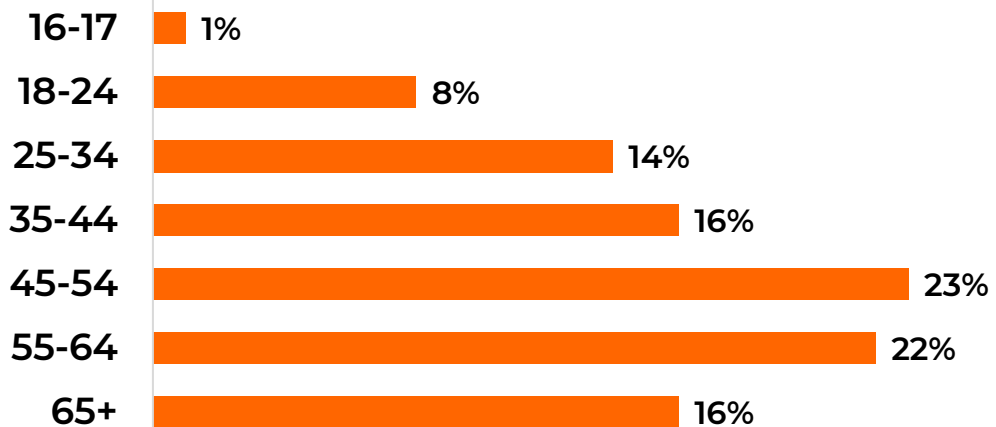## Respondent definitions

Throughout the report we have labelled respondents as either a Current Member, Stakeholder or Potential Member. A Stakeholder is anyone who is part of the Cancer UI Programme as part of their professional career, e.g., anyone that is paid for their involvement as part of their job. Whereas a Current Member is a Service User that does not get paid and is volunteering their time.

Sample Profile (1)

Background

Age

- 16-17: 1%
- 18-24: 8%
- 25-34: 14%
- 35-44: 16%
- 45-54: 23%
- 55-64: 22%
- 65+: 16%

Gender

- Female: 63%
- Male: 36%
- Non-Binary: 1%

Region

- Wigan 8%
- Bolton 4%
- Bury 5%
- Rochdale 5%
- Oldham 6%
- Salford 5%
- Manchester 41%
- Tameside 3%
- Trafford 12%
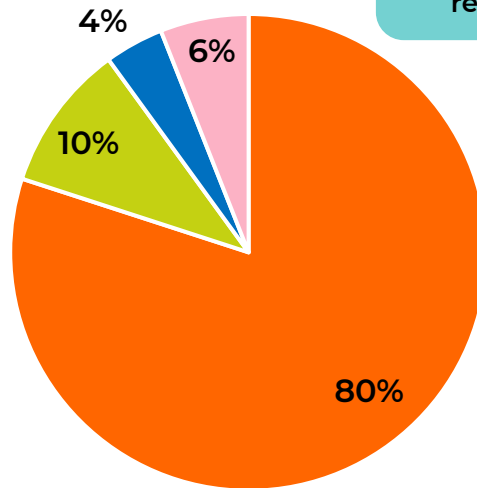- Stockport 11%
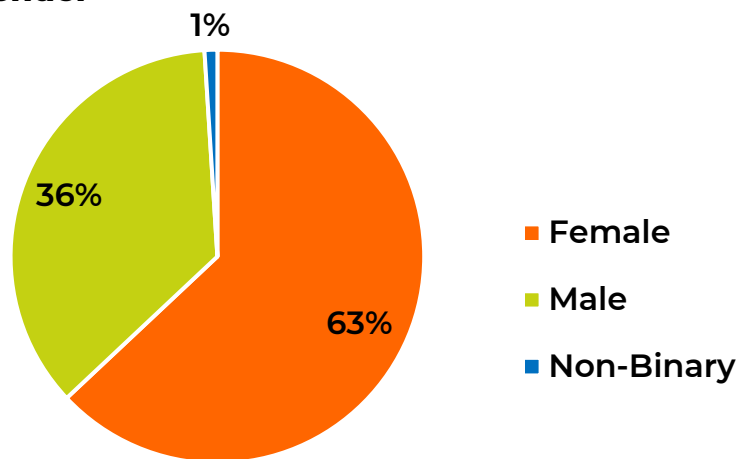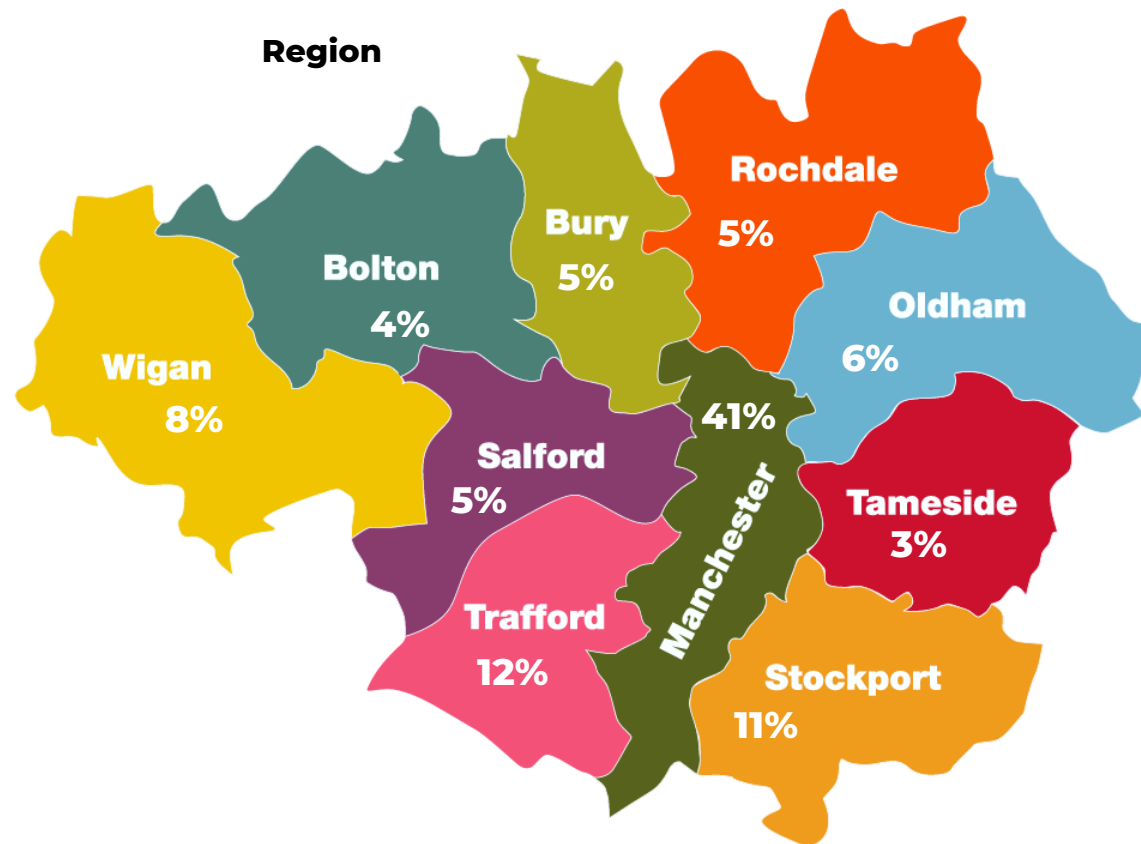
97% North West

3% North East, South East, South West and Midlands

Sample Profile (2)

Background

Ethnicity

Note: The ethnicity breakdown of respondents broadly mirrors that of the 2011 Greater Manchester Census (2021 Census results are yet to be published in full).

4%
6%
10%
80%

UK Social Grade

4%
27%
69%
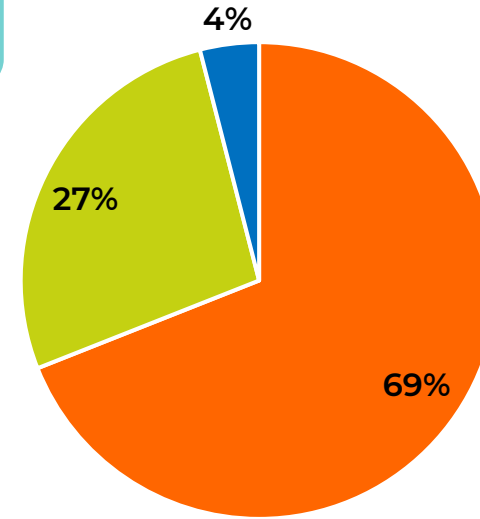
- ABC1
- C2DE
- Prefer not to say

■ **Asian / Asian British**
(i.e., Indian, Pakistani, Bangladeshi, Chinese, any other Asian background)

■ **Black / African / Caribbean / Black British**
(i.e., African, Caribbean, any other Black / African / Caribbean background)

■ **White**

■ **Mixed / Multiple ethnic groups**
(i.e., White and Black Caribbean, White and Black African, White and Asian, any other mixed / multiple ethnic background)

Base: Total participants (online survey current members / stakeholders / prospects, online community, focus groups and teams / telephone depths), n=206

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Key insights

Executive summary

The Cancer User Involvement Programme was launched in 2015 with objectives and processes co-designed and produced by the Macmillan cancer support team and service users. The programme is now funded by Greater Manchester Cancer Alliance and hasn't formally been reviewed since this change in funding. As it stands, people see the value in the programme, it's positively impacting the lives of people affected by cancer in Greater Manchester, and people want its success to continue.

Whilst there are many successes to celebrate, a lot has changed since 2015 to now, 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). There is a need to re-focus on the core objective of the programme and plan for the future, but change is always difficult and we realise there may be some resistance to change. This research has identified four insight streams (some of which naturally interlink), that if addressed, will make a significant difference to the programme's success:

DESIGN:	DELIVERY:	RELATIONSHIP:	COMMUNICATION:
Now is the time to take a blank sheet of paper approach to review and rebuild the programme from the foundations up. Start by putting the spotlight on the mission and values, ensuring clarity and simplicity throughout.	There needs to be more structure in the delivery of the programme and this will mean firming up or creating some processes. It is key to ensure expectations are managed and the Cancer UI Programme is delivered in a consistent way so everyone is treated equally.	More work and effort needs to go into forming and nurturing relationships to truly bring everyone together. This will need harnessing and co-ordinating. There is a need to raise visibility in underrepresented community groups via outreach.	The programme content and the way it is communicated is missing the mark – this includes content aimed at raising awareness, Cancer User Involvement Programme content and how you communicate with people more widely.

Potential Members and some new Current Members lack an understanding of what the programme is and how they can get involved. Those currently involved feel the programme has lacked consistency, structure and a lack of focus in recent years.	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 to go about it. Life in 2022 is fast paced and one size does not fit all; flexibility in delivery of the programme is key to ensure more diversity and accessibility.	There are a lot of good things happening across GM, but these are often happening independently of each other. The Cancer UI Programme has to get out into the communities proactively, rather than expecting people to come to the programme. This has to be ongoing and not one off to stand a chance of improving diversity.	There is a desire for improvements to comms and in particular in relation to sharing knowledge / best practice. Wider comms improvements (literacy / clearer purpose etc.) should assist in raising awareness and member acquisition. Ongoing comms improvements (Friday email / sharing success better etc.) should assist in getting Current Members more engaged.

If we address the above insight streams, then the end result should be 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.

What changes / improvements are current members and stakeholders likely to want from the Cancer User Involvement Programme (1):

Key Insights

	Less important	Nice to have	Must have
Raise awareness of the Cancer UI Programme with all professionals that interact with people affected by cancer		20%	80%
Create an easier explanation of the Cancer UI Programme for new Service Users	5%	22%	73%
Have a formal induction for new Service Users	6%	27%	67%
Create relationships with Heads of Patient Experiences within Greater Manchester trusts	3%	33%	64%
Create a menu of options for how Service Users can get involved with the Cancer UI Programme	3%	34%	63%
Update the 'Charter of Involvement'	7%	32%	61%
Have relationships with other cancer alliances to share knowledge and best practices	2%	38%	60%
Create a cross board group to discuss broader themes across all cancer care, rather than just one particular cancer type	6%	34%	60%
Share the successes of the programme more externally	8%	40%	52%
Share the successes of the programme more internally	6%	47%	47%

> More of a must have for Current Members (91%) cf. to Stakeholders (69%)

> More of a must have for Current Members (71%) cf. to Stakeholders (57%)

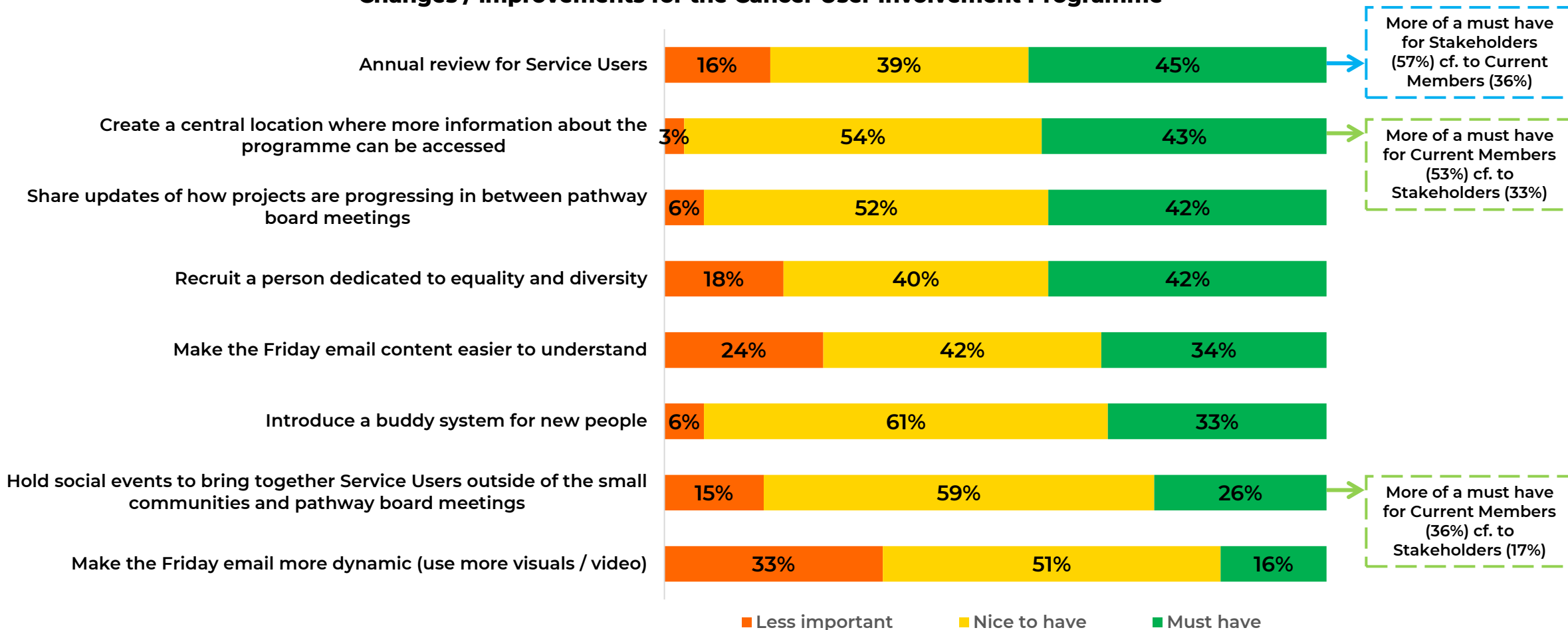> More of a must have for Stakeholders (67%) cf. to Current Members (56%)

Base: Total online survey current members / stakeholders, n=88
Q: We're going to show you some potential changes or improvements to the Cancer User Involvement Programme that could happen, and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this).

What changes / improvements are current members and stakeholders likely to want from the Cancer User Involvement Programme (2):

Changes / improvements for the Cancer User Involvement Programme

Change / improvement	Less important	Nice to have	Must have
Annual review for Service Users	16%	39%	45%
Create a central location where more information about the programme can be accessed	3%	54%	43%
Share updates of how projects are progressing in between pathway board meetings	6%	52%	42%
Recruit a person dedicated to equality and diversity	18%	40%	42%
Make the Friday email content easier to understand	24%	42%	34%
Introduce a buddy system for new people	6%	61%	33%
Hold social events to bring together Service Users outside of the small communities and pathway board meetings	15%	59%	26%
Make the Friday email more dynamic (use more visuals / video)	33%	51%	16%

More of a must have for Stakeholders (57%) cf. to Current Members (36%)

More of a must have for Current Members (53%) cf. to Stakeholders (33%)

More of a must have for Current Members (36%) cf. to Stakeholders (17%)

■ Less important   ■ Nice to have   ■ Must have

Base: Total online survey current members / stakeholders, n=88
Q: We're going to show you some potential changes or improvements to the Cancer User Involvement Programme that could happen, and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this).

Review of the current programme

Review of the current programme

Current Members get involved with the Cancer User Involvement Programme to use their voice and personal experiences to give back to the services they've benefitted from and to help improve services for others who are affected by cancer.

Reasons for getting involved with the Cancer User Involvement Programme

Interest in healthcare / advocate for cancer

To share my personal experiences

To give back

To make a difference, by improving services and helping others

"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." (Current Member)

"Mostly because I like sharing my views and opinions and I realised that patient focus seemed to be lacking. Having been given a second crack at life it's a small way I can give back." (Current Member)

"I wanted to give back. GM Cancer saved my life. The least I could do was to apply my skills and knowledge and mindset to things in the GM Cancer space." (Current Member)

"To improve services and shares my experience in the hope that it can help others or procedure and practice." (Current Member)

No matter whether people got involved with the Cancer User Involvement Programme as a result of a positive or negative experience, the key driver to get involved is the desire to make a difference.

The extremes of why some people get involved with the programme

Angry:
From having a __negative__ experience

Grateful:
From having a __positive__ experience

COMMONALITY:
Wanting to make a difference

Social:
Wanting to be part of a __community__ and meet others

Activist:
Wanting to create a __legacy__ and make changes

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"*I think there's* *a lot of good work that's been done already*. *And so a lot to build on and it's quite an established programme now that's been going quite a number of years…* *I don't think I've seen it done better in any other places*. *I mean, it's a massive challenge to get right, but the way that it's been done with the GM cancer is about as close as I've ever seen. I think they're doing it well and doing it right and taking it seriously enough and investing in it enough to mean that there is at least a decent chance of it not seeming tokenistic, but to seem like it is actually genuinely feeding into a conversation and having influence within that conversation.*"

Stakeholder

There are a number of significant strengths of the Cancer User Involvement Programme which benefit people affected by cancer, but also Current Members and Stakeholders.

Improves the experiences of people affected by cancer

Provides a unique insight from Current Members

Brings people together to share ideas

There is a commitment from those involved to wanting to do things well

Collaboration / Co-design / Co-production

The Greater Manchester Cancer Alliance team

Helps build Current Members' confidence

It's a way of meeting others who have been affected by cancer

Cancer User Involvement Programme strengths

"I think the main strengths are in the range of experience of the patients involved and the opportunities to use those to shape pathways and other things like treatment summaries and explanations. The programme gives a voice and opportunity to those who want to help others with cancer to have a less worrying and better informed time during and after treatment. I think that the use of patient input is helping clinicians to understand the impact of their actions and attitudes on patients under the stress of a cancer diagnosis." (Current Member)

"I think the fact that we have very few conversations about projects without the need for user involvement to be a significant part of any new project, I think, again, is a plus." (Stakeholder)

"[In relation to the User Involvement Manager Team] I think they're very approachable. I think they're really nice that they're really quick at responding to your emails as well. And if you need anything, I just find them really approachable to email." (Stakeholder)

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"*I think* *one of the things that cancer did to me was it trashed my confidence*, *like completely trashed my confidence... It has taken me a long time to get that confidence back, I'm five years post-cancer and I still feel like a bit of a shell of myself compared to where I was. So* *these kinds of voluntary roles are really good for me* *from a personal perspective.*"

Potential Member

Review of the current programme

Whilst the Cancer User Involvement Programme is noted as operating well, there is still room for improvement and to make a bigger impact.

Poor awareness amongst Potential Members and Stakeholders

No formal structure or induction for new members post COVID-19

Lack of knowledge on Current Members skillsets

Lack of new members joining the programme

Lack of diversity – including ethnicity, age, cancer type, etc

It can be difficult for Potential Members to understand what the programme is or how to get involved

Finding a balance between representing all patients and individual thoughts / feelings

Not everyone is on the same page, the community feels disjointed

Cancer User Involvement Programme weaknesses

"I speak to people in like data and analytics, who pull together patient data, and you think they might have heard of it, but no one has, and they're all talking about 'how do we understand the patient voice within the projects we deliver?' And I'm like, 'there's a user community, are you aware of it?' And it's like, no, what's that? So even looking for it in the hospital I've not been able to find any information out about it internally." (Current Member)

"We must get back to a proper induction programme as I see lots of the newer members have not had induction." (Current Member)

"I think that we certainly could improve the diversity on the programme. I don't think that it represents properly the population of Greater Manchester and the cancer patients that we see coming through our systems." (Stakeholder)
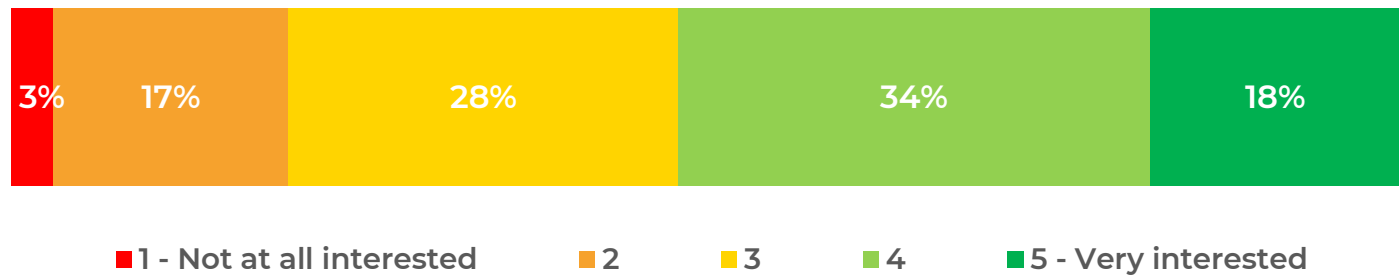
The initial perception of the Cancer UI Programme is positive amongst Potential Members. Whilst half are interested in getting involved with the programme, they need more information before fully committing to the idea of being involved.

Interest in becoming involved with the Cancer UI Programme (based on the description alone)

Greater Manchester Cancer Alliance work in collaboration with organisations across Greater Manchester to help people get diagnosed earlier, and provide better treatment and support people to live well with and beyond cancer.

Greater Manchester Cancer Alliance launched the Cancer User Involvement Programme in 2015. The programme 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.

As part of this programme, people affected by cancer share their experiences and opinions to help make sure that care provided is what people really need. There are lots of different ways to get involved, and people can give as much or as little time as they would like. Whether that's taking part in surveys, reviewing leaflets, helping to develop training programmes for doctors and nurses, or acting as a patient representative at board meetings.

| 3% | 17% | 28% | 34% | 18% |

52% Interested

■ 1 - Not at all interested   ■ 2   ■ 3   ■ 4   ■ 5 - Very interested

"[1] I'm not good with change." (Potential Member)

"[2] Time pressures would make it difficult." (Potential Member)

"[3] I would certainly need more information as it was a very limited description but the concept is something interesting to me." (Potential Member)

"[4] It seems a good thing to do but would like to know more before I decide if it's suitable for me." (Potential Member)

"[5] Because 1 in 2 people will get cancer and its something that affects everyone so if I can personally help in anyway then I will." (Potential Member)

Base: Total potential members (potential members from the online survey and potential members from the online community), n=61
Q: Based on what we've shared so far, how interested would you be in becoming involved in the Cancer User Involvement Programme? Please answer honestly, on a 5-point scale, whereby 1 means 'Not at all interested' and 5 means 'Very interested'.

Potential Members need for more information can also be seen in the top five barriers for involvement with the Cancer UI Programme.

% scoring 1 or 2 (a significant barrier shown)

I don't have any medical knowledge

44%

I work full time so wouldn't be able to fit it in

42%

I wouldn't know where to begin to get involved

42%

I'm not sure my experiences will be helpful to others
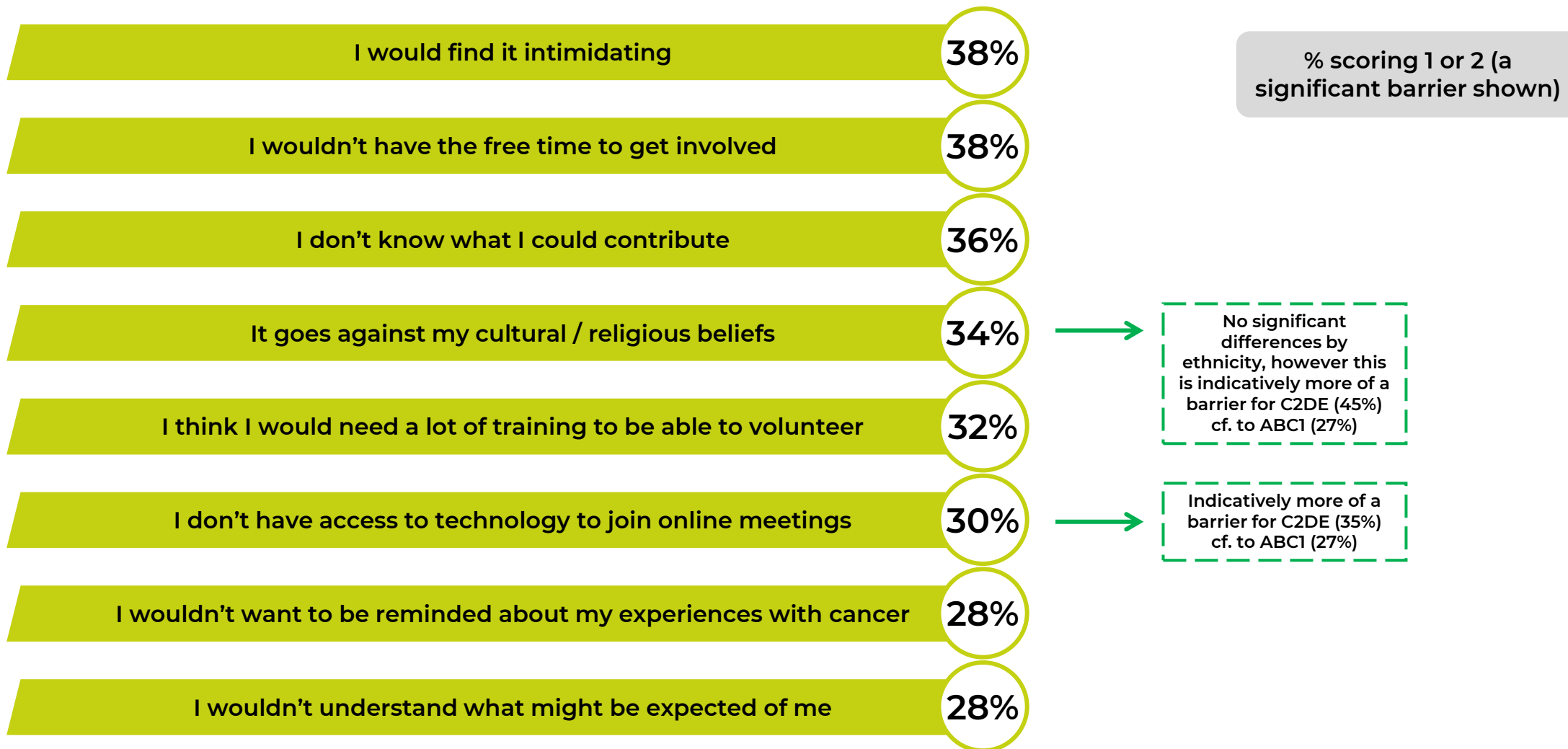
40%

I wouldn't feel comfortable sharing my experiences

38%

Base: Total online survey potential members, n=51
Q: Thinking about your own personal situation and life, can you tell us whether any of the following would be a barrier for you? Please answer on a scale of 1 to 5 whereby 1 means 'this is a significant barrier / would put me off from getting involved' and 5 means 'this would not be a barrier / put me off from getting involved at all'

Other barriers for Potential Members include lack of confidence and lack of available time to get involved.

I would find it intimidating — **38%**

I wouldn't have the free time to get involved — **38%**

I don't know what I could contribute — **36%**

It goes against my cultural / religious beliefs — **34%**

I think I would need a lot of training to be able to volunteer — **32%**

I don't have access to technology to join online meetings — **30%**

I wouldn't want to be reminded about my experiences with cancer — **28%**

I wouldn't understand what might be expected of me — **28%**

% scoring 1 or 2 (a significant barrier shown)

No significant differences by ethnicity, however this is indicatively more of a barrier for C2DE (45%) cf. to ABC1 (27%)

Indicatively more of a barrier for C2DE (35%) cf. to ABC1 (27%)

Base: Total online survey potential members, n=51
Q: Thinking about your own personal situation and life, can you tell us whether any of the following would be a barrier for you? Please answer on a scale of 1 to 5 whereby 1 means 'this is a significant barrier / would put me off from getting involved' and 5 means 'this would not be a barrier / put me off from getting involved at all'

Cultural and religious belief barriers for Potential Members will look different for each individual, however it could be a result of an unwillingness to discuss cancer due to the stigma around it in their community.

Macmillan spoke to Asian, Black and people from other ethnically diverse communities who have been affected by cancer, some of which reported a lack of ease, ability or willingness to discuss their cancer with others due to the stigma about cancer in their community.

There were also reports, from the individuals - as well as healthcare professionals, diversity specialists and academics - of Asian, Black and other ethnically diverse people being less aware than other groups about various aspects of cancer

"If anyone tries to bring out the topic [of cancer], then I immediately switch the topic... I just don't give them the chance to elaborate further and that is full stop. If they continue, then I will tell them, 'Don't we have something else that we can talk about? Why talk about this boring subject? We have come here to enjoy, so forget about the problem.' I don't get entangled in this conversation." (Asian man affected by cancer, 35-64)

"I never knew anything at all about cancer at [the point of diagnosis]. My steep learning curve was about to start." (Black woman affected by cancer, 35-64)

"I did not have family support... Currently in our group, we find that some husbands are unable to cope with their partner's condition in terms of diagnosis, feelings, body change, etc. This is particularly the older group around 55 plus." (Asian women affected by cancer, 35-64)

"I was told along with my parents and none of us knew what cancer was, let alone leukaemia" (Black women affected by cancer, 18-34)

Source: https://www.macmillan.org.uk/documents/aboutus/research/inclusionprojects/experiencesofbmepeople.pdf

MACMILLAN CANCER SUPPORT

Design
(noun)

Delivery
(noun)

The way in which something is planned and made

The fact of achieving or producing something that has been promised

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Currently it takes a few explanations of the Cancer UI Programme for Potential Members to understand what it is. Even after joining the programme it can take a while for people to fully understand what is expected of them in their new role.

Create an easier explanation of the Cancer UI Programme for new Service Users

Make the Friday email content easier to understand

Create an easier explanation:
- 73%
- 22%
- 5%

Make the Friday email:
- 34%
- 42%
- 24%
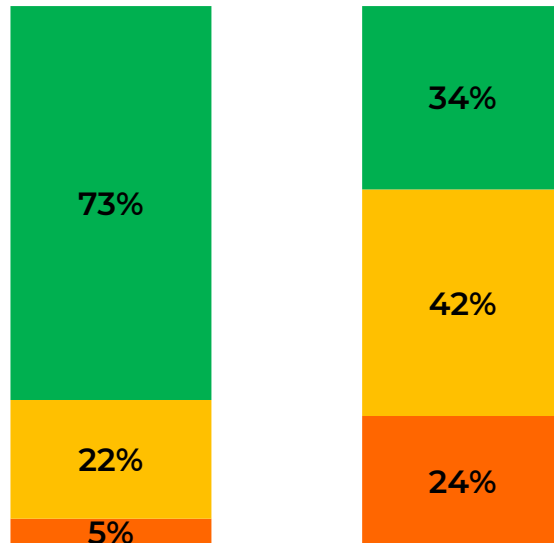
■ Must have
■ Nice to have
■ Less important

"[When I first became part of the Cancer UI Programme] The biggest issue was the acronyms and understanding the clinical process, which can be quite complex." (Current Member)

"I feel like there's a hint of uncertainty in the air, most of us I feel don't understand what is fully expected of us. I want to do more, and luckily I have the opportunity to give more detailed feedback on things due to being on the pathway board, but for others, there aren't many opportunities." (Current Member)

"Yes I was unsure about what the programme was [at first] but understand it more [at the end of the online community] and think it is a great project that can help a lot of people" (Potential Member)

Base: Total online survey current members / stakeholders, n=88
Q: We're going to show you some potential changes or improvements to the Cancer User Involvement Programme that could happen, and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this).

A clear explanation of what the Cancer UI Programme is and what the role could involve is a 'must have' for Potential Members.

Potential Members expectations of the Cancer UI Programme

	Less important	Nice to have	Must have
A clear explanation of what the Cancer UI Programme is	2%	26%	72%
A clear explanation of what the role could involve	4%	30%	66%
Ongoing support	2%	34%	64%
An Induction when you first join to introduce the Cancer UI Programme	6%	44%	50%
Ongoing training	6%	46%	48%
Examples of how the Cancer UI Programme has made a difference to cancer service in Greater Manchester	4%	52%	44%
A 'buddy system' to help you understand how the Cancer UI Programme works, supported by someone already on the programme	14%	60%	26%

Indicatively more of a must have for C2DE (65%) cf. to ABC1 (37%)

■ Less important   ■ Nice to have   ■ Must have

Base: Total online survey potential members, n=51
Q: If you were to get involved with the Cancer User Involvement Programme, what would you expect to happen? We're going to show you some potential things that could happen and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this). 29

"The majority of this country have a reading age of between seven and 11. *And we are pitching all our materials at Guardian and Times readers, which is not appropriate, and we should be pitching it at the level of more of a tabloid kind of read.* You also really need to put resources into how can I make this information accessible and engaging and an easy read, so you're not excluding the vast numbers of people who've got really poor health literacy. So, I think that's a huge barrier that really needs focus. And you can work in partnership with the voluntary and community sector to kind of translate materials that you've got into easy read and very basic English so they are more understandable than complex documents. *There is also translation into other languages to consider as well*."

Stakeholder

The Gunning Fog index, a readability test, further highlights a need to simplify Cancer UI Programme content so it's easier to digest and understand.

Gunning Fog Index

THE GUNNING FOG INDEX IS 15.69

- The number of major punctuation marks, eg. [.], was `6`
- The number of words was `153`
- The number of 3+ syllable words, highlighted in blue, was `21`

You can edit the numbers above and recalculate

`Recalculate`

EDITED TEXT

Greater Manchester Cancer Alliance work in collaboration with organisations across Greater Manchester to help people get diagnosed earlier, and provide better treatment and support people to live well with and beyond cancer[.] Greater Manchester Cancer Alliance launched the Cancer User Involvement Programme in 2015[.] The programme 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[.] As part of this programme, people affected by cancer share their experiences and opinions to help make sure that care provided is what people really need[.] There are lots of different ways to get involved, and people can give as much or as little time as they would like[.] Whether that's taking part in surveys, reviewing leaflets, helping to develop training programmes for doctors and nurses, or acting as a patient representative at board meetings[.]

What is the Gunning Fog Index?

The Gunning Fog formula generates a grade level between 0 and 20. It estimates the education level required to understand text. A Gunning Fog score of 6 is easily readable for 11-12 year olds. Text aimed at the public should aim for a grade level of around 8. Text above a 17 is aimed at graduate level.

Why is it useful?

The Gunning Fog index is used to ensure clarity and simplicity.

How is it calculated?

The formula for Gunning Fog is 0.4 [(words/sentences) + 100 (complex words/words)]. Complex words are those containing three or more syllables.

How does the alliance content fare?

During the Potential Member depth interviews, focus groups and online community, respondents were shown content that describes what GM Cancer Alliance does and introduces the Cancer UI Programme. The Gunning Fog index score for this content was 15.69. This is the equivalent reading age of 16-17 years old (and much higher than the easily readable index score of 6).

31

Whilst collating feedback on the website was not a project priority, anecdotal references highlight a need for the content and how it is presented to be improved.

> *"I think they need to do a fact finding exercise for them to sort of decide who the people are that are on their website and who their demographic is, and what are they looking for."*
> *(Potential Member)*

> *"That's another thing that needs to be updated the website and the information on the website."*
> *(Current Member)*

Check out our toolkit guidance on the principals of UX in the appendix

Design & delivery

Now is the optimum time to refresh the Cancer UI Programme as a result of this review. This should begin with a solid foundation of co-designing a clearly defined and easy to understand brand.

| **Purpose:** Why does the GMC Cancer UI Programme exist? | → | **Vision:** What would the world look like if the Cancer UI Programme succeeded in it's purpose? | → | **Mission:** How will the Cancer UI Programme achieve it's vision? | → | **Values:** What does the Cancer UI Programme stand for? | → | **Positioning:** How different is the Cancer UI Programme from others? |

Establishing the Cancer UI Programme brand should help to achieve a number of things:

- It can help ensure everyone (Potential Members, Current Members and Stakeholders) is aware of what is expected of them and their contribution to the programme.

- It can help the brand resonate and have meaning across all audiences.

"[To be the best in class Cancer UI Programme] A very clear and distinctive brand (name, brand and style). A very clear vision, very clear objectives, very effective in its delivery. All of the above to be recognisable, distinctive and easy for end users to understand. A household name - including for those who have not been affected by cancer." (Current Member)

"It would have been nice if we could go through the whole thing in terms of what exactly the whole programme means, what it delivers, how a new person can be involved into it. So a little bit of insight or induction, even probably an hour or so might be a bit more useful." (Stakeholder)

"For now possibly an update regarding the cancer user involvement aims and purpose, just to reiterate and make sure everyone on board is familiar with their roles and expectation and just to make everyone feel re-ignited with their purpose and remind us why we are all here." (Current Member)

After laying the foundations and outlining the Cancer UI Programme brand including its vision and values, the next step is to share this with everyone involved. One way of doing this is to create a formalised induction with volunteer agreements for both new and Current Members.

Have a formal induction for new Service Users

67% — Must have
27% — Nice to have
6% — Less important
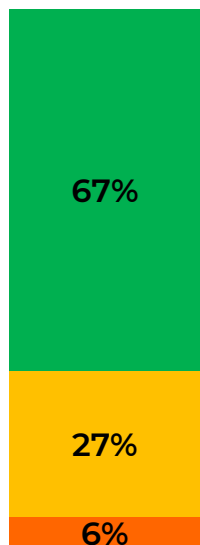
- ■ Must have
- ■ Nice to have
- ■ Less important

One process for everyone

→

Formal induction / set expectations

Volunteer agreement
(Refresh the volunteer agreement to factor in any changes and get everyone, including Current Members, to sign – to ensure everyone is aware of what is expected of them)

Skillset and interests survey
(For new and Current Members so these skills and interests can be utilised as part of the programme)

Annual review

←

Ongoing training
(if necessary)

←

Initial training
(e.g., How to join online meetings and Zoom / Teams etiquette)

Getting involved with the Cancer UI Programme should be easy – creating a menu of options (similar to a jobs board) of how people can get involved will help everyone understand what they might like to sign up for, or where their skills might be useful.

Create a menu of options of how Service Users can get involved with the Cancer UI Programme

63% Must have
34% Nice to have
3% Less important

- ■ Must have
- ■ Nice to have
- ■ Less important
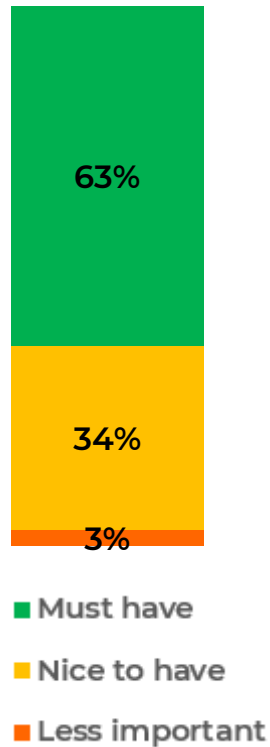
"I feel I have a great skill set which I could offer to the group but feel I have limited information to participate." (Current Member)

"The new contributors are really new (less than a year) and the old hands are 5+ years. Everyone is positive about it but the newer members don't really know how to contribute more or where to find the opportunities." (Current Member)

"I think what is missing, in addition to the Friday email, is a website with opportunities which is updated with current opportunities and perhaps a place to share what is happening." (Current Member)

The menu of options should include an easy (i.e. one click) call to action– so if someone is interested in putting themselves forward for anything they know how they can do that.

For example, this might be a contact number they need to call, or inputting their email address so they're contacted when the project they're interested in has begun.

The options should also have the ability to be filtered to narrow down different needs such as level of involvement or time commitment required.
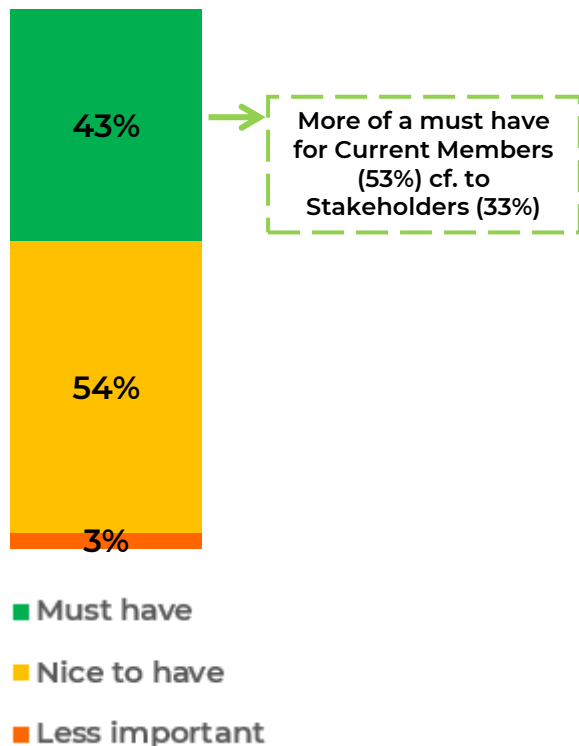
Base: Total online survey current members / stakeholders, n=88
Q: We're going to show you some potential changes or improvements to the Cancer User Involvement Programme that could happen, and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this).

35

The Friday email provides Current Members and Stakeholders with an insight into what's going on, but there is also a desire for a central location where more information about the Cancer UI Programme can be stored, including a menu of options of how to get involved.

Create a central location where more information about the Cancer UI Programme can be accessed

43%

→ More of a must have for Current Members (53%) cf. to Stakeholders (33%)

54%

3%

■ Must have

■ Nice to have

■ Less important

Some examples of what could be included in this central location

Menu of options of how to get involved

Programme successes

Updates on the progress of each project

Minutes from previous pathway board meetings

Training documents

Glossary of terms / acronyms

Base: Total online survey current members / stakeholders, n=88
Q: We're going to show you some potential changes or improvements to the Cancer User Involvement Programme that could happen, and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this).

Potential Members are interested in getting involved in a range of different ways, particularly by taking part in surveys and reviewing leaflets – this feels like a safe and easy way to start getting involved, this could help increase confidence.

How Potential Members would be interested in being involved

82%
Taking part in surveys*

40%
Reviewing leaflets

30%
Creative projects to improve cancer care

28%
Getting involved in small communities to discuss current projects relative to that cancer to help to improve cancer care

22%
Helping to develop training programmes for doctors and nurses

20%
Acting as a patient representative at board meetings

2%
I wouldn't be interested in any of these

"The surveys sound more appealing to me as I feel I wouldn't be able to mess them up." (Potential Member)

"I prefer the surveys and reviewing leaflets as I think the board meetings would be time consuming and isn't ideal for someone like myself who doesn't have much time." (Potential Member)

"Surveys are easy to complete, reviewing leaflets requires more focus and helping to develop training programs etc requires even more involvement and commitment." (Potential Member)

Base: Total online survey potential members, n=51
Q: There are different ways of getting involved in the Cancer User Involvement Programme, we want to know whether there would be any aspects that you'd be more interested in? *Context note - potential members were sourced from an online panel so will naturally be more accustomed to taking part in surveys

The majority would prefer a hybrid way of getting involved in the Cancer UI programme. The flexibility this offers is welcomed and needed for those with busy lifestyles.

How should people be able to get involved in the programme?

71%
would prefer a hybrid (mix of face-to-face / online) involvement approach
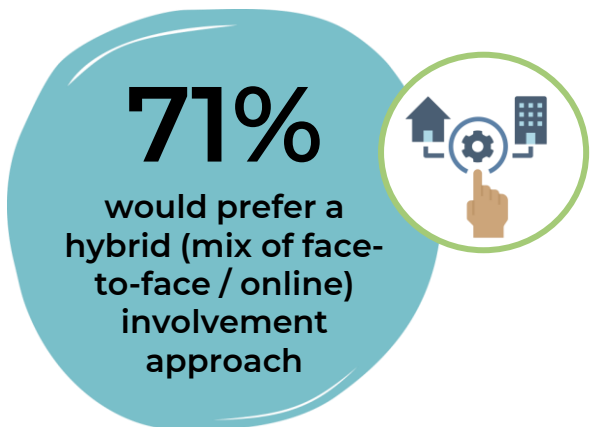
"Giving the option of hybrid meetings helps with highlighting some of the positives and flexibility of joining the community, as others may have reservations with the current pandemic with having constant face-to-face meetings, or can't physically make meetings due to health reasons or caring responsibilities and it will be unfair to lose a whole chunk of valuable feedback opportunities." (Current Member)
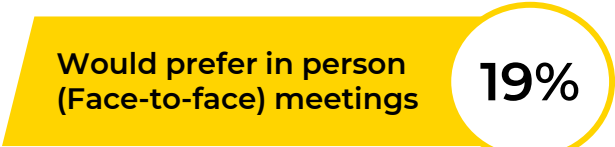
"I prefer the face to face stuff, getting my views and opinions across where possible. With my past experiences, I am relaxed and very comfortable speaking in front of people, and happy to collate ideas from participants to raise at meetings on their behalf." (Potential Member)

Would prefer in person (Face-to-face) meetings **19%**

Would prefer online (Teams / Zoom etc.) **10%**

Higher amongst Potential Members (20%)

"I'm a volunteer awareness speaker for Prostate Cancer UK and I've actually done a zoom call to 130 civil servants. Now, there's no way in million years that 130 civil servants from all over the UK would have been gathered in one point to listen to me talk about prostate cancer. It's much easier doing it online. So, it's in that respect. It's great." (Current Member)

Base: Total respondents (both current members / stakeholders and potential members from the online survey and current members from the online community), n=147
Q: What are your thoughts on how people can get involved in the Cancer User Involvement Programme, do you think involvement should be...?

In terms of meetings, there is not a common day and time that works for the majority – people want to get involved at all times of the day, even on a weekend.

Design & delivery

Preference on days and times of the week to be involved

Legend: ■ None of them ■ Morning (09:00-11:59am) ■ Early afternoon (12:00-14:59pm) ■ Late afternoon (15:00-16:59pm) ■ Evening (17:00-21.00pm) ■ All of them

Day	None of them	Morning (09:00-11:59am)	Early afternoon (12:00-14:59pm)	Late afternoon (15:00-16:59pm)	Evening (17:00-21.00pm)	All of them
MONDAY	18%	21%	27%	22%	19%	21%
Tuesday	20%	20%	24%	22%	17%	22%
WEDNESDAY	15%	21%	28%	25%	19%	21%
THURSDAY	22%	22%	26%	20%	17%	20%
FRIDAY	22%	20%	28%	21%	15%	22%
Saturday	51%	11%	12%	10%	5%	20%
Sunday	58%	8%	10%	11%	6%	17%

> **Indicatively, Potential Members are more likely than Current Members to select evenings (17:00-21:00pm) on 6 of the 7 days in a week.**

Base: Total online survey respondents (both current members / stakeholders and potential members), n=138
Q: If you were to attend any meetings (whether face-to-face in person or online) in relation to the Cancer User Involvement Programme, which days of the week and what times would work best for you? (Note: multiple selections allowed, so % for each day will not add up to 100%).

Verbatim comments from Potential Members highlight the need for more variety in meeting times / days. Having that variety could be what is needed to ensure more people are able (and willing) to be involved.

"Evenings once the kids are asleep. It's too hectic beforehand with them to sort out. I wouldn't be able to join in, be too difficult. I think if they can vary their times / days for getting involved, it will cover the whole population at some stage."
(Potential Member)

"I work shifts so it would change each week. Mostly daytimes when the kids are in school would likely be best."
(Potential Member)

"I have a very busy life style, so probably evenings."
(Potential Member)

Q: Thinking about your own personal circumstances, if you were to be involved with the Cancer User Involvement Programme, what days / times would work best for you? Why?

Personal views are important for the Cancer UI Programme, however, the priority needs to be what's best for the programme overall.

Whilst there is an awareness of the purpose of the Cancer User Involvement Programme – to improve the lives of people affected by cancer in Greater Manchester – some of the day-to-day conversations can become more personal.

Personal experiences are very important to the work of the Cancer Alliance. It is important too that we also consider the wider voices and needs of other patients across Greater Manchester. This can sometimes be a difficult balance..

A guiding question that can help us to achieve this balance is:

"What's best for the overall Cancer User Involvement Programme so we can achieve the purpose of the programme?"

"We're often getting people with [strong personal views], which drives them to want to come and contribute. And that's not necessarily wrong or bad, but it will possibly affect the balance of what you're hearing. And that makes it quite challenging. I think about our pathway board, which is, again, I give tribute to those who did have [strong personal views], because we did recognise that our pathway board came into creation because of this, were saying you're not doing well enough with looking after us emotionally, despite what you're doing to us physically. So you know, there is a value for personal [views], because there was actually a harmonised voice of multiple people saying the same thing, which was all their personal experiences... I just think we have to get that right. It's not bad. It's not wrong. It's just one way of looking at it." (Stakeholder)

"*I am part of a support group, but the only person in the group who has been involved with the User Involvement 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

"Sadly, I have regularly experienced incidents where Service User Representatives (SURs) were not respectful of the agenda or the focus of a meeting. As with any other member of the board, items must be added to the agenda in good time and agreed, as the timing of boards are extremely tight and the few times per year that a board meets are precious (and extremely costly considering the seniority of the workforce in the room). Time after time SURs have [brought up] very personal questions about their own care and this is not appropriate. I know that healthcare professionals find it very difficult to manage some SURs and are 'scared' by some SURs."

Stakeholder

Whilst many referenced positive experiences with meetings and them feeling like a safe space, some provided examples of situations where they didn't feel comfortable to share.

Update the 'Charter of Involvement'
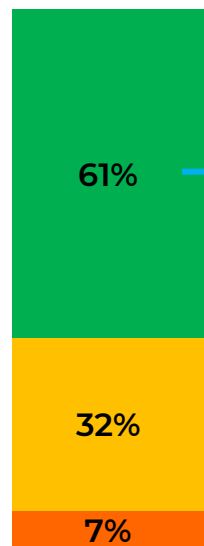
61%

32%

7%

More of a must have for Stakeholders (67%) cf. to Current Members (56%)

- Must have
- Nice to have
- Less important

Concerns over saying the 'wrong' things

"I feel sometimes healthcare professionals feel intimidated by some user involvement members or are worried about saying the wrong thing in their presence." (Stakeholder)

Some disrespect / shouting

"Sometimes it feels like "they who shout loudest" are heard. Everyone should have the chance to speak." (Current Member)

"It hasn't always been respectful to everyone involved - the disrespect has been from a small number of the service users and is by exception rather than the rule." (Stakeholder)

Cliques amongst attendees

"I haven't been involved in a meeting for a few years now and wouldn't particularly want to be involved again as I never felt particularly included and felt meetings involved cliques of people who knew all about each other and weren't very interested in what I thought." (Current Member)

"You can never guarantee that a meeting will be a safe space for everyone but *you can take robust steps to ensure that people are respected*; that they feel able to hear and respond to issues raised by others (when views may differ) and you can help everyone to be properly prepared for meetings. Some form of induction / buddying may be necessary for some before they feel confident enough to share and participate. Participants need to be aware in advance that they may hear sensitive information; they may strongly disagree with some views and strong emotions may be roused!"

Stakeholder

When Current Members and Stakeholders were presented with a list of suggestions to make meetings a safer space for all, all but 2% were on board with implementing some initiatives. The priorities are the suggestions which will have a more immediate effect.

Design & delivery

Priorities for ensuring meetings are a safe space for all

Priority	%
Encourage collaborative healthcare professional / user involvement member relationships, focusing on the problems together and how they can be overcome to improve patient care overall	82%
Make space for everyone to participate. Don't talk over each other	76%
Give everyone equal opportunity to speak during meetings	73%
Keep meetings focused and on time	70%
Ensure that everyone has an open mind / is non-judgemental	65%
Signing a pledge upon becoming involved to be respectful at all times	38%
None of the above	2%
Other	4%

All 1 mention: all should be a given at any meeting / have name badges / hold meetings by Zoom which allows people to indicate when they want to speak / welcome and encourage members new to the meeting.

Base: Total online survey current members / stakeholders, n=88
Q: Below are some suggestions on how Cancer User Involvement meetings can become a safe space for all and that everyone involved is treated with respect. Which of the below, if any, do you think should be more of a priority to ensure meetings are safe spaces for all?

46

Design & delivery

"In order to get more people involved, it needs to be simple, accessible (i.e. offering different times of day and mediums) and enjoyable or worthwhile (e.g. paid, or more opportunities arising from taking part or really seeing the changes coming to life, social aspect) 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."*

Current Member

47

An annual review can help Current Members feel valued for the contributions they've made to the Cancer UI Programme. A review can also help identify any potential areas where additional training or support is needed.

Annual review of Service Users

45%

More of a must have for Stakeholders (57%) cf. to Current Members (36%)

39%

16%

■ Must have

■ Nice to have

■ Less important
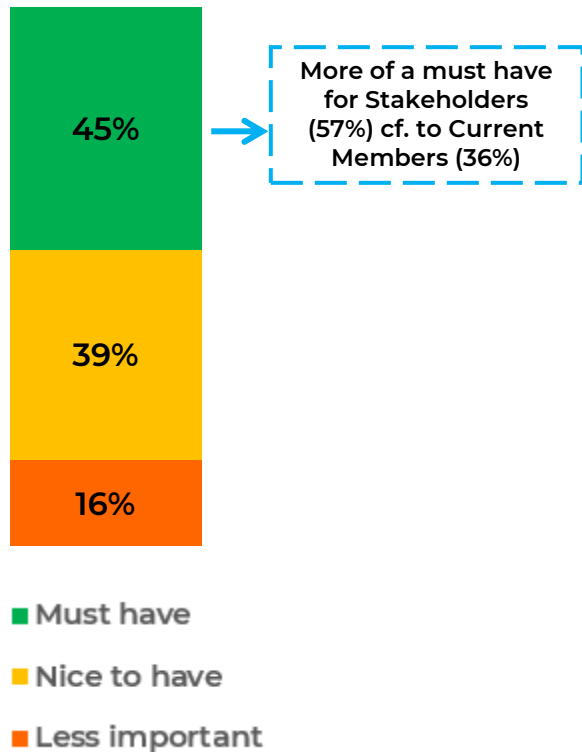
"That is a big danger if people don't feel appreciated for being there, they may just stop being involved." (Current Member)

"It is missing [reviews] because it'd be nice to be able to sit down with somebody or talk to somebody and for them to say, 'you don't say much do you' or something like that and you'd say 'okay, I'll be more involved' or [they'd say] 'thanks for your contribution, it's helped do this... this and this...'. You don't hear anything back like that." (Current Member)

Base: Total online survey current members / stakeholders, n=88
Q: We're going to show you some potential changes or improvements to the Cancer User Involvement Programme that could happen, and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this).

"When we were first enrolled we used to be given a Welcome Pack, I attach 2 images from this. A charter was coproduced in 2016, I attach an image of the cover. I also attach a copy of the role description for a pathway board member which states that the period of involvement was expected to be 12 months. This was extended to 2 years and has been longer for most of us."

Current Member

WE ARE MACMILLAN. CANCER SUPPORT

Greater Manchester Cancer

GREATER MANCHESTER CANCER PATHWAY BOARD MEMBER

Role Description

Type of Opportunity: Description:	Attending Board Member A Pathway Board is a multidisciplinary team that focuses on the development and improvement of cancer services in a particular cancer type or area. Each Board has representation from two people affected by cancer; they represent the views of other people affected by cancer.
Method of involvement:	Attending Pathway Board meetings Speaking in meetings representing the views of Service Users Review documents in preparation for meetings Report key issues to Steering Group and/or small community, as appropriate. Other, as required by the Board
Organisations involved:	Greater Manchester Cancer, Greater Manchester Cancer Vanguard, Macmillan Cancer Support and Partner Organisations
Location:	Greater Manchester and East Cheshire
Frequency of involvement:	4 - 6 meetings per year. Each meeting is 2 hours' long
Period of involvement:	12 months
Additional time commitment:	2 to 3 hours per month. Attendance at one Steering Group Meeting per annum
Expenses paid:	Mileage (45p/m), plus car park fee or public transport fare
Selection process:	Meeting with member of the Macmillan User Involvement Team (MUIT)
Cancer Type:	We are aiming to match people's cancer experience to the relevant Pathway Board
Type of Treatment / Person Affected by Cancer:	Any
Previous experience required?	No
Learning & Development required?	Yes — Induction / User Involvement Matters / Session specific to this role
Other support available:	Yes — One to one support with a member of the MUIT / Group support with member of MUIT / Peer to peer support

1

49

Almost half agree that pathway board members should step down from responsibilities should there be someone willing to take on the role with a more recent cancer experience. However, many are also unsure (providing a mid score of 3).

Agreement with comment about pathway board members 'stepping down'

"Success for me in all of this looks like this... I should be in less [meetings] because there are more people coming to the party to do it. I love what I do... But do you know what? If there's a young person who's 25 and they're from the right part of Manchester and they've just recovered from cancer, I would happily stand down and put them on there."

| 3% | 13% | 38% | 22% | 25% |

■ 1 - Do not agree at all ■ 2 ■ 3 ■ 4 ■ 5 – Completely agree

47% Agree

"[1] We all have something to bring to the table." (Current Member)

"[2] Experience is important too." (Current Member)

"[3] Just has to be the right person with the right motivation." (Current Member)

"[4] My cancer experience and knowledge is limited and not all up-to-date. A newly treated patient could have experience of improvements to pathways and treatments already put in place since I was diagnosed and first treated." (Current Member)

"[5] Because too much it is the same old faces, including me!" (Current Member)

Base: Total online survey current members / stakeholders, n=88
Q: We'd like to know if you agree with the following comment about pathway board members stepping down...Please answer, on a 5-point scale, whereby 1 means 'Do not agree at all' and 5 means 'Completely agree'

More are in favour of a tenure for people acting as a patient representative at pathway board meetings than not. For most two years is the ideal duration.

54%
Think there <u>should</u> be a tenure for pathway board members

23%
'Don't know' if there should be a tenure

22%
Think there <u>should not</u> be a tenure

Stakeholders are more likely to think there should be a tenure 67% cf. to Current Members, 47%.

How long should the tenure be?
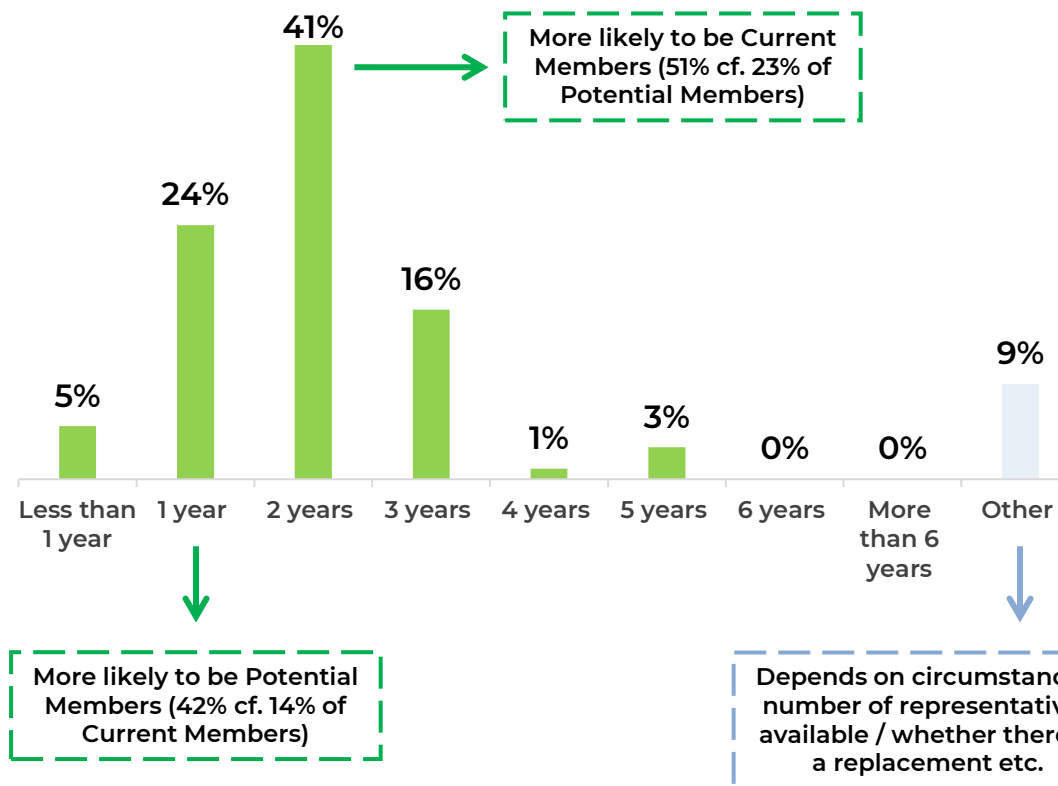
		41%						
Less than 1 year	1 year	2 years	3 years	4 years	5 years	6 years	More than 6 years	Other
5%	24%	41%	16%	1%	3%	0%	0%	9%

More likely to be Current Members (51% cf. 23% of Potential Members)

More likely to be Potential Members (42% cf. 14% of Current Members)

Depends on circumstances: number of representatives available / whether there is a replacement etc.

Base: Total respondents (both current members / stakeholders and potential members from the online survey and current members from the online community), n=147 / All who think there should be a tenure, n=75. Q: Do you think there should there be a tenure (set amount of time) for people acting as a patient representative at board meetings? / How long do you think the tenure (set amount of time) should be?

If a tenure is introduced, it's important this is clearly communicated to everyone as early as possible (ideally as part of a volunteer agreement) to help manage expectations.

Make it clear what the tenure is for someone acting as a patient representative at pathway board meetings.

Allow the patient representative to reapply for their position, if they would like to.

"I think it goes back to setting up expectations from the get go and then there's no surprises. A bit like when I set off on a clinical lead role, it's very clear that it's an annual review, based on an appraisal and the tender is three years and that it's open to competitive interview. It's very clear from the get go. So come three years, I'm not thinking well, hang on a minute, no one told me." (Stakeholder)

"Experience counts but also you could leave a board with no representation if people are forced to leave with no replacement." (Current Member)

In October 2021, NHS England and NHS Improvement (Greater Manchester Cancer Alliance is an NHS organisation and therefore considers NHS England to represent best practice in terms of their stance on renumeration) have made some changes to the way in which involvement payments are paid to patient and public voice (PPV) Partners

In October 2021 NHS England released guidance on 'reimbursing expenses and paying involvement payments'

Expenses paid so no one is 'out of pocket'

In valuing the contribution of PPV Partners, we recognise that we need to remove or minimise the financial barriers that can prevent or discourage participation. PPV Partners should not be out-of-pocket as a result of their involvement with NHS England and NHS Improvement so reasonable expenses will be reimbursed for most activities.

Involvement payment for 'expert' roles

Offering involvement payments to PPV Partners in PPV expert advisor roles. Such roles are typified by a significant input of time, skills and expertise, and a level of public accountability.

Any changes do not signal a move to contractual employment

PPV Partners will not be moving to a contract of employment and all other terms of the role will remain unchanged. The changes are to ensure that we pay PPV Partners in Roles 4 in a tax compliant way, in line with Her Majesty's Revenue and Customs (HMRC) guidance.

Whilst there was not a clear consensus on payment, many did feel that those involved with the programme should not be left out of pocket, so expenses could be covered as a minimum. People felt this should be optional and that this could also encourage those on lower incomes or in financial hardship to get involved.

However GMC decide to progress, an individuals earnings would need to be taken into consideration and any payment would be subject to statutory deductions (tax and NI).

Source: B0869_Working-with-patient-and-public-voice-partners-reimbursing-expenses-and-paying-involvement-payments.pdf (england.nhs.uk)

Desk research identified some organisations with 'involvement' roles are clearly stating remuneration opportunities within their content.

CANCER RESEARCH UK

Shaping Our Lives
Inclusive Involvement Matters

Cancer Research UK lists varying levels of 'voucher' payments for different involvement activities

Shaping our Live list 'opportunities to get involved' – some paid, some unpaid

Type of activity: Panel member

Organised by: Cancer Research UK's International Alliance for Cancer Early Detection (ACED)

Location: Online virtual meetings

Time commitment:

- Panel member: Eight 1-2 hour long meetings per year.
- Panel chairs: An additional four meetings per year.

Payment and Expenses: As per our involvement payment policy for panel members.

- Panel Chairs will be offered £150 when attending the regularly scheduled half-day executive board meetings

Time commitment	1.5hrs every two weeks. Day and time to be confirmed once panel members have been consulted on availability.	Various, one-off activity.
Meeting format	Virtual Up to 2 in-person meetings may take place per year. Expenses can be claimed in line with the expenses and payments policy.	Virtual
Payment	£25 per hour	Incentive voucher of: • £10 for 15 mins • £20 for 30 mins • £30 for 45 mins • £40 for 60 mins • £60 for 90 mins

- **Research looking into dental services for those with experience of severe mental distress – incentive – 20 x £10 prize draw vouchers**
- **Sharing your views on post-diagnostic support for autistic adults – complete three surveys and receive a £20 voucher**
- **RNIB – testing their new website – no incentive**

Perceptions on remuneration were mixed – more felt there shouldn't be a payment than should, but many were also unsure. Of those that did feel payment should be made, the majority felt covering expenses should be a priority.

Design & delivery

Should there be payment for involvement?

YES 28%

Stakeholders are more likely say 'yes' (31% cf. to Current Members, 22%)

ABC1 are more likely to say 'yes' (30% cf. to C2DE, 23%)

NO 44%

White people are more likely to say 'no' (52% cf. to Asian, Black and other ethnically diverse people, 19%)

I DON'T KNOW 27%

Expenses (travel to meetings etc.)	75%
Attending pathway board meetings	63%
Helping to develop training programmes for doctors and nurses	60%
Acting as a speaker at an event or conference	53%
Creating videos	48%
Contributing to projects	48%
Preparation for pathway board meetings	45%
Reviewing surveys / leaflets	43%
Attending small communities	43%
Creating infographics	38%
Taking part in surveys	38%

Base: Total online survey respondents (both current members / stakeholders and potential members), n=138 Total online survey
Q: Do you think people should be paid for their involvement with the Cancer User Involvement programme? / What do you think people should be paid for…?

"[On remuneration] *It's really conflicted, I think it's a really difficult question*. There's more of a movement towards paying people correctly for the time that they're spending. If they're sat in a room full of people who are being paid to be in that meeting and they're not being paid, they're instantly at a disadvantage to everybody else. However, that being said, if you're being paid to be there, and if you say something contentious [...]. It's like not wanting to speak up to your boss about what you really feel. So I'm very conflicted about it and I don't think I've settled with an answer yet."

Stakeholder

Expenses should be covered as a minimum so people aren't "out of pocket" as a result of their involvement, and that this is increasingly important given the current cost of living crisis. Others feel payment could help improve inclusivity, diversity and accessibility.

YES 28%

Should there be payment for involvement?

"Payment would help with inclusion and diversity.
(Current Member)"

"I think it would help more people get involved if they were paid.
(Potential Member)"

"Macmillan used to pay travel expenses for travelling to face-to-face meetings and workshops so members were not out of pocket. This is especially important at present with the costs of transport and fuel rising so much.
(Current Member)"

"I certainly don't think anyone should be out of pocket, especially since a cancer diagnosis can bring financial hardship. *(Potential Member)*"

"Things like travel, fuel and accommodation for face-to-face meetings where needed could be reimbursed, especially as we are all battling with the current rise in living costs. Also, internet subscriptions perhaps, not everyone has unlimited internet or WIFI access. *(Current Member)*"

"If having access into a payment method allows someone that would not be able to get to a meeting or to access some form of technology so they can join then absolutely.
(Stakeholder)"

57

"It could be more representative and I think that that isn't just representative of different groups across the city or across the region, but that's representative of different kind of socioeconomic groups as well. I think if having access into a payment method that allows someone that would not be able to get to a meeting or to access some form of technology so they can join them then that should absolutely happen because I suspect there are a wealth of views and opinions that probably don't come to the fore as quickly or as easily as they should."

Stakeholder

Those 'against' payment for involvement feel it's at odds with many of the philanthropic reasons for wanting to get involved. Some questioned who would fund the payment.

Design & delivery

NO **44%**

Should there be payment for involvement?

> **No, I believe this should be a volunteering post. Incentives are good for specific projects but shouldn't always be on the table.** *(Current Member)*

> **No I don't think so. Where would the funding come from?** *(Current Member)*

> **No, not really, you're not in it to get a bit of money.** *(Current Member)*

> **I don't really think that's the point of it because it's if I was to do something for, I would be doing it for me and other people to try and help.** *(Potential Member)*

> Desk research highlights that paying someone might change the role of someone's participation from volunteer to having a different role (perhaps requiring too much commitment and responsibility).

"It is a bit long winded, the Cancer User Involvement Programme, it sounds *very jargony and it sounds a bit boring,* it's not going to grab your attention."

Potential Member

Around seven in 10 think the name of the programme should be changed. Of those that want a change, 'Greater Manchester Cancer Community' is the favoured choice.

Should the Cancer UI Programme name be changed?

CHANGE the programme name

72%

KEEP the programme name

28%

Greater Manchester Cancer Community	42%
Patient Representative Panel	23%
Cancer Advisory Group	10%
Lived experience of cancer programme	8%
Experts by experience' group	8%
Other	9%

Current members were more likely to want to keep the name, 31% cf. 12% Stakeholders.

All 1 mention: Patient and public engagement group / North West Cancer Community / Cancer Patient Experience Advisory Group / Patient Representative Panel / Greater Manchester people with a lived experience of cancer group / Lived experience of cancer programme / Cancer patient representative panel / Advisory Group for People Affected By Cancer

Base: Total online survey respondents (both current members / stakeholders and potential members), n=138 Total online survey
Q: Prior to this survey, we have conducted research via other channels (focus groups, one-on-one interviews and an online community) where we asked participants to think of other potential names for the Cancer User Involvement Programme. If it was your decision, what would you do…?

"[On the name Service User] I say customer and the only reason why I say customer is because that's my day job which is like a customers because if you do that, business goes well. I think we're customers of the service and that's going to be weird terminology for everyone because culturally we're patients, service users, reps. *I don't even know what to call myself. Whenever I am in a meeting I say something different every time but I never say service user representative. It just sounds weird*, it just sounds bonkers. What it's called I don't really mind, but user just doesn't feel right. *It just doesn't feel human*. The challenge I've had when I've described it as people, patients, customers is that then *means relatives of are excluded by the title*."

Current Member

Approaching nine in 10 think the name 'Service User' should be changed. Of those that want a change it's close, but 'Patient Representative' just has the edge over 'Person affected by cancer'.

Should the term 'Service User' be changed?

CHANGE the name 'Service User'

86% ➡️

Patient Representative	26%
Person affected by cancer	22%
Cancer Voices	17%
Expert by Experience	11%
Lived Experience Representative	10%
Patient Partners	9%
Co-designer	0%
Other	4%

KEEP the name 'Service User'

14%

All 1 mention: Patient Voice Representative / Cancer patient representative / People Affected by Cancer / Unsure

Base: Total online survey respondents (both current members / stakeholders and potential members), n=138 Total online survey
Q: We also asked participants for suggestions on alternative names for 'service user'. Again, if it was your decision, what would you do...?
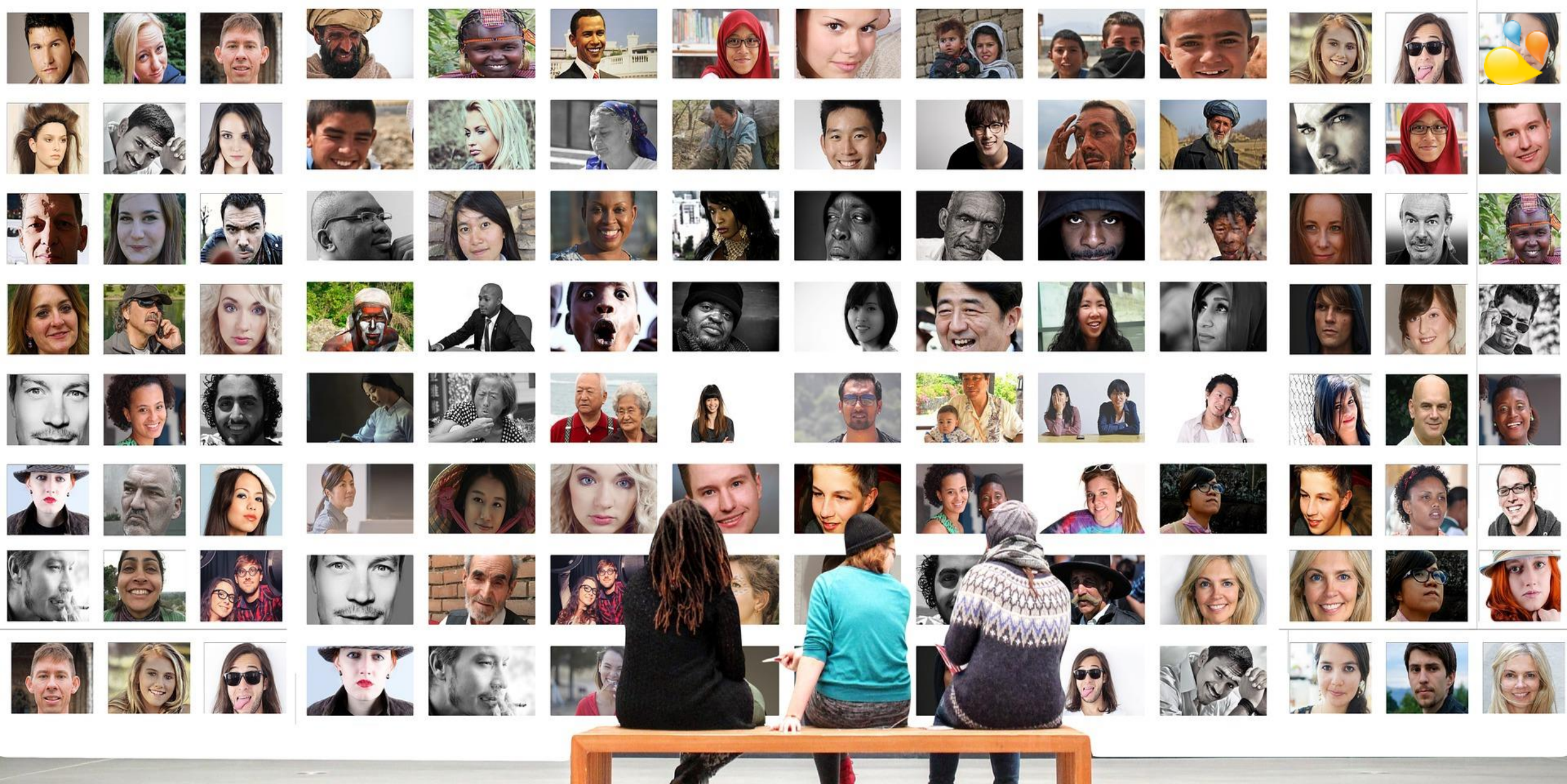
Chapter 2: Relationships & communication

Relationship
(noun)

The way in which two or more people feel and behave towards each other

Communication
(noun)

The process of sharing information, especially when this increases understanding between people or groups

Relationships & communication

Bringing on board new members is crucial for the success of the programme, but this can't be a rigid process. It should be informal and involve regular communication, so when each individual feels ready to join they know how they can get involved.

"I don't think we can dictate about the 'when' of involvement, it's about when people are ready, and if they if they feel that they can contribute." (Stakeholder)

As the recruitment needs for each individual is so different, it's important to help Stakeholders who are patient facing understand when it's the right time to recommend the Cancer UI Programme.

"It was my consultant who put my name forward, I wouldn't have a clue about it otherwise." (Potential Member)
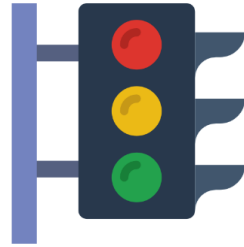
"And also, on the back of that they've their awareness and understanding and engagement of our workforce as well so that they they're aware of these programmes and they're aware that they can talk to patients about getting involved, if they want to. I don't think we can dictate when this person's diagnosed, we put a leaflet in their pack if they get involved... I think it's got to be more bespoke than that and more patient [driven]. More individualised, but it's that awareness of that there are these programmes for people to join if you do get a very active patient and you feel, you know that they would, they would want to contribute in some way that they know where to direct that to." (Stakeholder)

"There's a lot of really committed people who are willing to give up their time in order to improve services. But also *I'm struck by how badly the programme is promoted*. As I've said, I was not informed once about it during 2 years of treatment and only came to hear about it through a friend."

Current Member

There is a gap in awareness of the Cancer UI Programme amongst communities and organisations that could help support the growth of the programme and could benefit from the outcomes of the programme.

Increase awareness of the Cancer User Involvement Programme amongst:

Potential members

Clinical staff working in cancer services

Senior / specialist stakeholders
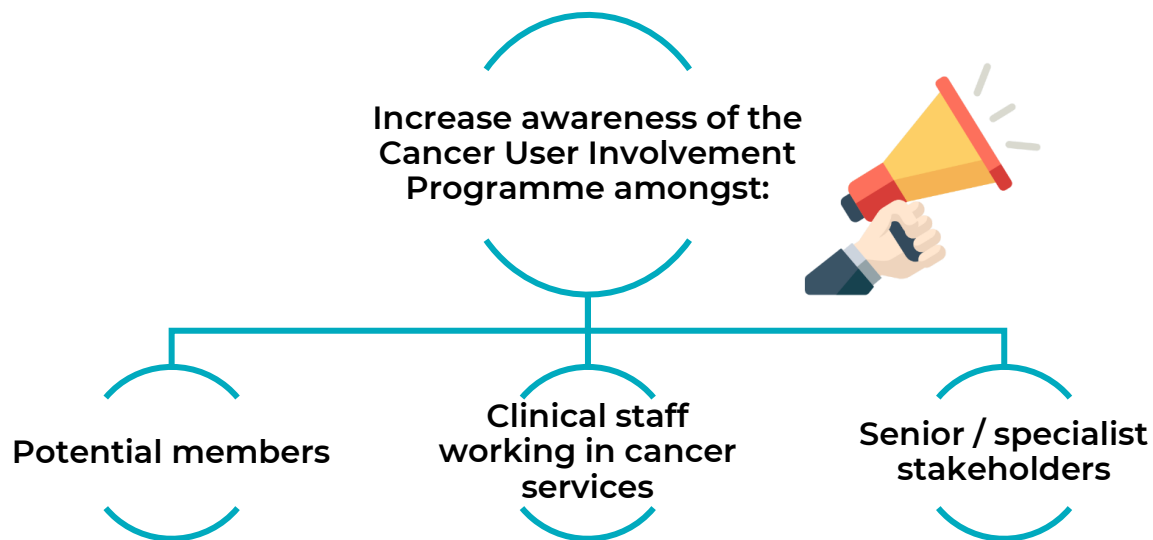
"I think you're missing a trick and I think you should educate the staff and on the floor because I well as a therapeutic radiographer, I was talking to patients for five weeks in a row when I really got to know them and there were some cracking patients that would have been fantastic for a user involvement program. But I knew nothing about it. I could have brought something up like that. I mean, I recommend all these different support groups and things that people can get involved in and so many patients wanted to give something back to the Christie." (Stakeholder)

"The other key thing is I think around providers and how you are working closely with your cancer centres, your acute trust and the teams there. You know, because we really feel like there's potentially a bit of a gap there between our leads and the lead cancer nurses or the heads of patient experience. So we're increasingly trying to look at each acute trust, there will be a head of patient experience and often they aren't well linked to the cancer alliance. And certainly when I worked in acute trust, I had no link at all to my cancer alliance. So it feels to us like there's a bit of a gap there and what can be done to because they're the ones with the direct patient contact." (Stakeholder)

"People in the workforce on the floor, seeing patients clinically, not just doctors or you know, it's got to be nurses, physios, occupational therapists, dietitians, everybody who has a conversation with the patient and I think everybody should know about it. So I think maybe advertising it to the workforce." (Stakeholder)

Relationships & communication

Raising awareness of the Cancer UI Programme involves creating and maintaining relationships, which needs to be an ongoing process.

Raise awareness of the Cancer UI Programme with all professionals that interact with people affected by cancer

- 80%
- 20%

Create relationships with Heads of Patient Experiences within Greater Manchester trusts

- 64%
- 33%
- 3%
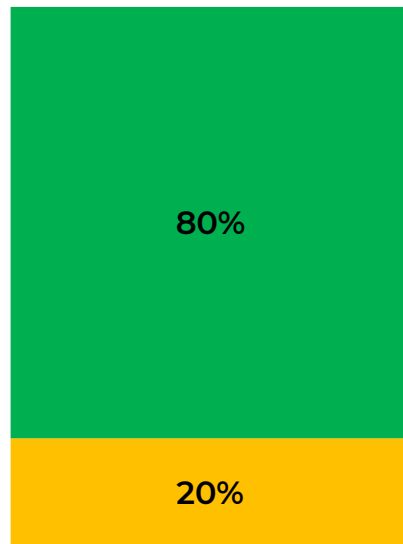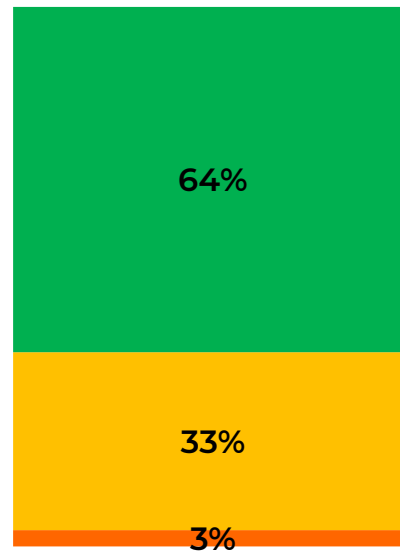
Create and maintain a relationship with other cancer alliances across NHS England to share knowledge and best practices
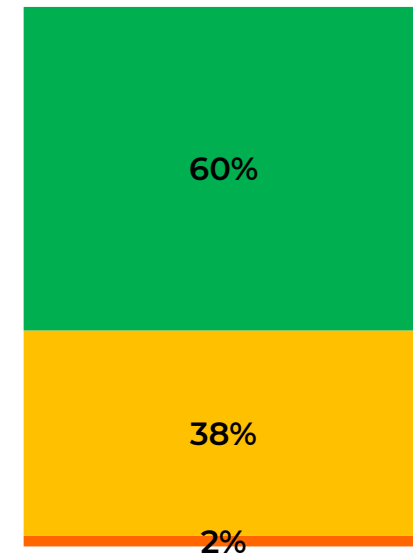
- 60%
- 38%
- 2%

■ Must have

■ Nice to have

■ Less important

There are currently a lot of small positive changes happening within the cancer community across Greater Manchester. Bringing these organisations and projects together can help increase their impact.

Greater Manchester Cancer Alliance can be the driving force behind combining forces and bringing together these different organisations and projects

"It's all about tying stuff together. I think that you do find in Greater Manchester that comms are great, but sometimes we've got, back to a lung examples again, we've got. Someone is doing some work with one group at the Christie. The others are doing some work here. Somebody else is doing the similar sort of work in that department. And it's all presented as 'oh we've all been doing this'. And actually if they'd communicated and joined together. It would have had a bigger impact... So you there's lots of little bits of great work going on. But occasionally, if everybody could just say, hang on a minute, what's everybody else doing? Could we make this more impactful." (Current Member)

As well as creating and maintaining relationships with a range of stakeholders and organisations, there is value in creating a cross board group and considering other factors that people affected by cancer have to contend with – such as, depressed, diabetes, etc.

Create a cross board group to discuss broader themes across all cancer care, rather than just one particular cancer type

60%

34%

6%

■ Must have

■ Nice to have

■ Less important
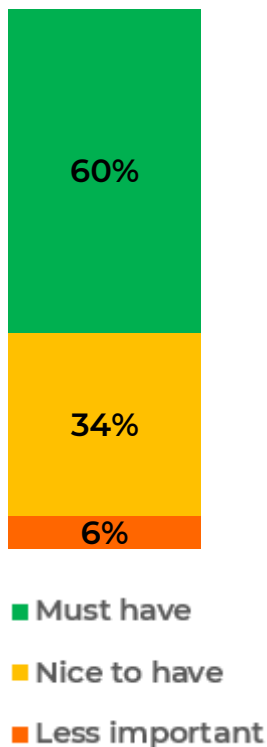
"I had a meeting with public health team, in terms of some of the work we're doing on the psychology pathway board the other day, and they're doing a wealth of things that could really tie into some of the stuff we're trying to, I guess, reinvent a little bit. And they're really keen to share their resource as long as they don't have to do the doing. So if we provide some content, they're going to provide the, you know, they'll, you know, for instance, there was the mention of a poster to advertise cancer support for people affected by cancer across GM. And they were really happy to sort of get the posters printed, if we provide the content and things like that. I just think we're really poor, working collaboratively, even in cancer. So we work in silos, in our provider trust, even within the cancer sector, and that's without it spreading over to everything else. And as we know, you know, people affected by cancer aren't just affected by cancer, they're affected by depression, heart problems, diabetes, millions of other things, life, debt, whatever else." (Stakeholder)

Base: Total online survey current members / stakeholders, n=88
Q: We're going to show you some potential changes or improvements to the Cancer User Involvement Programme that could happen, and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this).

Awareness of the Cancer UI Programme should come in a variety of channels, to increase the chances of raising awareness amongst a more diverse population.

How Potential Members would expect to find out about the programme

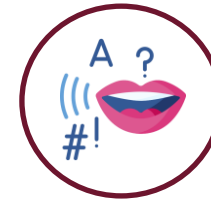| 64%	54%	50%	50%	42%	34%	34%	14%
Leaflets in doctors' surgeries, hospitals, etc.	Posters in doctors' surgeries, hospitals, etc.	Email	Social media	Through a doctor, nurse or other health professional	Through support groups	Via word of mouth	Through faith or community leader

"Social media NHS buildings / organisations, charity events, newspaper – e.g. free Metro or equivalent local paper, leaflet dropping. These cover most people nowadays, social media and online presence is the important one. It would catch most people. The ones not online could see it in other ways. Even places like supermarkets or corner shops, shopping outlets, public toilets." (Potential Member)

"Through the hospitals via leaflets, online or social media." (Potential Member)

"Through Cancer specialist hospitals, charities, Facebook, local community hubs and groups, doctors surgeries, schools, post office." (Potential Member)

Base: Total online survey potential members, n=51
Q: Where would you expect to hear or find out about the Greater Manchester Cancer Alliance User Involvement Programme?

"It's that use of the community, we were approached a few months ago about a group that were doing presentations to people in the deaf community about types of cancer and there's no, you know, we should be able to recognise that there are those groups out there for us to reach into, it's just doing so isn't it?"

Stakeholder

There is a lack of diverse representation in the Cancer UI Programme, this isn't a result of people from these communities not being affected by cancer, but more a lack of a relationship. The Cancer UI Programme needs to go into these communities.

Recruit a person dedicated to equality and diversity

42%

40%

18%
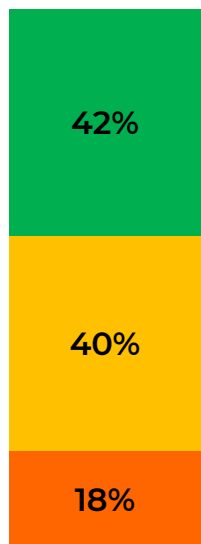
■ Must have
■ Nice to have
■ Less important

Raising awareness of the Cancer User Involvement Programme might overcome some barriers, but the biggest impact will happen when the programme goes to the people who are currently under represented. Relationships with these people and communities needs to be created and nurtured – there needs to be an ongoing conversation.

It is important that equality and diversity continues to be incorporated throughout the wider team and into everyday awareness and practice. By also recruiting one, or a few individuals to lead on this and connect with people or organisations that already exist, could be a helpful way to form meaningful relationships to help build trust with the Cancer UI Programme.

"Yeah, I mean, certainly an ongoing conversations would work best. I mean, if there was a role, maybe there's room for a role to be created, which is within the service user rep team, which is focused on building and maintaining community contacts, community relationships and organisations with VCSE partners right across Greater Manchester. And then, if we were aware that there were particular faith groups or ethnic groups, or any other groups, where we didn't feel we have that representation, then that role could then proactively look to engage with VCSE groups that have contact with individuals from that group." (Stakeholder)

"Speak to each community because every community is different, you've got a wide range of populations, like gender, sexualities, you need to get in contact with each specific community in that sense because you've got Muslims, Sikhs, Hindus, Jews, Christians, lesbians, gays, straight, bis, gender neutral, all these types of people now. If you're only getting a particular type you need to get involved in the communities, go to mosques, go to churches, go to synagogues, gay Pride, whatever. You need to get out and individually and personally see these communities." (Potential Member)

Base: Total online survey current members / stakeholders, n=88
Q: We're going to show you some potential changes or improvements to the Cancer User Involvement Programme that could happen, and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this).

"*I have never understood how patient representatives represent other patients when they have never come and asked us about our experiences and when I have tried to share or involve them in our group, I've never even had the courtesy of a reply.* We're here to consult but a patient representative needs to come to us *- those undergoing cancer treatment haven't usually got the energy to go looking for someone to share their concerns with.*"

Stakeholder

There are a number of effective ideas and initiatives that can be used as inspiration for improving the diversity of Cancer UI Programme members, to better reflect the diverse population of Greater Manchester.

"So I know that, for example, in Bolton, we had a nurse working with those who'd come from that area, and she's actually in Cancer Information Services and her challenge was that she was, although her patch was quite multicultural, they weren't, so from an information sharing point of view, a cancer information sharing, they were not getting the numbers that they would have expected from Asian populations particularly. And to cut a long story short, a really successful thing that she did was... there were some unused or disused kind of shops in the area. And she got some permission from the local council to do like a pop up kind of, just for a week, and it was all around cancer information. And it was within an Asian kind of neighbourhood or community. They were inundated. So I think it was just about them going to the area... So I think that, I think things like that, you know, we need to be more accessible. We need to be reaching out, we need to be speaking to the communities really. So encouraging them to be Users, and also understanding that what they get to know I know, I'm speaking from my specialty, but so for example, you know, Muslim patients traditionally want to care for their loved ones at home, if they possibly don't want to come into the hospital. I know that we have a fair smattering of Jewish patients who it's, kind of, like life at all costs, really. So some of their views on services a bit different to other groups. So I think it's, it's about reaching out to them rather than expecting them just to use our services as they exist at the moment. And maybe some sort of work in the communities themselves." (Stakeholder)

"Using outside the box thinking, for example, the Asian cricket match. There was a high number of people there, of the Asian demographic, and she, you know, she took time out of her working day to attend an external event, because she heard about this event and then she started talking, she worked for Macmillan at the time, she was confident enough to engage in that conversation and recruit people that way. So it's about you don't always necessarily find it within the cancer arena." (Current Member)

Relationships & communication

There are a lot of positives changes happening to cancer services in Greater Manchester as a result of the Cancer UI Programme, sharing these successes can help Current Members see the difference they're making – which feeds into the main reason they got involved.

Share the successes of the Cancer UI programme more...

...externally
- 52%
- 40%
- 8%

...internally
- 47%
- 47%
- 6%

■ Must have
■ Nice to have
■ Less important

You said this... → So we did this... → As a result, this happened...
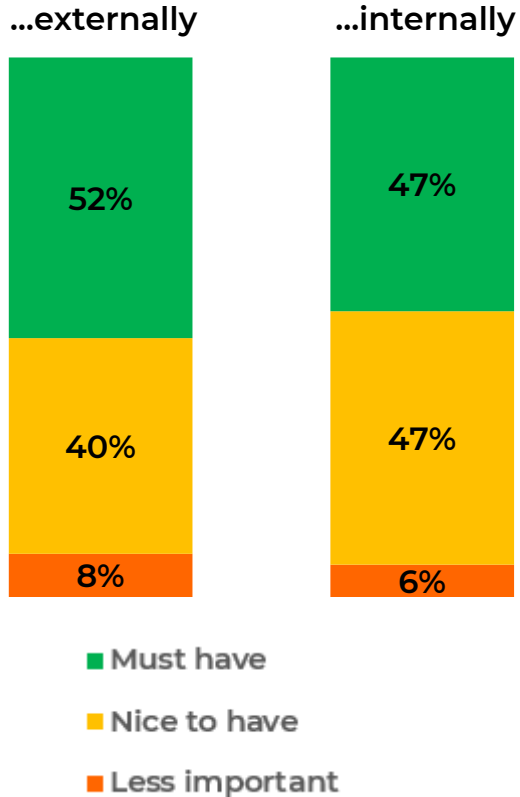
"More outcome information would make a difference to me, what impact has my involvement had?"
(Current Member)

"Let us know how we are making a difference, we like to hear the successes."
(Current Member)

Shouting about the successes of the programme will also help increase awareness.
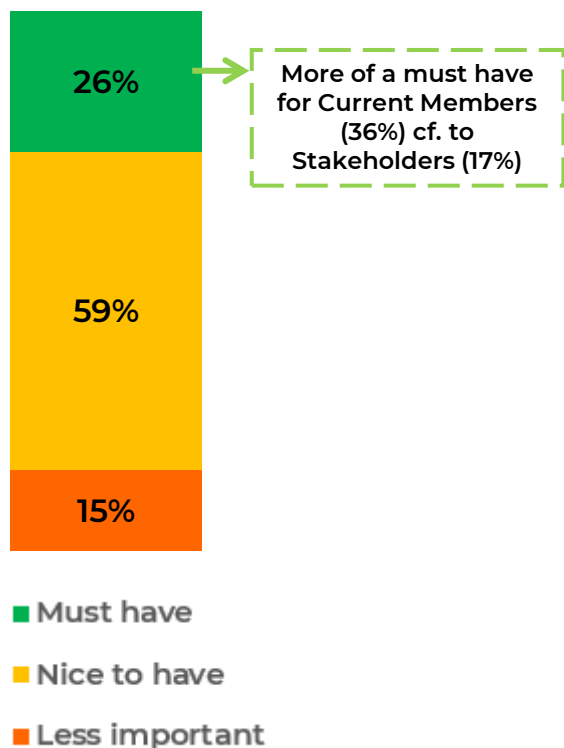
Base: Total online survey current members / stakeholders, n=88
Q: We're going to show you some potential changes or improvements to the Cancer User Involvement Programme that could happen, and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this).

"I think for me as well, it'd be good to just understand what there is to do. And even just hearing some of the successes, I've had to ask, what's the programme done? What's it here to kind of achieve? And they started telling me about a new role that they've put in that they're trialling with this Cancer Care Coordinator that's like a new thing. And like, but I didn't know, it was only because I asked, and that's the sort of thing it'd be nice to know that that's been an outcome from the programme."

Current Member

The changes that have been made as a result of everyone involved with the Cancer UI Programme are a reflection of the success of the programme.

<div style="writing-mode: vertical">**Relationships & communication**</div>

Share updates of how projects are progressing in between pathway board meetings

42%

52%

6%
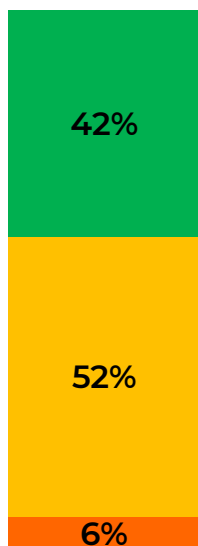
■ Must have
■ Nice to have
■ Less important

When measuring success, the ideal scenario would be to have a defined outcome where you can say 'this has helped improve the lives of people affected by cancer', however sometimes even the smallest step towards creating this change can feel like a success.

Current Members speak about the many changes and projects they've been a part of, but they also speak about feeling they've made a difference when their contributions to meetings have been noted or if they've been able to add an item to the agenda of a meeting.

"[My role in the Cancer UI Programme has made a difference] several times. Changes and improvements to patient service - MDT info graphic, treatment summary, patient information leaflets, late effects of radiotherapy raised at small communities group now an agenda item at pathway board." (Current Member)

"I know we have made a difference in many ways through helping to draft many patient related documents, Infloflrx system, contributions to meetings that have been noted, planning Cancer Conference, etc etc." (Current Member)

"Yes [my role in the Cancer UI Programme has made a difference] probably in too many ways to recount now. Calendar days versus working days is one key example. when something has been raised and it is carried forward makes me feel like I have made a difference, and seeing the end results of (say) patient information and leaflets, or advice to clinicians, just seeing it is rewarding." (Current Member)

Base: Total online survey current members / stakeholders, n=88
Q: We're going to show you some potential changes or improvements to the Cancer User Involvement Programme that could happen, and we'd like to know if you would consider this a 'must have' (i.e., absolutely essential), a 'nice to have' (would be good but not essential) or 'less important' (you'd be less bothered about this).

Relationships & communication

Many of the Current Members enjoy the social side of the Cancer UI Programme, it's a community where they can meet like minded people and put names to faces. There is a desire for the programme to facilitate more social events to bring people together.

Hold social events to bring together Service Users outside of the small communities and pathway board meetings

26%

→ More of a must have for Current Members (36%) cf. to Stakeholders (17%)

59%

15%

■ Must have

■ Nice to have

■ Less important

"Restarting the social side of it, you know networking, getting people together again." (Current Member)

"Two years ago, there used to be a lot of events, people used to turn up, they used to have a coffee, drink, chat and just mingle." (Current Member)

"With the Friday email we used to have a chat after that, didn't we? We used to have a Zoom meeting if you wanted to join. Like a coffee thing. But that hasn't happened for ages." (Current Member)

Recommendations

The Cancer UI Programmes evaluation has highlighted a need to build on the current strengths and make improvements. Here's what you need to do (under each of the 4 key insight streams identified) to make it happen:

DESIGN

- Refresh the Cancer UI programme (including new mission and values)
- 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
- Ensure there are ways of getting involved on weekdays and weekends, both in and out of working hours
- Offer tech support / devices to lower socio demographics
- Create a central location for all documents, including a menu of options for how people can easily get involved, to be stored and accessed

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 meet and get to know each other

COMMUNICATION

- Raise awareness of the Cancer UI Programme, using a variety of channels (including some 'outside the box' ideas)
- 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 GM

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Appendix

Comments from Potential Members in relation to not having any medical knowledge:

% scoring 1 or 2 (a significant barrier shown)

I don't have any medical knowledge

44%

"At first I was nervous at pathway board with much of the acronyms and terminology being new to me." (Current Member)

"I'm not sure I could bring much to the table with clinicians or board members." (Potential Member)

"Also, in all meetings, discussion of complex clinical items can be hard to follow which can feel exclusionary. A very short introduction to contextualise each agenda item (2 or 3 sentences) would support these meetings feeling more inclusive and safe, for clinicians as well as service users." (Stakeholder)

Base: Total online survey potential members, n=50
Q: Thinking about your own personal situation and life, can you tell us whether any of the following would be a barrier for you? Please answer on a scale of 1 to 5 whereby 1 means 'this is a significant barrier / would put me off from getting involved' and 5 means 'this would not be a barrier / put me off from getting involved at all'

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Appendix

Comments from Potential Members in relation to not having enough time:

% scoring 1 or 2 (a significant barrier shown)

I work full time so wouldn't be able to fit it in

42%

"I'm doing three shifts a day, and I just physically can't go anymore, and yeah, I couldn't commit myself, so I just, no, I had to just move on." (Potential Member)

"Time for me is a barrier, I pretty much work full-time, I have got two kids of primary school age." (Potential Member)

"The full time job and two young kids makes it so hard to commit to things at the moment." (Potential Member)

Base: Total online survey potential members, n=50
Q: Thinking about your own personal situation and life, can you tell us whether any of the following would be a barrier for you? Please answer on a scale of 1 to 5 whereby 1 means 'this is a significant barrier / would put me off from getting involved' and 5 means 'this would not be a barrier / put me off from getting involved at all'

Comments from Potential Members in relation to not knowing where to begin to get involved:

% scoring 1 or 2 (a significant barrier shown)

I wouldn't know where to begin to get involved

42%

"To be honest I don't really know how to get involved." (Potential Member)

"If people don't know, they won't sign up." (Current Member)

"It seems really good but couldn't fully commit as I don't know from day to day how I'd be getting involved." (Potential Member)

Base: Total online survey potential members, n=50
Q: Thinking about your own personal situation and life, can you tell us whether any of the following would be a barrier for you? Please answer on a scale of 1 to 5 whereby 1 means 'this is a significant barrier / would put me off from getting involved' and 5 means 'this would not be a barrier / put me off from getting involved at all'

Comments from Potential Members in relation to being unsure if their experiences will be helpful:

% scoring 1 or 2 (a significant barrier shown)

I'm not sure my experiences will be helpful to others

40%

"You don't really know what people might benefit from your experience." (Potential Member)

"I am unsure if anything is really going to change." (Potential Member)

"I felt like I could only tell my story so many times, so I didn't know, I didn't feel like I was bringing anything new, yeah, I just felt like I was saying the same thing." (Potential Member)

Base: Total online survey potential members, n=50
Q: Thinking about your own personal situation and life, can you tell us whether any of the following would be a barrier for you? Please answer on a scale of 1 to 5 whereby 1 means 'this is a significant barrier / would put me off from getting involved' and 5 means 'this would not be a barrier / put me off from getting involved at all'

Comments from Potential Members in relation to not being comfortable enough to share their experiences:

% scoring 1 or 2 (a significant barrier shown)

I wouldn't feel comfortable sharing my experiences

38%

"Maybe because of their personal experiences like trauma, you know, not many people wanted to talk about come talk about it." (Potential Member)

"I just didn't have the emotional capacity." (Potential Member)

"I think people need to be comfortably in their journey before they're going to be prepared to give that bit of themselves over." (Potential Member)

The principals of UX research (1):

1) First impressions really do count
It can take website visitors as little as 0.5 seconds to make a decision on whether they are interested in it or not.

2) Design should focus on experience
People don't always remember information presented, but they do remember what they feel. A site should effectively weave together a combination of text, graphics, layout, and interactive elements to ensure users have an experience, not just an informational view.

3) Usability first
No matter how aesthetically pleasing your site may be, it won't strike a chord with the user unless it is easy to use. We need to make sure that each icon, button, and snippet of information that is present within the design has a purpose. Concentrate on clarity by bringing only useful features to the user's attention.

4) Keep it consistent with other websites with similar goals
The more familiar your design is to others, the faster users can learn to use it, which enhances their experience.

5) Have a clear hierarchy
To create an easy flowing design for users, you need to place the important content prominently. The main navigation bar (primary hierarchy) must include the main sections. When you click into this it must take you to further sub-categories of content (secondary hierarchy).

The principals of UX research (2):

6) Meet the users' needs
Ensure that you focus on improving your users' experience with the purpose of your offer. What are the users visiting the website for?

7) Less is more
The less-is-more design principle was originally proposed by the architect Ludwig Mies van der Rohe who is regarded as one of the pioneers of modernist architecture. The less-is-more approach emphasises simplicity as opposed to clutter or over-decoration in design. People scan websites, they don't read them in the same way as they use other materials.

8) Consider how content looks on all devices in the design process
Build a nice responsive design versus just a responsive design. Remember to consider the content 'flow' as mobile is being increasingly used.

9) Scrolling is often faster than paging
Because it's faster to scroll down than to click, which means longer pages can be better than just more pages. Mobile use and swipes, flicking and panning up and down means we are instinctively becoming ever more familiar with scrolling.

Website inspiration – Macmillan Cancer Support

Content flows logically

Highlighting 'fresh' content

Clear mission / purpose

Clear call to action

Great use of icons

91

Appendix

Content flows logically
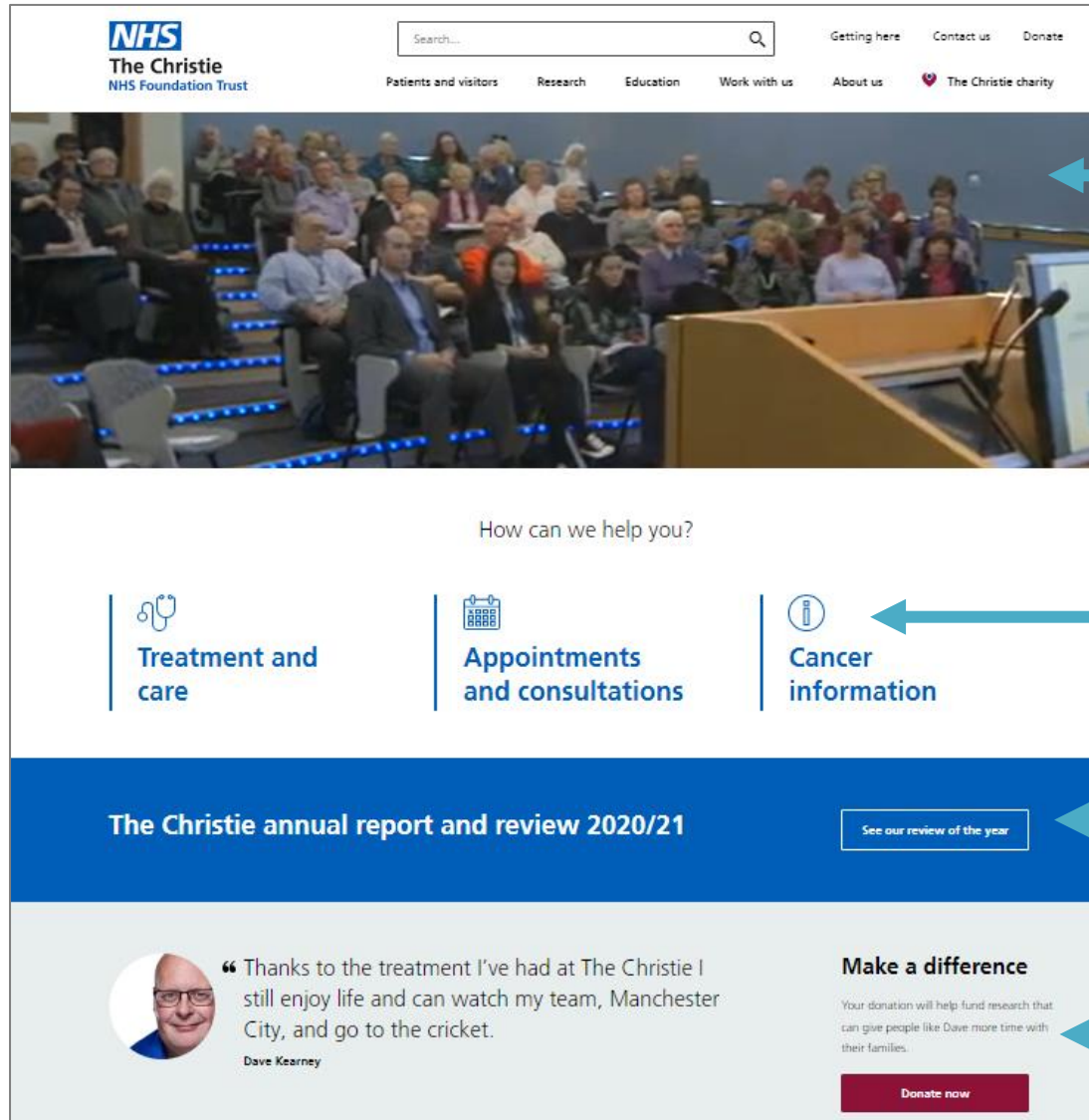
Visual – use of videography

Great use of icons / feels uncluttered

Highlighting important information

Call to action stands out by use of different colour

Thank you…

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