

## MACMILLAN ONLINE RESEARCH COMMUNITIES ANSWERS TO SOME FREQUENTLY ASKED QUESTIONS

1. What we are doing and why
2. How you can get involved
3. Support available to help you get involved

**Contact:** For any enquiries about his project and to tell us that you would like to take part in the research, please contact the Inclusion team using the details below.

Email: [Research.Learning@macmillan.org.uk](mailto:Research.Learning@macmillan.org.uk)

Tel: 020 7091 2189

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### 1. What we are doing and why:

#### **Q: What are you doing?**

Macmillan is setting up an online research community to understand the experiences of people living with cancer from often excluded groups, whom we suspect may be underserved by existing cancer services. Initially, we will focus our research on three specific themes, looking at how age, ethnicity and sexual orientation may impact on patient experience. So for this first phase of the research we want to understand the experiences of three groups of people living with cancer: LGBT, BAME (Black, Asian & Minority Ethnic), and Older People.

#### **Q: Why is it important?**

Macmillan wants to ensure that everyone has equal access to the best quality cancer services. This should happen regardless of ethnicity, gender, age or sexuality.

We know that despite improvements in cancer survival, care and experiences, inequalities persist<sup>1</sup>. Yet, there is an unacceptable lack of evidence on cancer inequalities, especially in relation to experiences of services. Existing national surveys – such as the Cancer Patient Experience Survey - can rarely shed much light on the specific experiences and needs of people in minority groups. Unless we understand the specific nature of service experiences for minority groups and focus directly in tackling these, inequalities will continue to deepen and to cost lives.

#### **Q: What are the aims of the research?**

There are four broad aims:

- To understand the experiences of people living with cancer who are from target groups whose voices are rarely heard in research.
- To understand what factors contribute to poor patient experience, and where this may be as a result of inequalities.

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<sup>1</sup> Macmillan has recently published a series of Rich Pictures, collating all existing evidence about the experiences of different groups of people living with cancer. They highlight that there are significant evidence gaps. Rich Pictures are available on the Macmillan website:

<http://www.macmillan.org.uk/Aboutus/Ourresearchandevaluation/Researchandevaluation/RichPictures/Richpictures.aspx>

- To test online research communities as a way to engage with people from target groups often excluded from research.
- To develop new relationships with partner organisations that can help generate insights about needs and unmet needs for excluded groups.

**Q: What will you do with the results?**

Results and findings will be published. The findings of the research will also inform Macmillan's plans for developing new services and for influencing decision-makers to bring about the changes that are needed. Over time, the results will help to build a picture of not only where inequalities in patient experience exist, but why that variation exists and what can be done about it.

**Q: What is an online research community?**

Online research communities are purpose-built, closed virtual environments where people are brought together to take part in research and consultation activities, including interviews, group discussions, diaries, surveys, polls, self-ethnography, etc. Community members participate in a series of research tasks and discussions, guided by an expert independent facilitator.

We will create a discrete online research community for each of the three target equality groups (BAME, LGBT and older people), and bring together both professional stakeholders and lay people living with cancer in each community. We think that this will be hugely motivating for all involved and will create high quality debates, evidence and learning.

**Q: Why have you chosen this method?**

Compared to standard research, benefits of this approach include:

- Convenience: It's more convenient for both health professionals and people living with cancer, and so will lead to better participation.
- Greater interaction: By interacting and debating while guided by an expert independent facilitator, community members can understand better other people's realities, resolve differences and define priorities.
- Flexibility: New stakeholders can be included, new methods added, and new themes explored in response to emerging evidence or changing circumstances.
- Cost effectiveness: Compared to standard research, online research communities are cheaper, faster and easier to run.

**Q: What are the timescales for the research?**

The research community will be live for 8 weeks starting in the first week of October and ending at the end of November. Participants will be invited to sign up to the community the week before the community goes live. Exact dates of each research activity will be made available at sign up.

**Q: If I sign up, how much time will I be expected to commit?**

Although the research community will be live for an 8 week period, participants will not be required to be available for all of that time. Questions and research tasks will be posted on the community for participants to respond to at a time that is convenient for them. Community members will be expected to log on regularly to follow debates and answer questions. As a rough guide, we would expect that it will take up no more than 2 hours a week to participate. Participation can take place at any time and from anywhere (from PCs, tablets or smart-phones).

### **Q: What are your policies on privacy, confidentiality, and data protection**

We promise to protect your privacy and to treat the information you give us as confidential. We will only use the information you give us for research purposes.

Access to the online research community is only granted to invited parties, that is, registered users with the relevant permissions to be in the community. Access is password protected and passwords are encrypted between peer and server. Such closed access makes online research communities more private than both social media sites and commercial open-access online communities.

When you first log in, we ask that you don't give your full name, home address or other identifying personal information, unless specifically required by the community manager to do so. For instance, we will ask you for your email address (so that you can take part in the research) and for your mobile number (so that we have a recovery method to reach you in case your email fails). But we suggest that you use only your first name (not your full name) and an initial or an alias (or nickname) while on the community. This will protect you while ensuring that others instantly recognise you as a community member.

We will process your personal data in accordance with the Data Protection Act 1998.

To request a copy of our full privacy and data protection policy, please email the Inclusion Department at [Research.Learning@macmillan.org.uk](mailto:Research.Learning@macmillan.org.uk).

## **2. How you can get involved:**

### **Q: Who do we want to recruit to take part in the research?**

We are looking for participants in two broad categories:

- 1) People with a cancer experience** who identify themselves as being from one of the three target groups: LGBT (Lesbian, Gay, Bisexual or Transgender); BAME (Black, Asian and Minority Ethnic); older people (for the purposes of this research, anyone 65 or over).
- 2) Professionals with relevant expertise** in health inequalities, patient care and cancer care, or experience and knowledge of the needs of our three target minority groups. This might include:
  - UK cancer charities focussing on patient care (as opposed to biomedical research only)
  - National research partners (e.g. NCRI, NCIN, King's Fund)
  - Relevant statutory experts (e.g. DH, NHSE, NCAT)
  - Academics specialising in cancer services in target groups
  - Charities specialising in health and social care (not only cancer) in target groups (BAME, LGB&T, and Older People).
  - Equality and diversity charities
  - Equality and diversity leads in the NHS
  - Oncology nurses from the target groups

### **Q: How can I get involved?**

Help us to find and recruit people living with cancer from the groups we are targeting, as well as health professionals (see above for a definition of health professionals); so that they sign up to the online research community by October. We cannot do this on our own, we need your help to:

**Promote:** If you are an individual or an organisation with links to the communities we are trying to recruit from, please promote our research through your networks in any way that you can. See section 3 below for details of how we can support you to promote the research.

**Sign up:** If you have a recent cancer experience and identify yourself as belonging to at least one of our target groups, or if you are a health professional, and would like to take part please get in touch to sign up.

We will contact all those who have expressed an interest to take part, in the week commencing 22<sup>nd</sup> September with further joining instructions for signing up to the online community.

To express an interest in signing up to or promoting the research, please get in touch with the Inclusion Department at [Research.Learning@macmillan.org.uk](mailto:Research.Learning@macmillan.org.uk).

**Q: What about people who don't have access to the internet, or have difficulty using computers?**

Whilst online research communities may be more convenient for some, there is a risk of excluding those who have not got access to the internet, are not IT literate, or who may have other difficulties participating in online research communities. We would like to work with partners to explore these challenges and support more people to participate in the research. If you have a concern in this area, please contact the Inclusion team to discuss at [Research.Learning@macmillan.org.uk](mailto:Research.Learning@macmillan.org.uk) or on 020 7091 2189.

### 3. What support is available from Macmillan?

**Communications:** We can provide you with materials to help you promote the research:

- Flyers to distribute by email, post, or at events. If you would like us to send you printed flyers to distribute at events, please let us know.
- Copy for social promoting the research via your social media channels
- Copy for promoting the research through your newsletters and / or websites.

**Grant funding:** Any organisation can apply for a Macmillan User Involvement grant to support activity which helps people living with cancer from our target audience to take part in the online research communities. Please contact the Inclusion team to discuss your needs.

For any enquiries about communications materials, grants, or support needs please contact the Inclusion team at [Research.Learning@macmillan.org.uk](mailto:Research.Learning@macmillan.org.uk).

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