Community Cancer Insight Group (C.C.I.G.) Listening Session Summary

What does cancer risk mean to communities in Greater Manchester?

13th December 2024

What's the C.C.I.G.?

The BRC Cancer Prevention and Early Detection (CPED) theme of the National Institute for Health and Care Research (NIHR) Manchester Biomedical Research Centre (BRC) has conducted extensive work with local communities to identify priorities and recommendations for inclusive research. But there's still important work to be done to apply these learnings.

The C.C.I.G. is a dedicated public group of 12 community members based in Gorton, which was established to continue to build trusting relationships between research and under-served communities and inform health equitable approaches across the CPED theme.

To find out more about community engagement and inclusive research work in CPED, please email Anya (anya.webber@nhs.net) or Emma (emma.thorpe@nhs.net).

You can find out more about the C.C.I.G. in this blog post.

What happened at the listening event?

Both CPED researchers and C.C.I.G. members prioritised the topic of 'cancer risk' for discussion to advance inclusive research approaches across CPED research. Understanding the impact that conversations and content on cancer risk can have, especially in under-served communities, is integral to ensuring that CPED research can drive meaningful improvements in cancer care.

The listening event explored the C.C.I.G.'s views and opinions on the risk of cancer. The C.C.I.G. invited four PED researchers (Emma Crosbie, Garima Dalal, Vicky Woof & Jean-Ellen Johnson) to join and listen in.

How can you apply learnings from the event?

The listening event was a unique and valuable opportunity, in which C.C.I.G. members spoke openly about their experiences and perspectives on the risk of cancer. This summary captures the key messages from the C.C.I.G..

We invite you to take this opportunity to pause, listen and reflect on what members of local communities are telling us.

Discuss the prompt questions and explore how these learnings could help strengthen your research now and in future applications to bring about meaningful change.

Cancer risk…	What's important to C.C.I.G. members?	What could these learnings mean for your research?
Is unjust	Cancer risk can be seen as a "long-term" issue of lower priority compared to "day-by-day survival" and concerns, like food and housing. Actions to manage cancer risk are often NOT inclusive and are only obtainable to people of "privilege".	• What impact could information about cancer risk have on a person with experience of health inequities? • How does privilege affect who is able to take part or benefit from your research? • How will your work be designed to address health inequities? • How do we consider structural inequities when discussing actions that individuals can take to manage their risk?
Requires action	Information about cancer risk MUST be presented with meaningful ways to respond to the risk. Family is central to cancer risk. • Family motivates people to act and share appropriate emotional and spiritual support. • Information on family members' and friends' cancer risk is more important than finding out people's own cancer risk. There's a difference between risks that people perceive they can and can't control. • People are less comfortable and open to information on risks that can't be changed, like family history. • Information on cancer risk can feel futile when people are affected through "no fault of their own", for example "why do children get cancer?". People may not think about cancer risk until they develop cancer (i.e. retrospectively), where they may ask 'What could I have done differently?'.	• Do you present information about cancer risk with consideration of meaningful and inclusive ways to manage the risk? • Who may perceive cancer risk as controllable or uncontrollable? How could you tailor your research to address these differences in perspectives? • How could you be more transparent about the unknowns and complexities of cancer risk? • How could you include consideration of the importance of friends and family to aid cancer prevention and provide support? • What effect could information on cancer risk have on people with a diagnosis? What are the risks or benefits of sharing this information with them?

Can disengage	People get "tunnel vision when they hear *cancer*". It's important to be clear that: • Warning signs and symptoms may not always be cancer. • If a person is at risk of cancer, it does not mean they will definitely develop it. It's easier to think about cancer risk and avoid disengagement by: • Focussing on a holistic view on health, rather than *cancer* specifically • Talking about other people's cancer risk, as this approach feels less direct/personal. • Considering the effect of rephrasing a cancer risk statistic "1 in 7 people are at risk of [x] cancer" vs. "6 in 7 people are *not* a risk of [x] cancer".	• What are the risks and benefits of talking about cancer risk in your work? • How could you communicate about cancer to avoid anxiety or disengagement? • Could asking people how they feel about their family/friends' cancer risk facilitate more open dialogue about cancer risk? • How could your research help improve understanding of risk?
Extends beyond health	The risk of cancer does not just affect a person's health, it impacts people socially and financially. Taboos and stigma about cancer can lead to "anxiety", "spiralling", "pressure" and "judgement" in a person's support network. This can cause people to: • Worry about how to seek support from friends, families and communities. • Judgement relating to health behaviours. For example, "I wouldn't want to be with friends and family who were smoking".	• What impact could information on cancer risk have on a person beyond their health and your research? • Have you considered how the support networks of research participants might be impacted or respond to information about cancer risk? • How do we equip people to talk about their cancer risk and overcome stigma in communities?

Needs to be person-centred	"Doctors always tell you to eat healthily." • People are desensitised to general information on cancer risk. Information about cancer risk MUST be tailored and relevant to individuals. Every person is an expert on their own perception of risk. • Researchers can't assume what information about cancer risk will mean to individuals. For example, 8% might be a "high cancer risk" to clinicians but the public might not think the same. Perspectives on cancer risk are affected by many contextual factors, for example: • Age - a younger C.C.I.G. member said, "I wouldn't think about any of this". • Faith - some members referenced religious teachings about illness being brought on through worry and anxiety. • Family - one member's attitude to risk changed once they'd had children.	• Do current approaches sharing information about cancer risk engage the public and have the intended effect? • Have you made any assumptions on perspectives about cancer risk – how could you broaden your view? • How can researchers ask participants about what risk means to them? • Are numbers important when communicating about risk in your specific project? • How do we categorise risk in a way that is meaningful to the public? • How could you personalise risk information and support to consider wider contextual factors? • Should PED consider engaging with people who are low risk e.g. young people so that they are better informed of cancer risk?

Needs transparency	People do not always trust information about cancer risk. • Distrust can develop if people feel this has not been informed by sufficient or relevant information. “They [the researchers] just completed a questionnaire, and we were given a risk score without any tests. We didn’t think much about the results.” Managing people’s expectations about cancer risk and accessing services, like screening, is important. • For example, people feel anxious or “given up on” when they’ve stopped receiving invites of follow-up letters without explanation. People are entitled to know how research works. • For example, why a certain study population is being focused on, so that others do not feel unfairly excluded.	• What information is available to describe how cancer risk scores are generated and what these could mean for individuals? • Have you clearly communicated how people should expect to receive information about their participation before, during and after the study and why this is? • How do we justify research into cancer risk in a way that feels relevant to the public? • Have you justified why you have focused on a specific population?
Is dynamic	The risk of cancer is dynamic but is often presented as static statistics, such as “1 in 2 people will get cancer”. Attitudes towards cancer risk are dynamic and can rapidly shift along a spectrum from fatalistic to optimistic.	• Should we communicate about changeable cancer risk (e.g. risk influenced by health behaviours) in a different way to communication about fixed risk (e.g. genetics)? • How can we best communicate that risk is not static? • How could your research account for changing attitudes towards cancer risk?

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