

Cancer Board Public Involvement Workshop

Thursday 30 March 2023 – 10am–12pm on Microsoft Teams (online)

On Thursday 30 March 2023 the Leeds Health and Care Partnership held a public workshop to discuss the provision of cancer care for people in Leeds. The aim of the workshop was to ‘develop our approach to public involvement in the population board’. The slide presentation is available on our website here: <https://www.healthandcareleeds.org/have-your-say/shape-the-future/populations/cancer/>

Comments taken from the chat box during the workshop are available at [Appendix A](#).

The **objectives of the session** were to:

- Introduce population health and the cancer board
- Review and agree the findings of the insight report
- Begin planning involvement on the gaps in our knowledge
- Review and agree the draft outcomes for the board
- Agree how we represent people at the board and provide public assurance

The **outcomes of the session** were:

- Understand the role of the cancer board
- Discuss the findings of the draft insight report
- Discuss gaps in our knowledge
- Discuss the draft outcomes for the cancer board
- Explore ways we can provide assurance that people's voices are heard at the board
- Influence our approach to public representation and assurance on the board

The **agenda for the session** was:

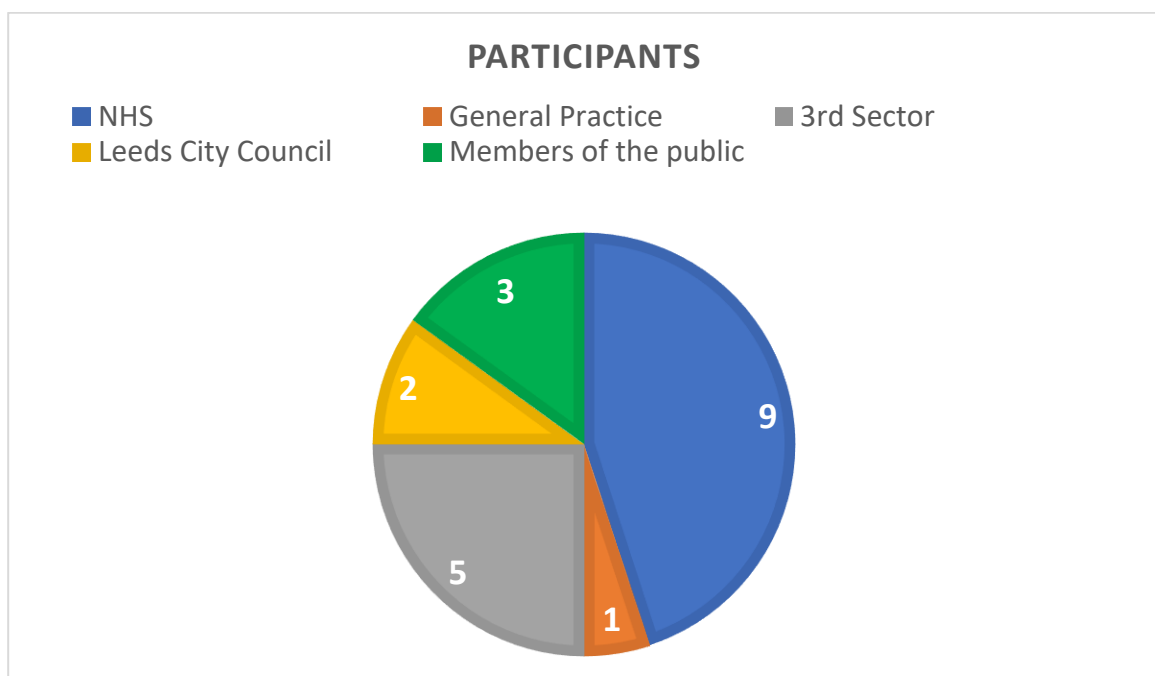
- Population Health - What are population boards and what is their role?
- Experiences of cancer care - What do we know about the experiences of people receiving care for cancer, and their families and carers?
- Population outcomes - How do we want things to be different for people receiving care for cancer, and their families and carers? (outcomes)
- Public representation and assurance – What does public representation look like on the cancer board?
- Next steps - What happens next?

Session Summary

The session was attended by 20 public and voluntary sector staff and members of the public with an interest in the provision of cancer care and support.

Organisations represented included:

- The NHS Integrated Care Board (ICB) in Leeds
- NHS partner organisations
- Public Health at Leeds City Council
- Yorkshire Cancer Community
- West Yorkshire & Harrogate Cancer Alliance
- Macmillan Cancer Support
- Volition
- Forum Central
- Primary care (GP)



Attendees included:

- 9 NHS staff members
- 1 member of staff from a GP surgery
- 5 people representing third sector organisations
- 2 members of staff from Public Health at Leeds City Council
- 3 members of the public

Workshop summary and main discussion themes

The Chair of the cancer population board, GP and University of Leeds researcher, Steve Bradley, welcomed attendees to the workshop. Introductions to the main speakers were made.

Caroline Mackay, from the Insights, Communications, and Involvement Team at the ICB in Leeds, outlined the aims, objectives and agenda for the workshop. She also introduced our approach to starting with what we already know about the needs and preferences of people in Leeds who are receiving cancer care and support, and their families and carers.

The findings of the cancer board insight report were shared, and participants asked for their thoughts on the themes and gaps.

- There was general agreement with the main themes identified in the insight report:
 - **Information** – Receiving a diagnosis is overwhelming. People can be in shock, so information can “go in one ear and out the other”. There is so much to take in. What is the best way to deliver (and receive) information at that point, and what information is most appropriate.
 - Macmillan is funding a Leeds Teaching Hospitals Trust (LTHT) post for a year to carry out a scoping exercise, to better understand people’s communication needs.
 - The amount of information can be overwhelming and then, at the end of treatment, everything just falls away and there is no information at what can be the most difficult time.
 - **Communication** – The main themes resonate with LTHT findings. Complaints received often relate to communication and information, particularly communications.
 - Macmillan have also recently done some work, nationally, looking at what matters most to people, including information and communications (also highlighted that people want care closer to home, in the community).
 - Now there are patient hubs, but people are bombarded with text and email reminders about appointments and have to navigate their phones to organise calendars, etc. It’s a lot for people to manage.
 - Issues with communications between hospitals and GP practices were discussed – patients can receive letters but find the information hasn’t yet been added to their GP records. The fact there are two different IT systems can be a barrier to the flow of information, leaving the patient frustrated and appointments can be missed or fall through the gaps.
 - Can’t cancer patients have a flag on their records to alert staff of their diagnosis?
 - The method of communication is so important – receiving your diagnosis by letter is unacceptable. At least a phone call should be made to relay this news.
 - False reassurance was highlighted – where staff may keep telling you not to worry, “it won’t be anything...” and then it is!
 - **Health Inequality** – LTHT have been doing some work around this and recognise the issues in relation to this.
 - The cultural aspect needs to be taken into account – in some communities even talking about cancer is difficult.

- The cost of transport to and from appointments can be a barrier, especially as public transport, and even taxis, is so hit and miss now.

Other issues were raised during the discussion:

- The excellent quality of care once referred for treatment was highlighted. The main challenges seem to be getting a diagnosis in the first place, and then post-treatment, when for example chemotherapy has stopped. However, people continue to be affected – may still be taking medication or need support in managing the after-effects of chemotherapy.
- **Workforce** - There was an acknowledgement that cancer services “are so stretched” and that the third sector offers a lot of the additional support, from much needed psychological support to the hospices offering end-of-life care.
- It was felt that cancer staff may need more support / mentoring and there was a mention of training to avoid giving false reassurances.
- GP training, for example, in relation to cancer in general, but specifically around the after-effects of chemotherapy, and to support the cancer care reviews, was mentioned.

There were no specific comments made in relation to potential gaps in our existing insight.

Tom Daniels, Pathway Integration Leader (Cancer and Diagnostics) at the ICB in Leeds, then provided an overview of the outcomes, or ambitions, which will help the board to measure its progress. The outcomes have been developed together with staff and members of the public. They explain what we want to achieve to improve the lives of people accessing cancer care and support, and their families and carers:

- More cancers will be prevented.
- People with cancer in Leeds will be diagnosed earlier.
- People will receive safe and effective cancer treatment.
- People with cancer will receive person-centred care.

Initial thoughts from those present included:

- In relation to the ambition for more people being diagnosed earlier, the biggest factor here is fear – the culture of fear around cancer and that cancer equals death. For people to come forward for screening, we need to address this culture of fear. The role the media plays in perpetuating this fear can be seen regularly on TV, whether in soap dramas or through fund-raising stories which tug at the heart strings where people lose loved ones to cancer... it's rare to find stories about survivors, so this helps continue the idea that receiving a diagnosis is a death sentence. We need to do something to address this culture of fear to encourage people to come forward.
- It was mentioned that the outcomes are very idealistic (maybe aspirational), but whilst for example, the NHS maintains strict age limits on screening, these targets will be hard to achieve. There is a middle ground between perhaps the NHS's idealistic ambitions and the public's more realistic expectations, and maybe a more honest

conversation is required. The outcomes could also be written in more accessible language for sharing publicly.

Caroline Mackay then outlined the importance of public representation and assurance. This includes developing our approach to ensuring that partners and members of the public can be confident the board is putting people at the heart of its decision-making.

Participants discussed the idea of representation at the board and providing public assurance:

- The question was raised about how people, members of the public / patients, find out about the board and the work it's doing. For example, in the Bexley Wing, or similar dedicated settings, there is nothing explaining it or showing how to get in touch or get involved.
- It was acknowledged that across the ICB (not just in relation to cancer) we need to do more work to raise the profile of the boards and the work they do.
- Thinking about the communications, complaints, or letters, which are already received – how many of these are acted upon?
- It was also raised that having more information about wider support, and particularly peer support, would offer people more opportunities to get more involved. But it was also acknowledged that not everyone wants to have a say – for some people, they just want to get on with their lives and not have cancer as an ongoing “soundtrack to their lives”.
- If one person is sitting as a representative they need to be listening to, and gathering information on, all the other groups and networks. They also need to be on equal footing with all the professionals round the table, and their input needs to be acted on and fed back for it not to be a tick box exercise. There needs to be assurance that they're valued.
- Having a panel, or linking with existing networks, for example the West Yorkshire & Harrogate Cancer Alliance (which has a patient panel) were discussed. This is an existing resource that the board could link with from time to time.
- The importance of hearing people's experiences was raised – the best people to help patients understand cancer are the people who've been through it themselves.

Ross Lavery, the citizen / expert by experience at the cancer board, gave some background to his own experience and what brought him to taking on the role. He also highlighted the purpose being part of the West Yorkshire & Harrogate Cancer Alliance has given him, and the hope that it will be made more use of as a valuable resource - turning people's experiences into something positive especially for future patients.

Steve Bradley, the Chair of the board, reflected on the experience of having Ross at the board, and the work to ensure his input is not tokenistic:

- He asks questions, that maybe others round the table also have, but don't ask!
- He brings a level of challenge and a reminder of what's important.

Some written guidance has just been produced for people bringing papers to the board, and at the top is a reminder about the use of jargon and terminology.

Other workshop participants agreed that there is value in people / patients attending at such meetings – their input can be insightful, can trigger different thoughts and approaches and different ways of working... and they ask good questions!

Next steps

We will:

- Share the slides from the workshop and a link to the evaluation survey
- Add the recording of, and this report on, the workshop to the cancer board webpage: <https://www.healthandcareleeds.org/have-your-say/shape-the-future/populations/cancer/>
- Members of the public who registered for the workshop will be invited to join a working group to:
 - Develop an approach to representation and assurance
 - Explore the gaps in our insight and prioritise involvement

The workshop closed with many thanks to all participants, and particularly those who felt able to share their very personal cancer stories – very much appreciated!

Stay in touch

Stay involved in our work to improve health and care services in Leeds by joining our citywide public network here: www.healthandcareleeds.org/have-your-say/shape-the-future/join-our-network/

For more information about our work on involving people with the work of the cancer board, please email caroline.mackay2@nhs.net

Appendix A

Notes taken from the Chat box during the Cancer Board Public Involvement Workshop (30 March 2023)

Main themes

Information / communication - Macmillan supply information about Cancer in several different languages (SM)

Health inequality - Ross is highlighting a common point that it takes a relatively high level of education and confidence to navigate the systems and that makes it hard for everyone and is going to make it even harder for people facing the most health inequalities. It's also very time consuming. I am sure there is lots of information from PALS and health complaints highlighting common issues. I assume that this information is fed into the insight reports (CN)

Communication - Jan's point is a common issue with systems. People explain their needs but it doesn't seem to be recorded clearly on notes and they have to re explain every time which makes a difficult time more traumatic (CN)

Health inequality - Need to make sure the insight and boards are linked up and themes across the need are captured and addressed. There seems to be a bit less detail on the cancer insight report linking to health inequalities - the core 20 plus 5 work (CN)

Health inequality - It would be useful if the insight reports had information on the common cancers and groups with the poorest outcomes so we can target relevant insight e.g, from the community of interest (COIN) network (CN)

Carers - Leeds carers stats provided by Carers Leeds, and the importance of support for carers:

Carers provide 1.5 million hours of unpaid care per week in #Leeds. That is the equivalent of £1.4 billion a year in paid for care. (Assuming 37.5 hrs/week, this is equivalent to 40k FTE staff) <https://carersleeds.org.uk>

Important, therefore, to consider their health & wellbeing, their experience as a key segment of the H&C workforce, as well as how they are involved in a patient-centred approach (CN)

Going back to communication, carers often don't ask for support or link to services until they are at crisis point. This has a greater impact on their health as well as the health and experience for the person that is unwell (CN)

Outcome measures

Are there any outcome measures for secondary cancer? Also re survival 5 years is one measure but any measure on quality-of-life post treatment?

This is a great point. I can check with Karen if there is anything in cancer experiences survey we could use to measure this (SB)

Public representation

I have only heard of the board through my job, not as a result of having cancer. Places like Maggie's and Robert Ogden Centre would be places to potentially raise awareness (A)

The Cancer Alliance has a patient panel (LM)

We support 3rd sector organisations and even if they are aware of the boards they have very limited time and resources to join extra meetings especially as they are trying to support an over stretched care system. The language and the papers involved can be overwhelming in terms of time to digest, process and feedback on. Especially as 3rd sector reps we want to get a wider view from the sector but there is limited capacity, we are losing staff, less people can afford to work or volunteer in the sector and though people are keen to be involved in system change they are busy fire fighting and trying to live with cost of living pressures. Especially people who are working with the most deprived, the people that have the worst outcomes and we want to reach (CN)

It's important to think about the wider determinants and as a large employer the NHS has an important role and scope of influence. There are also the opportunity around nutrition and access to good and nutritious food when in hospital both as a patient, staff and anyone else in that environment. This goes back to the links across the population boards and outcomes / health improvements / health equity e.g. weight management, smoking cessation (CN)

Ross has made a really important point that we hear from the 3rd sector reps, the speed of the meetings and the language and the time it takes to properly engage (CN)

CANCER SUPPORT UK offer mental health support on line post treatment (SM)

Agree Jan - we do have as an interim you can access 6 sessions of counselling through the Macmillan Support Line <https://www.macmillan.org.uk/.../get-help/macmillan-support-line> (LS)