

Executive Summary from the North Tyneside Cancer Plan Public Involvement Event held on 5 October 2018

To prepare for the involvement of patients and carers in the North Tyneside Cancer Plan we held a session at the Langdale Centre, North Shields on 5th October 2018. This session was a collaboration between North Tyneside CCG, Northern Cancer Alliance, and Macmillan Cancer Support and we were assisted in the planning and delivery of the day by local colleagues from both NHS and third sector organisations. We had originally planned for the day to be aimed at people affected by cancer only, but we recognised that there was a great deal of interest from other colleagues so adapted the approach to a more holistic co production model including both patients/carers and professionals.

The costs for the session were met by Macmillan Cancer Support.

Following a number of presentations to set the scene for our session we posed three main questions to participants;

1. What makes good engagement?
2. How do we make this happen?
3. Where do we start?

Answers were mapped on flipchart sheets and fed back to the main group. The full verbatim responses are found in the main document and have been triangulated to identify core issues. These are as follows:

1. What makes good engagement?

1. Resources

This includes practical issues such as accessible venues and travel expenses. It also includes the use of a variety of communication tools to promote the work and gather insight.

2. Organisational Behaviours

This includes the need to take time to engage people properly and having a clear vision of what we are trying to achieve with this process. We are expected to invest in our work with people affected by cancer to ensure they can play a meaningful role; this may require training for them to understand the system they are influencing.

3. Respect & Honesty

This describes the relationship between the professionals and patients/carers. In general, openness and inclusivity were the key issues people wanted to address, and also reassurance that the engagement would have a purpose and not just ask the usual questions of the usual people.

2. How do we make this happen?

1. Organisational Behaviours

As above, a number of practical steps were identified that included *How to hold meetings, Who to work with, What resources are needed, Budget, Communications, and Mindset.*

2. Data Management

Issues included *Communication Style and Balance of statistics and narrative data.*

3. Partnership Working

The importance of parity of esteem between patients/carers and professionals was considered, and also issues of accessibility and equality.

4. Individual Dynamics

This concerned the qualities/mindset needed to successfully collaborate with individual patients and carers. They stress the importance of thought given to how to deploy and support people effectively.

3. Where do we start?

1. Planning

Participants were invited to identify actions that they could take to further deliver this process. These included *Mapping, Planning, and Promotion/Communication.*

2. Recruitment

It was considered important to attract further participants, particularly among patients and carers.

3. Attitude and mindset

Participants mapped out what the values of the process should be.

4. Support

This was more practically focussed and described the support that people would like through their cancer journey. There were a number of cross cutting themes identified that would apply to engagement as well as treatment.

In all, nineteen patients, carers, professionals, and other members of the public were involved in this session and feedback was generally positive. We are guided that future sessions should have less presentation and more conversation, but one participant also commented that “it actually feels like engagement might really happen this time”. The next session is planned for March 2019 and will be planned and promoted according to the feedback and insight from this session.

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