Executive summary
We want to deliver the best cancer outcomes for Leeds patients. We will achieve this by working together across the range of health and social care organisations to ensure we provide quality care to the people of Leeds.

We want to involve local people as we continue to develop the Leeds Cancer Strategy.

This event aimed to:
‘Raise awareness of the Leeds Cancer Strategy and explore opportunities to involve patients, carers and the public in its development and delivery’

People across the city were invited to attend the event. 47 people attended the event representing different areas of Leeds. We commissioned an illustrator to record the day visually.

The presentation gave information about the prevalence of cancer in the UK and Leeds and also highlighted inequalities in cancer. The event also outlined how we had used patient feedback to develop our Leeds Cancer Strategy to date and introduced the four ‘domains’; ‘prevention, screening and awareness’, ‘early diagnosis’, ‘living with and beyond’, ‘high quality modern services’.

The first groupwork session exploring people’s priorities around cancer identified a number of areas that were important to people, including:
- Patients, carers and the public need to be empowered and well informed to support their decision-making
- The strategy needs to consider the needs of all the different communities in the city
- GPs need to be well informed and knowledgeable

The groupwork session exploring ways people wanted to get involved in the strategy identified a number of areas that people thought were important:
- Involve local organisations and groups that have established links in the community
- ‘Reach-out’ to communities such as seldom heard and employed people
- Use different ways to promote activities - it should be easy and fun to get involved
- There should be opportunities for volunteers to learn and develop their skills.

21 of the 47 participants evaluated the event and told us that they were very satisfied with the event. Many people complained about the acoustics in the room.

Following the event the Leeds Cancer Strategy project team will use the feedback to develop the strategy. They will also create ways for people to get involved in the project as it further develops.
1. Introduction

Cancer incidence in Leeds is generally rising due to the aging population, historical smoking and other lifestyle behaviours linked to poverty and deprivation including alcohol and obesity as well as low uptake of population screening opportunities in some areas.

In July 2015 an Independent Cancer Taskforce published ‘Achieving world-class cancer outcomes: a strategy for England 2015-2020’. The aim was to improve survival rates and save thousands of lives. There was a six week consultation on the strategy in 2015. The six key recommendations from the report include:

- Improving prevention and public health
- Achieving earlier diagnosis
- Establish patient experience as being on a par with clinical effectiveness and safety
- Improve support for people living with and beyond cancer
- Invest in services so that they are modern and high quality
- Improve how cancer services are commissioned (planned and paid for)

We are developing a cancer strategy for Leeds in line with the national strategy. The Leeds Cancer Strategy will deliver the best cancer outcomes for Leeds patients. We will achieve this by working together across the range of health and social care organisations to ensure we provide patient driven, quality care to the people of Leeds.

We know that involving local people in developing healthcare services will help us commission and provide better cancer care. We want to involve patients, carers and members of the public in developing our strategy. This event aimed to:

‘Raise awareness of the Leeds Cancer Strategy and explore opportunities to involve patients, carers and the public in its development and delivery’

Outcomes – by the end of the session participants will:
- have a good understanding of the challenges and opportunities facing the city
- have a good understanding of how we have used patient experience and feedback to shape our initial plans
- be able to give examples of what the strategy might mean for patients in Leeds
- have the opportunity to share their experiences and thoughts on cancer in Leeds
- have the opportunity to shape ways to get involved future cancer work.

Our day was held at the Leeds City Museum and was brilliantly captured by Arts and Minds illustrator, Tom Bailey @tombaileyleeds. The Arts and Minds network brings together people in Leeds who believe the arts can promote mental well being. You can read more about their work here: [http://www.artsandmindsnetwork.org.uk/](http://www.artsandmindsnetwork.org.uk/)

You can follow the day and find all the information about our Leeds Cancer Strategy on our website here: [https://www.leedswestccg.nhs.uk/leedscancerstrategy/](https://www.leedswestccg.nhs.uk/leedscancerstrategy/)
2. Recruitment and promotion for the event

We wanted the event to be attended by a range of people representing different communities in Leeds. We used the following methods to promote the event:

- Twitter
- Sharing with our CCG public network (3,500 people)
- At citywide events such as the Forum Central Massive Marketplace Event
- Posters in every GP practice in Leeds
- Shared with providers including Leeds Teaching Hospitals Trust, NHS Leeds Community Healthcare Trust, NHS Leeds and York Partnership Foundation Trust
- Local and national voluntary, community and faith sector (VCFS) organisations working with cancer such as; Macmillan, Yorkshire Cancer Centre, Ellie’s Friends, Breast Cancer Haven and Candlelighters
- Universities including the Leeds Institute of Cancer and Pathology
- The wider VCFS via Voluntary Action Leeds
- Healthwatch Leeds
- Press release was sent to the local media i.e. Yorkshire Evening Post, Morley Observer, Yorkshire Post, West Leeds Dispatch
- Case studies based on the experiences of local cancer survivors
- Internal staff via the staff bulletin
- GP practice staff via the primary care bulletin

In total 47 people attended the event.

- 11 members of the public
- 19 people representing VCFS
- 16 NHS staff
- 1 other

We also offered providers stalls at the event. 13 providers requested stalls at the event and due to limited space, the following organisations were given a stall:

- Unique Improvements
- Look Good Feel Better
- Leeds Rhino Foundation
- Yorkshire Cancer Research
- Macmillan/Sir Robert Ogden Centre
- BRCA
- Breast Cancer Haven
- St Gemma’s Hospice
3. Groupwork A: Peoples priorities

The first groupwork session gave each group one of the four domains in the Leeds Cancer Strategy and asked them to discuss the domain and share their own priorities. The aim of the session was to ensure that the domain reflected people’s own priorities and identify gaps in the strategy. We acknowledged that the event was not represented by all the different communities in Leeds and we asked people to also consider the needs of people with different needs and characteristics.

The following themes were identified in the group work (in order of popularity):

- There needs to be more and better **awareness** in the community about cancer. **Jargon** should be avoided at all costs. Education in schools is important if we are to involve young people in the strategy.
- The Leeds Cancer Strategy needs to recognise **‘hidden’ communities** in Leeds. There should be good education for community-specific cancers, information available in alternative formats and advocacy to support vulnerable groups in treatment.
- Patients need to be **empowered and confident** to manage their own care.
- **GPs need to be knowledgeable** about cancers and pathways into treatment.
- There needs to be investment in **innovative** ways to engage patients in the development of the strategy and self-care. This might include mobile clinics in supermarkets or sporting events.
- Statutory and voluntary organisations need to work in **partnership**. This includes all stakeholders such as pharmacists and patients.
- There needs to be more support for **local support groups**
- There needs to be more **emotional support** for people living with and beyond cancer and their carers.
- Access to **test results quickly** is important.
4. Groupwork B: Involving local people in the strategy

The second groupwork session gave each group the opportunity to explore the different ways people could get involved in the Leeds Cancer Strategy. The aim of the session was to ensure that there are different opportunities for people to stay informed and volunteer. We acknowledged that the event was not represented by all the different communities in Leeds and we asked people to also consider the needs of people with different needs and characteristics.

The following themes were identified in the group work (in order of popularity)

- Need to engage with existing groups and organisations. These people have established links with local people and are able to facilitate engagement. This might include Duke of Edinburgh Award, schools, GP practices, VCFS.
- Need to involve 'under-represented' communities. Be aware of 'less traditional' barriers to involvement such as employment, finance, childcare. Consider ‘reaching out’ to them and making involvement accessible.
- Promoting involvement activities is important. Use a variety of different methods including social media and news.
- Provide creative ways for people to get involved. Use the arts and make participation easy and fun.
- Consider the needs of volunteers such as supervision and training.
- Consider asking role models/celebrities to help you recruit
- Avoid jargon
- Show people what difference they have made ‘you said, we did’

People made a number of suggestions as to how people might want to get involved:

- Community networks
- Research
- Virtual groups
- Visiting hospices
- Fundraising
- Sharing patient stories
- Cancer ambassadors in workplaces
5. Recommendations

Following the event the engagement team at the CCG group partnership make the following recommendations to the Leeds Cancer Strategy Project Team:

- Use the feedback from the event to identify engagement gaps in the strategy, in particular around:
  - Communication and awareness (especially with young people)
  - Meeting the needs of diverse communities
  - Self-management
  - GP knowledge of cancer and it’s pathways
  - Innovation to engage the public
  - Working in partnership
  - Involving the voluntary sector
  - Stakeholder mapping
  - Supporting mental and emotional health
  - Quick access to test results

- Use feedback to develop a range of ways for people to get involved in developing the strategy. Give consideration to barriers and opportunities to meaningful involvement and participation, including:
  - Working with established groups
  - Involving ‘under-represented’ communities
  - Promotion of activities and events
  - Providing creative involvement opportunities
  - Supporting people who get involved
  - Asking for support from local role models
  - Using plain English
  - Showing people what difference they made

- The project needs to find ways to ‘reach out’ to the public to encourage engagement.

- Low attendance at the event suggests that the voluntary sector does not see this initiative as a partnership. The project team need to consider ways to involve the voluntary sector in the project and promote the message that the Leeds Cancer Strategy is a partnership between statutory, voluntary services and patients.

- Share this engagement report with people who attended the event. Share widely with relevant networks

- Provide regular updates and information about the Leeds Cancer Strategy to people who are interested

- Hold a similar event next year to demonstrate the progress you have made towards the recommendations in this report.
6. Feedback on the event

We asked all participants to tell us if we met our objectives at the event and share and other thoughts on the Leeds Cancer Strategy. 21 of the 47 participants filled in the survey.

The event evaluated very well and people told us that they agreed or agreed strongly that we met our objectives.

The event was not representative of the wider community and the evaluation suggested gaps in the following areas:

- Children and young people
- Various ethnic minorities
- Transgender
- LGBT community
- Pregnancy and maternity

It should be noted that over half of attendees did not fill in the equality monitoring form and several of those who did chose not to disclose the status.

The evaluation form allowed people to share their thoughts on the day. Below are a couple or comments that reflected the mood.

- Superb opportunity to involve a diverse group of people in fighting cancer.
- Workshops good especially good idea to have briefed and elected writer/spokesperson.
- Really good mix of representation.
- Event has allowed people to talk - good. Need to engage in wider groups including minorities.
- Not a good environment for hearing disabled people. Dreadful acoustics, and can people be made to use the microphone properly i.e. near the mouth!
- Acoustics were very poor with or without the microphone and I couldn't hear what was being said. Projection screen was very high - had to tip head back to look at it.
7. Next steps

We’d like to thank people for attending this event and supporting us to put patients at the heart of our cancer services. Over the next few months we will continue our work to develop and deliver projects that will enable us to deliver the best cancer outcomes for people in Leeds. Feedback from this event, along with wider patient experience will help us to continue to develop the strategy, prioritise the work we do and to create ways for local people to get involved in our work.

We will set up a network of local people who want to stay involved with the Leeds Cancer Strategy and keep up to date with changes that are happening. We will share updates on our work and provide opportunities for people to get more involved in specific cancer projects. Early next year we will write an update report which outlines our progress against the recommendations in this report. We will also invite you all to join us again in a years’ time to reflect on what we have achieved, celebrate our successes and also explore with you all our future plans.
Alternative formats

An electronic version of this report is available on our website at www.leedswestccg.nhs.uk
or please contact us direct if you would like to receive a printed version.

If you need this information in another language or format please contact us by telephone:
0113 84 35470 or by email: commsleedswestccg@nhs.net

Further information

If you would like any more information about this project, or have any questions or comments, please write to:

Joanna Bayton-Smith
Macmillan Leeds Cancer Strategy Programme Manager
NHS Leeds Clinical Commissioning Groups Partnership
Suites B5-B9
Wira House
West Park Ring Road
Leeds, LS16 6EB
Tel: 0113 8435634
Email: Joanna.Bayton-Smith@nhs.net
www.leedswestccg.nhs.uk