

OFFICIAL



Northern Cancer Alliance Public Involvement Strategy
October 2020

Version	Date:	Revisions made:	Author	Approved By:
1.0	18/02/2020	FINAL VERSION	Jo Mackintosh	PIAF
2.0	27/10/2020	Review	Jo Mackintosh	PIAF

1.0 Introduction:

The Northern Cancer Alliance is one of 20 Cancer Alliances in England. It is a multi-agency collaborative that brings together providers, commissioners, third sector organisations and public representation who work together to improve cancer survival across the North East and North Cumbria.

Key to the achievement of improved survival rates is a reduction in health inequalities, improvement in cancer outcomes for patients and a positive patient experience. There is growing recognition of the value that involving people in health services can bring including improving patient safety, the patient experience and health outcomes. It is essential that involvement activities are shown to be meaningful, have impact and are not tokenistic or regarded as a “nice to do” activity. For this to happen, involvement needs to be fully embedded within NHS services and organisation’s and regarded as “usual business”.

2.0 National context:

National policy documents such as Achieving World Class Cancer Outcomes, the NHS Constitution and NHS Long Term Plan recognise the importance of involving people in designing and delivering the changes necessary to drive forward improvements in cancer survival rates.

Local context:

Cancer survival is now the highest it has ever been. In 2016 the percentage of people surviving at least one year following diagnosis increased from 65.5% in 2006 to 70.6% across our region. In spite of this improvement our survival rates remain below the England average. More cancers are also being diagnosed early when curative treatment is more likely and patient reported experience of care is high (as measured through the National Cancer Patient Experience Survey). Despite this, too many people have their lives cut short or are significantly affected by cancer both of which can have a consequent impact on their families and friends. The overall one-year survival figure masks variation that ranges from 69.2% to 73.5%.

3.0 Health Inequalities:

Reducing *health inequalities* means giving everyone the same opportunities to lead a healthy life, no matter where they live or who they are’. COVID-19 has shone a light on a range of health inequalities within our communities. These same inequalities are apparent within cancer diagnosis and mortality rates. They affect the people living in the most socially deprived areas of the North East and North Cumbria, members of our BAME communities and people with a learning disability as well as other marginalised communities.

A primary function of all Cancer Alliances is to reduce inequalities in cancer experience and outcomes. To be successful they must develop services and interventions that are centred around the needs of the most vulnerable members of our communities.

Thus, it is critical that the people who are most at risk of cancer have the opportunity to inform and shape cancer related services and interventions. The Northern Cancer Alliance will develop targeted approaches to all of its involvement activities that seek to engage with those with the highest levels of risk. They will aim to remove the barriers that can prevent the most vulnerable members of our communities from getting involved.

Barriers to involvement can include accessibility of written information and over reliance on digital platforms as a way of communicating with people. The COVID-19 pandemic has removed our ability to engage with communities and individuals on a face-to-face basis. The Cancer Alliance will work to reinforce partnerships with community organisations, identify community assets and strengths, and develop alternative ways of working that remove barriers and create equitable opportunities for involvement.

5.0 Purpose of strategy

This strategy describes the approach adopted by the Northern Cancer Alliance to involve the public at all levels of its workplan. It is aligned to, and forms part of, the Northern Cancer Alliance communication and engagement strategy.

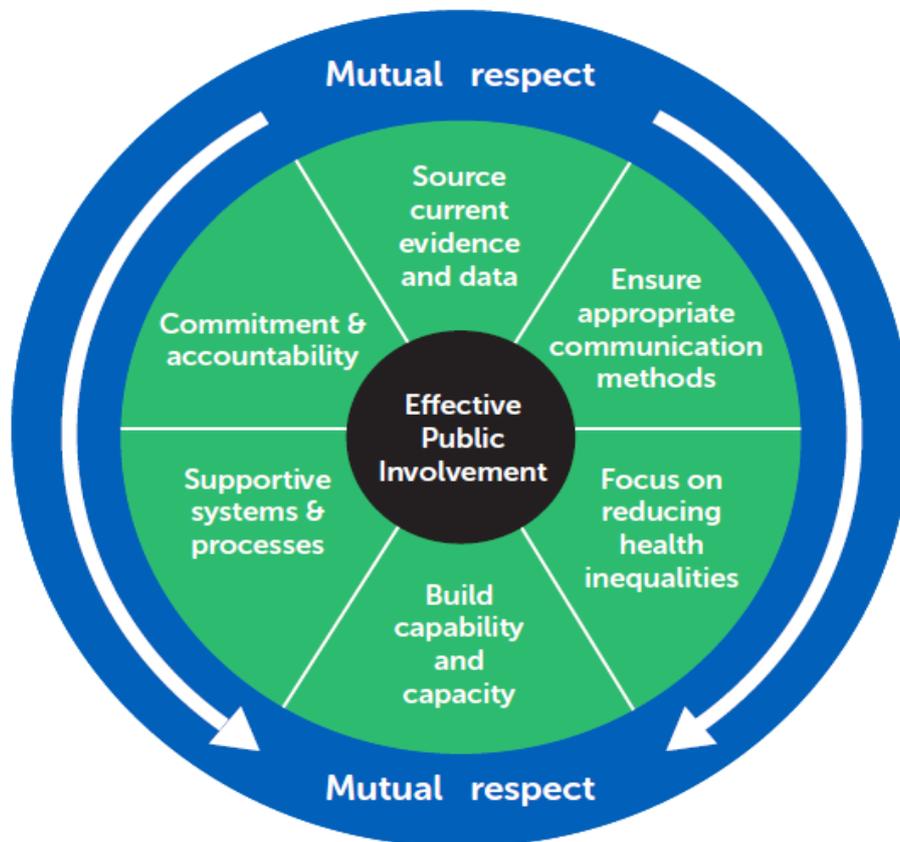
5.1 Stakeholders:

The Northern Cancer Alliance views members of the public as equal partners and key to improving these health inequalities. It is committed to involving people at all levels of its work plan, demonstrating the value that involvement can bring and recognises the link between the patient experience, clinical safety and effectiveness.

This strategy underpins and informs involvement activities with members of the public as well as partnerships with a wide range of stakeholders from health, social care, local authority, third sector organisations that support effective public involvement.

6.0 Northern Cancer Alliance framework for public involvement

The NCA Framework for Public Involvement underpins and informs all public involvement activities across the Cancer Alliance. This framework was co designed by people with lived experience, members of the public and other key stakeholders from across the Alliance.



<http://www.northerncanceralliance.nhs.uk/pathway/public-involvement/nca-framework-for-public-involvement/>

7.0 Northern Cancer Alliance approach to public involvement

The Alliance is committed to using language that is easy to understand. It recognises that a number of different terms are often used to describe partnership working between health professionals and patients, their carers and the wider public. With this in mind, the Alliance has adopted “public involvement” to describe all their partnership activities.

“Public” describes everyone living in the Alliance area affected or potentially affected, by cancer. “Involvement” describes any partnership activities with the public to improve cancer outcomes and services. This includes:

- Providing information.
- Talking to people to understand their experiences and gain their views.
- Patients working in partnership with professionals to develop clinical pathways and wider NHS cancer services.

One of the primary aims of the Northern Cancer Alliance approach is to ensure “*the right people are involved in the right way*”. To achieve this aim, the Alliance has defined the local population into three distinct groups:

7.1 Lay Representatives:

A Lay Representative is an individual who has a broad knowledge and understanding of the NHS landscape and governance related issues. They also understand health inequalities and their interaction with the cancer experience.

A Lay Representative may not have experienced cancer personally but will have the ability to champion the views and experiences of communities located within the Alliance geography.

Context for involving Lay Representatives:

- As a member of Alliance strategic groups i.e. Board and Tumour Pathway Boards, to bring the perspective of community experiences and acting as critical friend.
- Providing support to the members of the cancer Alliance support team, holding them to account on public involvement activities and the patient centred approach across the Alliance work plan.

7.2 People with lived experience:

This includes people who have received treatment for cancer or have cared for someone who has received treatment for cancer.

Context for involving people with lived experience:

- Provide and insight and understanding based on recent experience to shape and develop specific clinical pathways or services (involving people whose experience is >1 year or <5 years)
- Involving patients whose experience is greater than 5 years may include the development of policy and membership of patient forums/committees.

7.3 Members of the wider public:

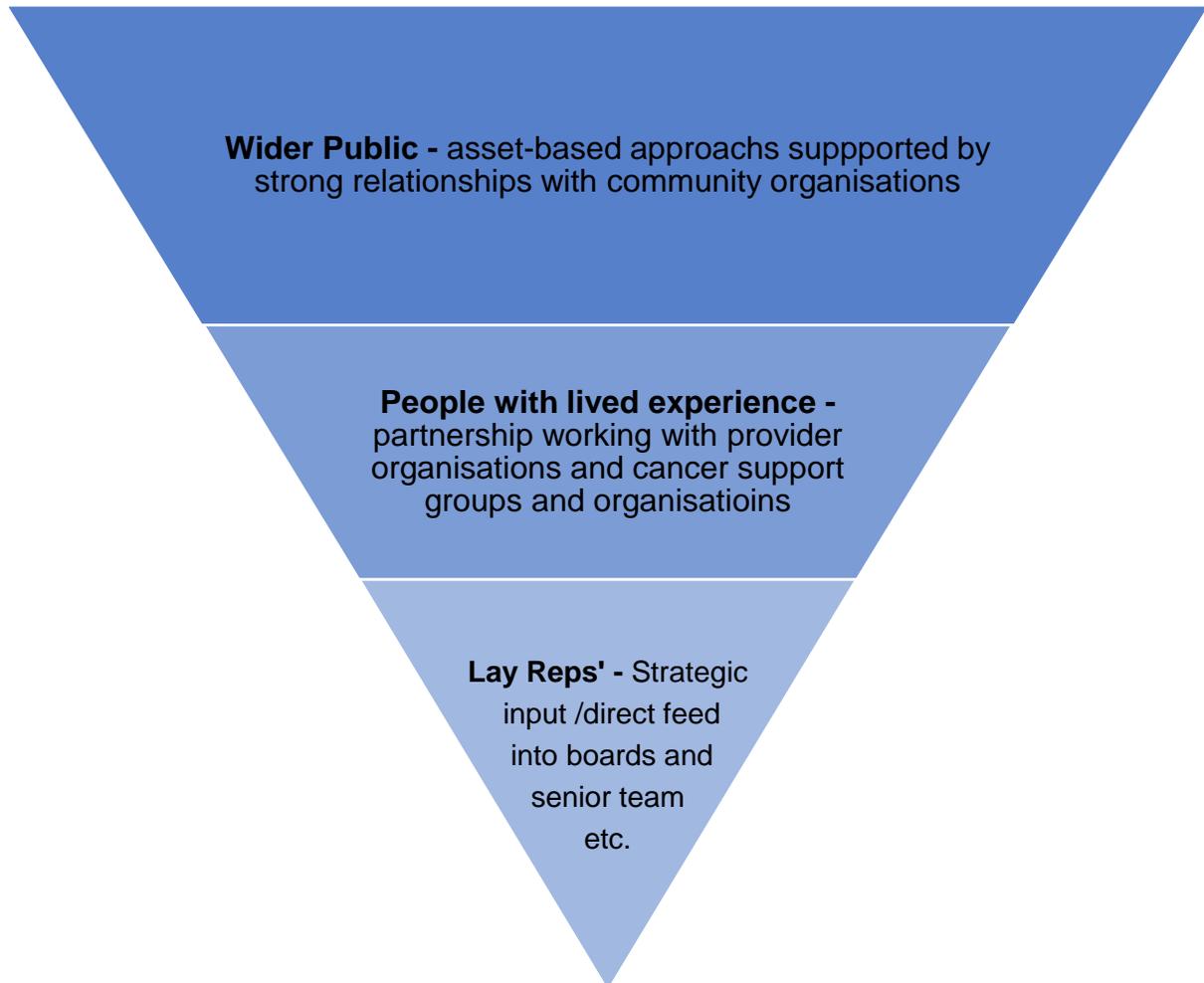
This includes wider members of the public including those who may not have been touched by cancer.

Context for involving wider members of the public:

- Raise awareness potential cancer signs and symptoms.
- Increase early diagnosis rates
- Reduce the risk of cancer through the adoption of a healthy lifestyle behaviours.
- Improve the uptake of national cancer screening programmes.

7.4 Connecting with the right people:

The Cancer Alliance will adopt approaches that provide the best opportunity of connecting with the right people:



7.5 Methods of involvement

The Cancer Alliance utilises a number of involvement methods. The methods adopted are dependent on a number of factors that include:

1. Creating an inclusive approach that is considerate of inequalities.
2. Availability of resources e.g. time and manpower.
3. The objectives of the Alliance service improvement project or workstream.

Each of the methods below may be used in combination with each other or in isolation and will be dependent on the factors detailed above:

	<p>Provide balanced and objective information in a timely manner to help the public understand the issues, alternatives and/or solutions.</p>
	<p>Listen - obtain feedback from the public on services, analysis, issues or proposals.</p>
	<p>Discuss - exchange information to clarify, understand and influence the issues, alternatives and solutions and make sure that hopes and concerns are understood.</p>
	<p>Collaborate - partner and work together with the public in each aspect of decision-making</p>
	<p>Empower - placing final decision-making in the hands of the public</p>

Reference: The International Association for Public Participation (IAP2)'s Public Participation Spectrum 2014

8.0 Governance and accountability:

The Alliance is accountable for the public involvement activities across its workplan. This is overseen by the Northern Cancer Alliance Public Involvement Accountability Forum (PIAF) whose primary function will be to scrutinise the involvement activities and provide assurance to the Alliance Board.

The forum sits within the Northern Cancer Alliance governance structure alongside clinical leadership group and the commissioning forum. The forum will also hold the Alliance to account for its performance within the annual National Cancer Patient Experience Survey. This will involve understanding the following:

1. How the Alliance performs in relation to other Cancer Alliances and the national scores.
2. How each of the 8 Trusts within our region have performed.
3. The potential for developing quality improvement interventions at an Alliance level.

9.0 Measurement and reporting:

The Alliance will produce an annual report for the Public Involvement Accountability Forum that will detail involvement activities across the workplan over the previous 12 months. The report will evidence how the Alliance has achieved the following quality standards for public involvement quantified by an evaluation framework consisting of a number of key performance indicators:

Quality Standard	Key Performance Indicator
Effective use of existing data sources to inform and justify the approach to involvement activities.	Demonstrate an understanding of the performance within the National Cancer Patient Experience Survey (NCPES) at an Alliance level.
	<p>Identify areas for improvement within the NCPES that would benefit from an improvement approach developed at an Alliance level and demonstrate the approach taken to improve the patient experience.</p> <p>Demonstrate an understanding of individual Trust NCPES performance and provide evidence of any direct work with individual Trusts to support the improvement of patient experience.</p>
Collaborative relationships with the public and partners that value everyone's contribution and supports mutually respectful and productive relationships.	Produce at least 4 public involvement case studies that demonstrate the following; producing accessible patient information, collaborative relationships with community organisations and the third sector, and addressing health inequalities.
	<p>Produce at least 4 public involvement case studies that demonstrate the following; producing accessible patient information, collaborative relationships with community organisations and the third sector, and addressing health inequalities.</p> <p>Provide evidence of engagement activities with the wider public to promote cancer prevention and early diagnosis messages.</p>
A governance structure that supports collaborative relationships with partners and the public	Communication approaches that ensure information is produced in a format that is accessible to the target audience.

Quality Standard	Key Performance Indicator
<p>Strategic and operational systems that facilitate effective involvement activities at all levels of the Alliance workplan with the public and partners.</p>	<p>Provide evidence of Northern Cancer Alliance Lay Representative involvement and influence within Alliance key strategic meetings and project groups.</p> <p>Provide evidence of the Northern Cancer Alliance Public Involvement Forum including attendance at each meeting, activities and actions.</p>
<p>Promote learning opportunities that develop the confidence and skills for effective involvement activities.</p>	<p>Provide evidence of the number opportunities the Alliance has provided for health professionals and members of the public to attend public involvement events and courses.</p> <p>Provide evidence of the number of health professionals and members of the public attending the 10 Steps to Better Public Engagement training day.</p>
<p>Approaches to involvement that are considerate of and aim to, reduce cancer experience health inequalities.</p>	<p>Produce at least 4 public involvement case studies that demonstrate the following; producing accessible patient information, collaborative relationships with community organisations and the third sector, and addressing health inequalities.</p>
<p>Demonstrated the benefits that involvement activities have brought to the work of the Cancer Alliance and the patient experience.</p>	<p>Produce annual report that demonstrates the value and impact of involvement activities within the Cancer Alliance.</p>

10.0 Feedback Mechanisms:

The Cancer Alliance will provide evidence that demonstrates the impact public involvement activities have had on the delivery of its workplan. This information will be included in the annual report presented to Alliance Public Involvement Accountability Forum and shared on the Cancer Alliance website.