



# Northern Cancer Alliance Public Involvement Strategy

**July 2022**

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
3.0	16/01/2021	Updated	Jo Mackintosh	NA
4.0	21/07/2022	Review	Jo Mackintosh	PIAF

## **1.0 Introduction:**

The Northern Cancer Alliance is 1 of 21 Cancer Alliances in England. It is a multi-agency collaborative that brings together NHS providers, commissioners, third sector organisations and members of the public who work together to improve cancer outcomes and patient experience across the North East and North Cumbria.

There is a recognition of the value that involving people in health services can bring to improving patient safety, patient experience and health outcomes. However, it is essential that public 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 should be embedded across a health care system and regarded as “usual business”.

The involvement of the public in the development and improvement of NHS cancer services is a fundamental element of improving patient experience and reducing health inequalities.

## **2.0 National context:**

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 outcomes and patient experience.

“Understanding and improving experience of care by embedding patient, carer and public voices in policy and service development and delivery” is also one of the NHS Cancer Programme delivery principles for Cancer Alliances in 2022/23.

## **3.0 Local context:**

“The North East and North Cumbria region has the highest mortality rates, lowest life and healthy life expectancy rates in England. There are also significant health inequalities within our region linked to marginalisation and disadvantage” ([Inequalities and marginalised communities - ARC \(nihr.ac.uk\)](https://www.nihr.ac.uk/about/inequalities-and-marginalised-communities/)).

In 2018 the Northern Cancer Alliance had the 3<sup>rd</sup> highest rate of cancer incidence in England at 643.3 cancers diagnosed per 100,000 people (England average 616.3). In 2018 the percentage of people surviving at least one year following diagnosis increased from 70.6% in 2016 to 72.5% across the North East and North Cumbria. Despite this improvement survival rate remains below the England average (73.9%). The Alliance overall improvement masks a variation and inequity with ranges from 71.8% to 73.4%.

#### **4.0 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'. Health inequalities includes life expectancy, healthy life expectancy, avoidable mortality, and access to and experience of health services. People living in our most socially deprived and marginalised communities are more likely to experience a greater prevalence of cancers, poorer outcomes and are less likely to have a positive patient experience.

A primary function of all Cancer Alliances is to reduce inequalities in cancer outcomes and patient experience. To be successful it is critical that the people from the most vulnerable sections of our communities have the opportunity to inform and shape the improvement and development of cancer services.

The Northern Cancer Alliance has developed a targeted approach to public involvement activities. We do this by seeking to engage with those with the highest levels of risk and disadvantage so we can remove the barriers that can prevent people from sharing their views and experiences.

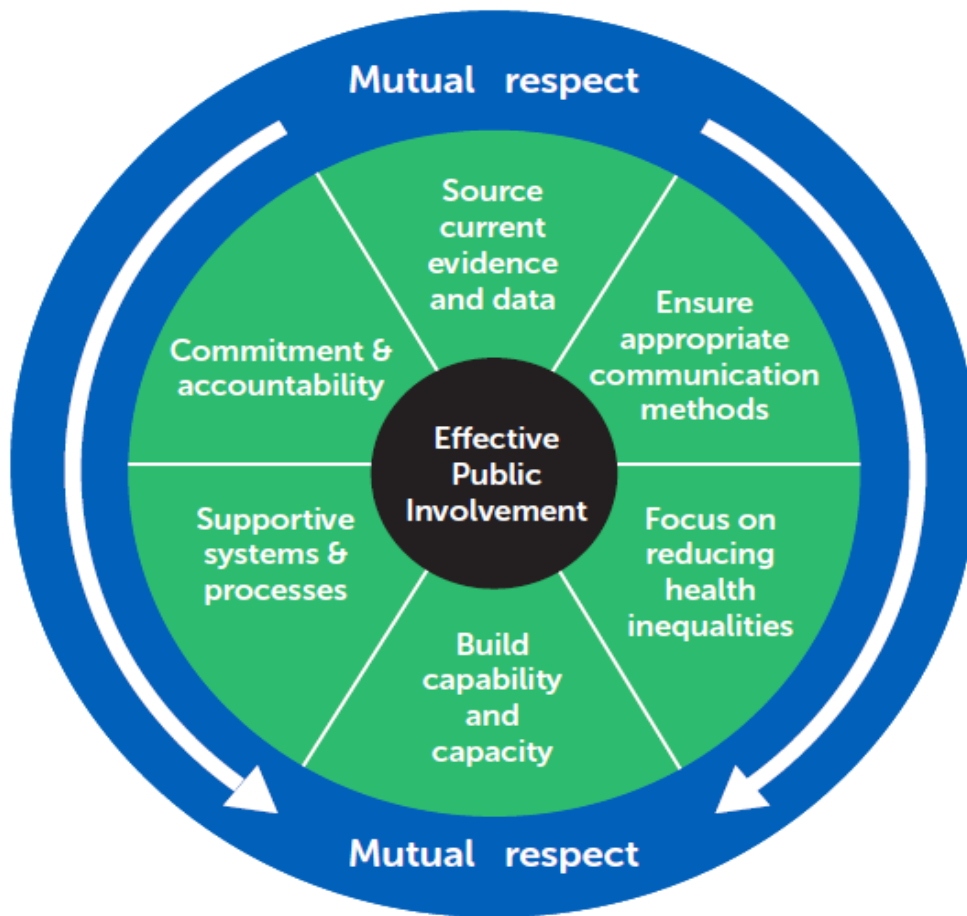
The basis for this approach is collaborative working to build trust and form reciprocal relationships with community leaders and organisations. Identifying community assets and strengths and developing alternative ways of working that create real opportunities for involvement across the most vulnerable sections of our community.

#### **5.0 Purpose of the strategy**

This strategy describes the approach adopted by the Northern Cancer Alliance to involve the public at all points of its work plan. It is aligned to, and forms part of, the Northern Cancer Alliance communication and engagement strategy. It informs all activities and partnerships that support effective public involvement in our communities. Partnerships include individuals and a wide range of stakeholders from health, social care, local authority and third sector organisations.

#### **6.0 Northern Cancer Alliance framework for public involvement**

The Alliance framework for public involvement underpins all 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 North East and North Cumbria.



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

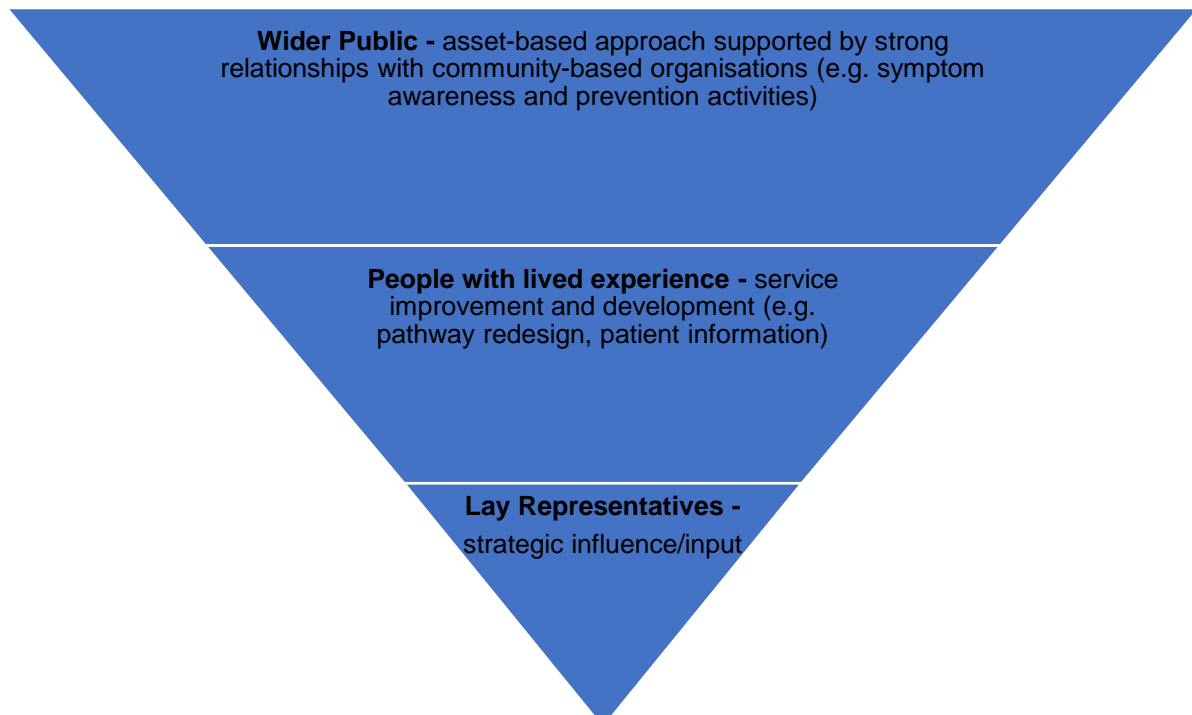
## 7.0 Northern Cancer Alliance approach to public involvement

The Alliance is committed to using language that is easy to understand. It recognises that different terms are often used to describe partnership working between health professionals and patients, carers and the wider public. The Alliance has adopted “public involvement” to describe all our 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 access to timely and appropriate information.
- Listening to experiences and understanding views and ideas.
- Working in partnership to develop and improve cancer outcomes and patient experience.

The primary aim of the Northern Cancer Alliance approach is to ensure “*the right people are involved at the right time*”. To achieve this 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 cancer outcomes and patient experience.

A Lay Representative may not have experienced cancer personally but in addition to a broad understanding of the NHS landscape they can also champion the views and experiences of communities. They hold the Alliance to account on how they involve the public and address inequalities across all areas of the annual work plan. They act as a “critical friend” to the Alliance.

#### Context for involving Lay Representatives can include:

- Membership of Alliance strategic groups and committees bringing the perspective of community need and achieving a positive patient experience.
- Membership of project steering groups, pathway boards and forums, holding the NCA to account for public involvement activities and for the focus on health inequalities.

## **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 can include:**

- Providing insight and understanding based on recent experience to shape and develop tumour specific clinical pathways, wider cancer services and research projects.
- Development of local policy, patient information, symptom awareness campaigns and patient experience stories.
- Membership of patient forums and advisory panels e.g. the Northern Cancer Alliance Public Involvement Accountability Forum

## **7.3 Members of the public:**

This includes all members of the public including people with lived experience and those who have cared for someone with cancer.

### **Context for involving members of the public:**






- Development of symptom awareness, prevention, and screening health campaigns.
- Provide insight and understanding of the likelihood of adopting healthy lifestyle choices, attending for cancer screening appointments and presenting early with suspected signs and symptoms of cancer.
- Understand what matters most to people receiving NHS treatment and care.

## **7.4 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. the availability of people to action the involvement activities and the timeframe.
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:

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

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 work plan. This is overseen by the Northern Cancer Alliance Public Involvement Accountability Forum. The forum sits within the Northern Cancer Alliance governance structure, reports direct to the Alliance Board, and sits alongside the clinical leadership group and the commissioning forum. The overall aim of this forum is to hold the Alliance board to account in improving patient outcomes and experience of care. This is also done by ensuring that the Northern Cancer Alliance Framework for Public Involvement is used and integrated into the core business of the Alliance.

The key objectives of the forum are as follows:

- Review and scrutinise the NCA work plan, ensuring it is fit for purpose.
- Provide assurance to the board that the commitment to appropriate and effective public involvement is evidenced in all aspects of Alliance core business.
- Provide a forum for the sharing of information and examples of best practice.
- Develop the group as a partnership, agreeing the responsibilities of each member in relation to each other.
- Hold the Alliance to account for its performance within the National Cancer Patient Experience and Quality of Life patient surveys
- When required, form working groups of members and the wider population to support Northern Cancer Alliance to achieve its work plan objectives.

## 9.0 Measurement and reporting:

The Alliance produces an annual report for the Public Involvement Accountability Forum. This report details involvement activities across the Alliance work plan over the previous 12 months. It evidences how the Alliance has achieved the Northern Cancer Alliance Framework for Public Involvement quality standards. These standards are quantified by a number of key performance indicators detailed in the table below:

	Quality Standard	Key Performance Indicator
1.	Effective use of existing data sources to improve patient experience and inform approaches to public involvement.	<p>Demonstrate an understanding of local performance within the National Cancer Patient Experience and Quality of Life patient surveys. Evidencing steps taken to improve the patient experience and quality of life through partnership working with people with lived experience and other key partners.</p> <p>Evidence how other patient and public insight data sources have been utilised to inform service improvement and reduce health inequalities across the Alliance work plan.</p>
2.	<p>Collaborative relationships with the public and community partners that value everyone's contribution, support mutual respect and productive relationships.</p> <p>Approaches to involvement that focus on reducing health inequalities.</p>	Evidence of collaborative relationships and approaches that aim to improve cancer outcomes, patient experience, and reduce health inequalities whilst involving the right people at the right time.
3.	Communication activities that are accessible and inclusive.	<p>Evidence of varied communication activities that are accessible, inclusive, and appropriate to the target audience.</p> <p>Evidence of where public involvement has supported the development of accessible information.</p>
4.	Strategic activities and a governance structure that supports collaborative relationships with partners and the public.	<p>Evidence of how the Northern Cancer Alliance Lay Representatives are involved in strategic groups and forums.</p> <p>Evidence of Alliance strategic groups and forums that focus on public involvement, patient experience and reducing health inequalities.</p>



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	Operational systems and activities that facilitate effective public involvement at all levels of the Alliance work plan.	<p>Evidence how the Northern Cancer Alliance Public Involvement Accountability Forum is provided with the opportunity to influence the development of the Alliance work plan.</p> <p>Evidence how the forum is provided with opportunities to scrutinise public involvement activities across the Alliance work plan.</p> <p>Evidence of operational activities within the NCA team that support effective public involvement.</p>
5.	Promote learning opportunities that develop knowledge and skills appropriate to effective involvement activities, a positive patient experience and reducing health inequalities.	Evidence how the Alliance has provided appropriate learning and development opportunities and shared best practice.
6.	Demonstrate the benefits that public involvement brings to patient experience and the reduction of health inequalities.	Production of the annual Northern Cancer Alliance Public Involvement Report detailing public involvement activities and impact.