

OFFICIAL



# Northern Cancer Alliance Public Involvement Report

**April 2021 to March 2022**

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## **1.0 Introduction:**

The Northern Cancer Alliance is 1 of 21 Cancer Alliances in England. We are a multi-agency collaborative that brings together NHS providers, commissioners, third sector organisations, local authorities, and members of the public who work together to improve cancer outcomes, patient experience and quality of life 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. The involvement of the public in the development and improvement of NHS cancer services is a fundamental element of improving the standard of care for all, improving patient experience and reducing health inequalities.

We view the public as equal partners and are committed to involving people at all levels of our work plan and to demonstrating the value that public involvement can bring. Central to our approach is the [Northern Cancer Alliance Framework for Public Involvement](#). This was co-produced with members of the public and health professionals and defines the best practice evaluation measures.

## **2.0 Purpose and scope:**

This report forms part of an assurance process that is undertaken by the Northern Cancer Alliance Public Involvement Accountability Forum. It covers the period from 01/04/2021 to 31/03/2022. It includes details of the involvement activities that the Cancer Alliance has been directly responsible for, and examples of how we support and enable additional public involvement throughout the North East and North Cumbria.

## **3.0 Context for 2021 to 2022:**

The Covid-19 pandemic continued to have a huge impact on the NHS. Except for some face to face activities across the summer period of 2021 (when restriction levels at the time allowed), most Alliance public involvement activities continued to adopt a virtual approach. Our primary focus during the last year has been to overcome the barriers to public involvement that the pandemic had created, and as much as possible, return to “usual business” for public involvement across the Alliance work plan.

We have also continued to develop new partnerships with community organisations, community leaders and patient and carer groups. These partnerships have all been enablers to involving the right people at the right time in the work of the Cancer Alliance over the last year.

Our social media over the last year has expanded from a Twitter account to include a new Facebook account. The aim of this account is to support the adoption of healthy lifestyle behaviours, early presentation/diagnosis, encourage uptake of screening invitations and to promote participation in national patient surveys and research including the NHS Galleri trail.

#### **4.0 Northern Cancer Alliance Public Involvement Accountability Forum:**

The overall aim of this forum is to assist the Alliance to improve patient outcomes both in terms of survival and experience of care. This is 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 Alliance 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.
- When required, form working groups to support Northern Cancer Alliance to achieve its work plan objectives.

Meetings occur every 8 weeks with a good level of attendance. Membership has grown in the last year to include the Chair of Northern Cancer Voices, a new regional cancer patient collaborative; and members of Cancern (a collaborative of Voluntary, Community, Faith-based or Social Enterprise organisations)

Forum members have had opportunities to learn about key aspects of the Alliance work plan with presentations from Alliance team members and key stakeholders from across the region. The forum also reviewed the second annual [Northern Cancer Alliance Annual Involvement Report](#). The report was co-produced with the Lay Representatives and shared with the forum membership for their endorsement. The endorsement was subsequently reported to the board on 21/06/21.

Other activities for the forum during the year have included:

1. Coproducing a public information animation describing the Northern Cancer Alliance and providing an overview of its annual work plan.
2. Contributing to the development of the Northern Radiotherapy Network website and patient information films.
3. Contributing to the development of a research project to understand public preferences for multi-cancer early detection tests (MCED).
4. Providing feedback on patient information publications e.g. “My Guide to Prostate Supported Self-Management”.
5. Overseeing public involvement activities within the Non-Surgical Oncology Service Review process.

## **5.0 Northern Cancer Alliance Lay Representatives:**

Lay Representatives are part of the Alliance core team and act as critical friends to the Cancer Alliance. They have a broad knowledge and understanding of the NHS landscape and governance related issues, as well as an understanding of health inequalities and their interaction with the cancer experience.

There are currently 4 Alliance Lay Representatives who sit on all strategic groups within the Alliance governance structure, these include Alliance Board, Clinical Leadership Group, Commissioning Forum, Finance Group, Tumour Pathway Boards, and they also chair the Public Involvement Accountability Forum. Over the last year the Lay Representatives have also contributed to the breast and non-surgical oncology service reviews. This has involved being on the service review steering groups and coproducing the public engagement strategy document and implementation for the non-surgical oncology review.

The Lay Representatives have also worked with other Cancer Alliances from across the country including Greater Manchester Cancer Alliance, local clinical networks and the North East and Yorkshire Genomic Medicines Alliance to advise and guide them on the development of their own public involvement strategies and approaches.

2021/22 saw the recruitment of a new Lay Representative. Nahida Aktar is a health and wellbeing lead at the Sunderland Bangladesh International Centre. Nahida brings a wealth of understanding and insight into the health experiences of ethnically diverse communities. Nahida was involved in last year's NHS England/Improvement "Cancer Improvement Collaborative". This involved supporting North Cumbria and Northumbria Foundation NHS Trusts to improve the experience of patients from ethnically diverse communities.

### **Reflections from the Northern Cancer Alliance Lay Representatives:**

*"I've been part of the Alliance as a lay representative for over 5 years and looking back it's amazing how public involvement and the lay representative role has developed. From co-designing our approach and the framework in the first 2 years to making it happen and embedding involvement in all the work of the Alliance. Alongside this it's very pleasing that ideas and contributions to programmes, boards and other meetings are valued and integrated into the improvement of care.*

*To pick out two of many examples during the last year; I've made a difference in several ways to the design of self-management treatment follow up; and to the development of the national quality marker checklist for the Faster Diagnosis System. It's a total pleasure to be part of an Alliance where involvement really is at the heart of everything that we do.*

Annie Dolphin – Northern Cancer Alliance Lay Representative

*"The lay rep role is often described as an 'outsider inside' I would say that for me it is better described as an 'insider inside'. I feel we are very much embedded into the core team and feel both valued and valuable, listened to and involved with pretty much everything at all levels, I am proud to say nothing passes us by. You could say you can't see the join".*

Karen Gannon – Northern Cancer Alliance Lay Representative

*“I became a Cancer Alliance lay representative because I’m passionate about Health and Wellbeing of the local BAME community, and I would like to understand and increase my knowledge around Cancer.*

*As a lay rep, I can contribute to increase awareness, improve access, and influence service delivery as I understand the needs of individuals and the wider community.”*

Nahida Atkar – Northern Cancer Alliance Lay Representative

### **Reflections from members of the Cancer Alliance Team:**

*“I have really enjoyed working alongside the lay representatives since joining the Northern Cancer Alliance last October. They are so passionate in ensuring the patient is at the heart of everything we do and are an integral part of the wider team. They provide challenge that encourages and supports our thinking, and often provide a different perspective that is always welcomed”.*

Vicky Wester, Northern Cancer Alliance Delivery Lead – Personalised Care

*“Over the last year our Lay Representatives have continued to be a vital element of all the work we do within the Cancer Alliance. They are central to our overall approach to public involvement; bringing the perspective of communities and patient experience, as well as holding us to account in our efforts to reduce health inequalities. They are a critical friend to the Alliance and an essential member of all our decision-making groups and forums”.*

Alison Featherstone – Northern Cancer Alliance Director

## **6.0 The use of data to improve patient experience and quality of life:**

One of the key principles of the Alliance Framework for Public Involvement is in utilising existing sources of data to improve the patient experience and quality of life. We are committed to avoiding unnecessary questions about people’s experiences and views. The first step to involving people in the development of cancer services is to understand what data is currently available before embarking on a new process of public involvement. Examples of when we have utilised existing data sources include:

**Improving the uptake of the Quality of Life patient survey** – the data detailing the local response rates for the Quality of Life patient survey has been used to inform the design of a project that will aim to increase survey response rates across the region. Members of the public have coproduced a patient information leaflet that aims to encourage participation in patient surveys. This leaflet is being piloted and evaluated within a local trust.

**Understanding the experience of cancer patients from ethnically diverse communities** – the key findings from [The experiences of cancer patients from ethnic minority backgrounds in England: a qualitative study 2020](#) have been used to initiate a project to improve the cancer outcomes, patient experience and quality of life for people living in ethnically diverse communities. It will run for 2 years, is led by the [Sunderland Bangladesh International Centre](#) and is funded by Macmillan

**The recovery of urgent cancer referral rates** – throughout the pandemic the National Cancer Programme Team have produced a monthly COVID-19 Equity Data Pack. These packs include the latest and pre-COVID activity data on the number of urgent Two-Week Wait referrals (seen by a specialist), broken down by patient factors: deprivation, age, sex, and ethnicity. This data has been used to understand the recovery of urgent referral rates for patient groups and demographics. Target symptom awareness campaigns, within identified communities and geographic areas with the aim of reducing health inequalities, have been shared and broadcasted as a result. These campaigns were coproduced with members of the community and people with lived experience.

### **7.0 Partnership working and reducing health inequalities:**

Partnership working is an essential element of effective public involvement. We work in partnership with a range of community organisations and groups. All of these have a wealth of knowledge and expertise relating to the needs of their local community. They are aware of their community assets and leaders and understand what will work when aiming to improve patient experience and reduce health inequalities.

Two case studies detailing some of the partnership work that we have been involved in over the last year are presented below:

**Partnership working with NUR Fitness:** NUR Fitness is a community organisation based in Middlesbrough. It is committed to improving the health and wellbeing of women and children from ethnically diverse communities in the local area. We are working with NUR Fitness to identify ways to improve cancer related outcomes and the patient experience of people living in Middlesbrough and further afield. Read more [here](#).

**Busting cancer myths in the community:** We support Cancer Community Awareness Workers located across our region, with the aim of reducing health inequalities and improving the rates of early diagnosis. Cancer Community Awareness Workers target communities where cancer is either more prevalent or outcomes from cancer are poorer. They raise awareness of the causes of cancer, it's signs and symptoms, and encourage people to take up their invitations to the cancer screening programmes. Read more [here](#).

### **8.0 Development of involvement knowledge and skills:**

We believe that public involvement is everyone's business and not just the responsibility of an individual or team. One of the principles within the Northern Cancer Alliance Framework for Public Involvement is a commitment to build capability and capacity across the cancer system for effective involvement activities. We aim to achieve this by providing opportunities for gaining appropriate knowledge and skills through training programmes, learning events, and sharing best practice. Over the last 12 months this has involved the following activities:

1. Promotion of national and local public involvement events with key stakeholders e.g. 2021 NHS England Engagement Practitioner Network annual event.
2. Presentations at national and local conferences, sharing the Northern Cancer Alliance approach to public involvement and reducing health inequalities e.g. the 2021 British Association of Urological Nurses conference and the Alliance Rapid Diagnosis Navigator learning event.
3. Providing advice, guidance and support to key stakeholders embarking on public involvement activities and/or developing involvement plans and strategies. This has included working with Northern Radiotherapy Network, North East and Yorkshire Genomic Medicines Alliance, Greater Manchester Cancer Alliance, and a University of Newcastle research team.
4. Developing the knowledge and skills of individuals e.g. the Alliance Delivery Manager for Communications and Engagement has recently received training to produce digital patient experience stories. This training will allow us to work in partnership with patients to share their experiences in this valuable format.

### **9.0 Plans for the year ahead:**

Over the coming year we will continue to develop our approach to involving the public. It will continue to offer a range of options that will include both virtual and face to face approaches, with the aim of providing a greater level of access to all members of the public. Involvement activities will focus on the following areas within the Alliance work plan, including:

1. Increased early diagnosis rates with a focus on areas of high deprivation and other marginalised groups.
2. Implementation of the Faster Diagnosis Programme Quality Marker Checklist for patient experience.
3. Increasing uptake of the Quality of Life patient survey in populations with lower response rates.
4. Increasing uptake of cancer screening programmes and compliance with FIT symptomatic testing.
5. Patient experience within the non-surgical oncology and breast service reviews.
6. Utilising patient insight data sources such as the National Cancer Patient Experience and Quality of Life survey to improve patient experience and personalised care for all sections of the community.
7. Review and update the Alliance strategy for public involvement.