

OFFICIAL



# Northern Cancer Alliance Public Involvement Report

**April 2022 to March 2023**

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## 1.0 Introduction

I am delighted to introduce this 4th Northern Cancer Alliance Public Involvement Report covering the period April 2022 to March 2023.

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.

The Northern Cancer Alliance are keen to recognise the value that involving people in health services can bring to improve services; 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. 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 that we embed in our work.

I am sure you will agree that this report clearly demonstrates the value that public involvement can bring. On behalf of all members of the Alliance I would like to thank all of the people who have given us their time, their energy and their support by being involved in our work and by acting as our advocate and critical friend. I am delighted to see that we have grown our membership and seen two relatively new partnerships in [Cancern](#) and [Northern Cancer Voices](#) continue to grow and flourish.

I would particularly like to thank Annie and Karen for collating this report on behalf of members and for being a very important piece of the Alliance makeup.

Alison Featherstone  
Managing Director  
Northern Cancer Alliance

## 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 (PIAF). The report covers the period from 01/04/2022 to 31/03/2023. It includes some of the involvement activities that the Cancer Alliance has been directly responsible for, and examples of how we support and enable public involvement throughout the North East and North Cumbria.

## 3.0 Context for 2022 to 2023

The impact of the pandemic caused an ongoing challenge to meet recovery of services to pre-pandemic levels throughout the year. However, some of the changes made in the height of the pandemic have been positive for public involvement in the Alliance. We have continued with PIAF Microsoft Teams meetings and as a result we have seen higher levels of attendance from NHS professionals, partners, and patient representatives across our geography. This has resulted in a much wider partner representation and a lot of valuable input and feedback from VCSE organisation members in addition to PIAF individual members.

This is Business as Usual for us now and our focus on developing partnerships with community organisations, community leaders and patient and carer groups continued in the year. These partnerships continue to enable involvement of the right people at the right time in the work. Progress with ongoing projects and programmes started in 2021/2 made for a busy first half of the year. As well as this ongoing project work, we have focused particularly on Personalised Care, and Health Inequalities.

Our Communications and Engagement Delivery Manager post became vacant in September 2022 and due to recruitment changes has had to be covered by the core NCA team, the NCA Managing Director, and supported by Lay Representatives.

## 4.0 What Involvement in the Northern Cancer Alliance Looks Like

The Alliance utilises several involvement methods which are dependent on a number of factors that include:

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

There are different levels of involvement:

- Wider public - asset-based approach supported by strong relationships with community-based organisations e.g., symptom awareness and prevention activities.

- People with lived experience - service improvement and development e.g., pathway redesign, patient information
- Lay Representatives - strategic influence/input e.g., Alliance Board.

More information is in our 2022 Involvement Strategy [here](#)

## 4.1 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 outcomes 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:

- To review and scrutinise the NCA work plan, ensuring it is fit for purpose.
- To provide assurance to the Alliance board that the commitment to appropriate and effective public involvement is evidenced in all aspects of Alliance core business.
- To provide input and feedback to Alliance and partner projects and programmes.
- To provide a forum for the sharing of information and examples of best practice.

There are online meetings every 8 weeks with a consistent and high level of attendance. Membership has continued to grow in the last year with 4 new patient group “place” chairs joining us. We have also welcomed a number of colleagues and stakeholders who have provided information, presented their work, updated progress on specific projects; and requested help and feedback from members.

Forum members have learned about key aspects of the Alliance work plan along with presentations from Alliance team members and key stakeholders from across the region.

Other activities for the forum during the year have included:

1. Co-producing public information animations describing the work of the NCA, and the personalised care workstream. View an example [here](#).
2. Ongoing contribution to the development of the [Northern Radiotherapy Network](#) website and patient information films.
3. Contributing to the NEY Genomic Medicine Service Alliance patient Dihydropyridine Dehydrogenase (DPYD) pathway and the patient information document.
4. Giving feedback on the NCA Quality of Life sleep questionnaire for patients.
5. Input to the digital Passport to my Health and Wellbeing developed by Middlesbrough and Stockton Mind
6. Easy read co-production of information – e.g., [what is a rapid diagnostic service](#) and the [role of cancer care coordinators](#).

7. Support for online campaigns and for the Bus-ting Cancer Tour event in Sunderland such as patient stories.

## 4.2 The NCA Lay Representative Role

Lay Representatives are part of the Alliance core team and act as critical friends to the team and the wider 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.

Lay Representatives sit on all strategic groups within the Alliance governance structure, these include Alliance Board, Clinical Leadership Group, Commissioning Forum, Finance Group, some Tumour Pathway Boards, and they also chair the Public Involvement Accountability Forum. Lay Representatives are also regularly involved in other discussions to provide advice prior to wider consultation.

### Reflections from Aaron, Head of Programmes NCA

As a relatively new member of the alliance team, I would say that “Involvement” is a crucial element of the Alliance work; it cuts across all our programmes of work and is something that is considered early in our planning cycle.

Our Lay reps are a key part of the Alliance team, and we involve them in strategic groups and project groups. For me, one example has been the oversight group for the Targeted Lung Health Check project. Lay reps contribute the public perspective, provide challenge and support and keep the group grounded in patient experience of care.

Our Public Involvement and Accountability Forum (PIAF) give us the ability to share our work programme and seek the views of our public when considering how we develop our projects. Most recently we have co-developed a Plan on the Page with our Lay reps, sharing this with PIAF members to review content, provide comments and challenge us to use plain English and move away from NHS jargon.

## 5.0 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.

The Patient Experience and Quality of Life forum was formed in July 2022 to oversee, and support improvement interventions based on data from the National Cancer Experience and Quality of Life patient surveys. The members: Trust Cancer Nurse Leads, VCSE representation and NCA Lay Representatives developed implementation plans for 2 projects based on the survey data; improving psychosocial support and addressing sleep issues.

Patient experience data has also prompted a focus on Primary Care Cancer Care reviews to ensure that patients with a cancer diagnosis have the opportunity to discuss their concerns with a health professional on a regular basis.

## 6.0 Partnership Working and Reducing Health Inequalities

Partnership working is an essential element of effective public involvement. The Alliance have supported the development of two networks; Cancern (North) and Northern Cancer Voices. Cancern is a new network of VCSE organisations dedicated to improving quality-of-life outcomes and providing personalised care and support for anyone affected by cancer in the North East and North Cumbria. Northern Cancer Voices aims to be the voice of cancer patients across our geography. We also work in partnership with a range of other community organisations and groups with a wealth of knowledge and expertise relating to the needs of their local community. They are aware of community leaders, community assets, and understand what will work to improve local patient experience and reduce health inequalities.

These case studies demonstrate some of the partnership work that we have been involved in over the past year:

### **Promoting early diagnosis and screening in the workplace**

During 2022/23 we reached out to private businesses through [Better Health at Work](#) with the aim of developing partnerships that would support raising awareness of the potential signs and symptoms of cancer, and the importance of taking up cancer screening invitations. This approach resulted in a number of businesses from across the North East and North Cumbria e.g. Stagecoach North East and Nissan UK, actively promoting the importance of early diagnosis and raising awareness of cancer screening programmes through communication activities and events. These partnerships were also supported by the local [Cancer Community Awareness Workers](#) who delivered a range of face to face activities within the workplace.

### **Cancer Community Awareness Worker Programme**

This programme was developed by the Alliance in partnership with community and statutory authorities. The Cancer Community Awareness workers work in some of our most deprived and vulnerable communities. Using available data we are able to see how factors such as deprivation, digital poverty, age, sex, and ethnicity have increased health inequalities across pockets of our geography. This data has highlighted how referral rates in specific places and for certain patient groups, have not recovered as well as we would have liked. Cancer community awareness workers work with individuals and groups in communities where cancer outcomes are poorer and prevalence of cancer is higher, leading to poor patient experience. They have significantly contributed to the cancer prevention agenda with their innovative and focussed approach, e.g., [fancy dress](#) features high on their agenda!

### **Head and Neck Cancers**

Following the pandemic effort was focused on pathways that were not recovering referral rates back to pre-Covid levels. Head and Neck was identified as needing some targeted work. The Head and Neck campaign raises awareness of symptoms focused on 50—75-year-old men who were smokers and drinkers. Based on

behavioural science and “nudge” theories our Cancer Community Awareness Workers extensively tested the materials in locations such as betting shops, social clubs and community centres. Read more [here](#).

### **NUR Fitness Cancer Research UK (CRUK) Translated ‘Talk Cancer’ Sessions**

The Alliance has continued to develop its partnership with NUR Fitness in Middlesbrough to improve cancer outcomes and patient experience of people from ethnically diverse communities. This has involved working with CRUK to deliver translated “Talk Cancer” sessions to women from the local community with the aim of raising awareness of the early signs and symptoms of cancer, and the importance of cancer screening. Read more about this important project [here](#).

### **Learning Disability and Be Cancer Aware**

“Be Cancer Aware” is a co-production project that works with learning disability experts by experience from six self-advocacy organisations across the North East and North Cumbria.

Together they deliver education and training to the learning disability community and support campaigns raising awareness of cancer. The aim is to ensure that people with a learning disability can make informed decisions about their health and wellbeing and can talk about and understand cancer.

The project is managed by the North East and Cumbria Learning Disability Network and supported by the Northern Cancer Alliance. In September 2022, for this amazing work on raising cancer awareness, the learning disability community were proud to be recognised by the Patient Engagement Network National Awards. They were runners up in the Cancer Experience of Care category and Winners in the Engaging and Championing the Public category. Read more [here](#).

There is also a short video which introduces the Be Cancer Aware people and some of the team. View the video [here](#).

## **7.0 Development of Involvement Knowledge and Skills**

The Alliance recognises that to effectively engage with and involve all patients, their families, and the wider community our cancer workforce should be supported to continually develop their knowledge, skills and expertise.

### **Promoting health equity**

In 2022/23 the Alliance commissioned a number of culturally focussed training sessions for members of the cancer workforce. The aim of these sessions was to support professionals to effectively engage with patients and their families from ethnically marginalised communities.

3 online training sessions were provided by [English Unlocked](#) and [Haref](#) covering the following topics:

- How to communicate with patients who have English as an Additional Language (English Unlocked).
- How to work effectively with interpreters (English Unlocked)
- Cultural competency (Haref).



Sessions were well attended and received positive feedback.

*“Will any more of these sessions be running? It was very useful and lots of my colleagues would benefit...”*

### **Improving mental wellbeing in cancer project**

The first research phase of this project, to review the psychological support available across our area, took place throughout the year. The findings from the research were presented at a launch event on 2 February 2023 with wide attendance, including Cancer Care Coordinators, Cancer Nurse Specialists, Allied Health Professionals (AHPs), Primary Care staff, patients and PIAF members.

This event was very successful in raising understanding of what matters to patients and carers. Using patient and carer videos provided powerful messages about what could be done to improve patient experience and quality of life. View a patient video [here](#).

### **National Personalised Care Leadership training**

This training was held on teams and included 2 VCSE leads, NCA Lay Representative, NCA GP lead, and the NCA project leads. The training ran for several weeks and was aimed at developing the knowledge and skills of individuals involved in personalised care. It led to a focus on improving Primary Care Cancer Reviews that is ongoing.

## **8.0 Plans for the Year Ahead**

- Our Communications and Engagement lead post has been vacant since September 2022 and whilst this continues to be covered by the core NCA team, and the NCA Managing Director, supported by Lay Representatives, we are concerned at this loss of infrastructure. The role is crucial in facilitating the work of PIAF and the gap means potential important links and opportunities for involvement could be missed.
- We will review our involvement strategy and processes in conjunction with our ICB and Trusts to maintain people and community engagement. These structures enable co-production throughout all work programmes within the Alliance.
- We will continue to support work across the system to develop quality improvement action plans to improve experience of care. We will focus on collection and utilisation of insight and feedback to develop co-produced plans with people with relevant lived experience.
- We will continue to work with PIAF members and our wider membership to ensure the public voice is embedded in all partners' work as well as the Alliance workplan.
- We'll consider how data can be used to measure and contribute to the demonstration of involvement success. There are no specific national data measures for this and PIAF members will look to explore how patient experience data can enhance work planning in line with the NCA strategy. However, we recognise we will need some infrastructure to support this work.

- Working with Trust lead cancer nurses and cancer locality groups we will develop plans in response to both quantitative, qualitative and narrative feedback. We will use Cancer Patient Experience Surveys, Friends and Family Test, Patient Reported Outcome Measures, complaints, feedback via Northern Cancer Voices and local reviews and insight across the whole cancer pathway including primary, secondary and tertiary care.