

OFFICIAL



# Northern Cancer Alliance Public Involvement Report

**April 2020 to March 2021**

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## **1.0 Introduction:**

The Northern Cancer Alliance is one of 21 Cancer Alliances in England. It is a multi-agency collaborative that brings together providers, commissioners and third sector organisations who work together to improve cancer outcomes across the North East and North Cumbria. The national policy driver for Cancer Alliances is the NHS Long Term Plan (2019) this reinforces the importance of involving people in the development and improvement of NHS services.

The Northern Cancer Alliance views the public as equal partners. It is committed to involving people at all levels of its work plan and demonstrating the value that public involvement can bring. Informing the Alliance approach to involving the public is the [Northern Cancer Alliance Framework for Public Involvement](#). This was co-produced with members of the public and provides the principles for good involvement.

## **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 provides details of the public involvement undertaken by the Northern Cancer Alliance from 01/04/2020 to 31/03/2021. This includes details of the activities the Cancer Alliance has been directly responsible for, and examples of how the Cancer Alliance supports and enables involvement activities throughout the region.

## **3.0 Context for 2020 to 2021:**

The Covid-19 pandemic has had a huge impact on the NHS, its effects have been felt in every aspect of the services the NHS provides.

The first national lockdown removed the opportunity for face-to-face public involvement and this resulted in all planned activities being postponed and ultimately cancelled.

The initial impact on Cancer Alliance involvement activities included a pause to the Public Involvement Accountability Forum meetings (resumed in September 2020) and a curtailment to community-based activities. The pandemic did not however stop all public involvement. Lay Representatives continued to work with the Cancer Alliance, attending all strategic groups and forums via Microsoft Teams.

Although not able to connect with people on a face to face basis, the Alliance has worked to identify alternative ways of working throughout the pandemic. This has included developing a remote approach to involving people with lived experience and members of the wider community in the development and delivery of communication activities to support the recovery of NHS cancer services.

Whilst the level of active public involvement has been reduced this year, it has remained the focus of the Northern Cancer Alliance. Utilising all options available to them, they have continued to involve people within the constrictions of a pandemic.

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

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

In spite of the pandemic when meetings were paused for the first half of 20/21, the forum has continued to develop and establish its function within the Northern Cancer Alliance governance structure.

During this period involvement activities and communications continued with the membership, including the publication of the first annual [Northern Cancer Alliance Public Involvement Report](#). Co-produced with the Lay Representatives, it was shared with the forum membership for their endorsement and this was subsequently reported to the Alliance board in June 2020.

Forum meetings resumed during the second half of 20/21 with a strong membership, bringing together a wide range of perspectives based on lived experience and health inequalities.

Activities for the forum across these meetings have included:

1. Updating the [Northern Cancer Alliance Strategy for Public Involvement](#) to include a greater emphasis on the reduction of health inequalities.
2. Collecting reports to form a repository of evidence detailing the patient experience during the pandemic.
3. Overseeing the development of the local “Help Us Help You” campaign.
4. Playing an integral role in the oncology review public engagement process, scrutinising and overseeing engagement activities, as well as forming a smaller working group to contribute to the public engagement process.
5. Developing partnerships with members of the National Cancer Programme Patient and Public Voice Forum and the Cancer VCSE Support Network.

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

Lay Representatives 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. Lay Representatives sit on strategic groups within the Alliance governance structure including; Alliance Board, Clinical Leadership, Commissioning Forum, Finance Group, Tumour Pathway Boards and they also chair the Public Involvement Accountability Forum.

Throughout the pandemic the Lay Representatives have continued to be involved in all levels of the Cancer Alliance work plan including the Alliance response to the pandemic and recovery activities. Their contributions have included:

- Attending all Alliance strategic meetings.
- Co-producing the first Alliance annual public involvement report.
- Identifying new ways of involving people in the work of the Cancer Alliance during the pandemic.
- Reviewing and updating the Alliance public involvement and communication strategies to include an increased focus on health inequalities.

Reflections from members of the Cancer Alliance Senior Team:

*“Lay representatives are integral part of the NCAs culture and the way we work. They assist in all aspects of business to provide a patient focused voice and critical but supportive challenge. They assist in commissioning discussions with our CCG colleagues, support pathway boards to implement effective guidelines, assist policy and strategies to be developed and are helping to shape the patient experience within Rapid Diagnostic pathways. Having Lay reps within our structures provides a practical safety net and confidence that as an NCA we are placing patient concerns at the centre of transformation within cancer services”.* Andrew Copland, Northern Cancer Alliance, Programme Manager.

*“Being able to contact the public involvement forum and lay reps to seek opinion and advice has supported all of my work and helped us all to have confidence that the work we do has considered and taken the opportunity to include public involvement”.* Katie Elliot – Northern cancer Alliance Clinical Director – Primary Care

*The Lay Representatives play a valuable role in bringing a different perspective to discussions and as well as ensuring public involvement is considered in all aspects of our work. They ask considered questions that can enhance the quality of our discussions in all the meetings they attend and, in the projects, they are involved in.* Alison Featherstone – Northern Cancer Alliance – Director

## **6.0 The use of data to improve the cancer patient experience:**

One of the key principles of the Alliance Framework for Public Involvement is in utilising existing sources of patient experience data to inform the work of the Cancer Alliance. The Alliance is committed to not overburdening people with questions about their experiences and views. The first step to involving people in the development of

cancer services should always be to understand what has already been shared, before embarking on fresh data collection.

This approach to involvement has been adopted by the current non-surgical oncology service review. As part of the public engagement process for this piece of work, the Cancer Alliance has utilised existing patient experience data from local and national sources. Analysis of this data has provided an understanding of what matters most to patients and their families. This was then used as a basis for focus group discussions which in turn allowed for a deeper understanding of the oncology patient experience themes through discussions with patient and public groups.

Please note the 2020 National Cancer Patient Experience Survey has been rolled out on a voluntary basis. Just over third of all trusts in England have participated. There will be no benchmarking across trusts or national reports. Data from participating trusts is expected later this year.

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

Partnership working is an essential element of effective public involvement. The Cancer Alliance routinely works in partnership with community and voluntary organisations. These organisations possess 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 reduce health inequalities.

Two case studies detailing some of the partnership work in which the Cancer Alliance has been involved in over the last year are presented below:

- **“Help Us Help You” urgent cancer referral recovery campaign**  
The pandemic saw a dramatic drop in the levels of urgent cancer referrals. A key area of focus for the recovery of NHS cancer services has been to achieve a return to pre pandemic levels of urgent referrals. A large part of this work has involved the development of the local “Help Us help You” public health campaign. This work has involved members of the community co-producing and delivering peer to peer messaging. Read more [here](#).
- **Information for the trans/non-binary community**  
Over the past year the Northern Cancer Alliance has worked in partnership with Healthworks Newcastle and “Be North” to co-produce a “Cancer Champion” training programme and cancer screening information leaflet for members of the trans/non-binary community. Read more [here](#).

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

The Northern Cancer Alliance believes 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”. The aim is to enable effective and meaningful public involvement activities. One of the ways the Alliance aims to achieve this is to provide opportunities for developing involvement knowledge and skills.

### **8.1 NHS England 10 Steps to Even Better Public Engagement**

This training session is aimed at NHS staff, who want to involve patients and the public in the development of NHS services. This session provides them with the opportunity to understand a 10-step approach to involvement based on best practice. The Northern Cancer Alliance has been a member of a working group led by NHS England who have developed this previously face-to-face session to an online version. This will now allow the Cancer Alliance to enable virtual training opportunities to health professionals from across the North East and North Cumbria.

### **8.2 Asset-based community development**

At the beginning of 2020 the Cancer Alliance provided funding for North Tyneside Cancer Locality Public Involvement Group to commission an [asset-based community development training programme](#). This is an approach to involvement that adopts a bottom-up way of working with communities, focussing on community strengths and assets rather than on deficits and problems. After one (of two) full day training session (pre pandemic), members of the group worked with the company involved to deliver the remainder of the training programme online. This meant that all of the original participants were able to complete the course. Attendees included members of the public, health care professionals, members of the voluntary sector and public health team members.

### **8.3 Cultural competency training – HAREF**

The Cancer Alliance has worked in partnership with [HAREF](#) Newcastle to provide the [BAME Cultural Competency](#) training sessions to frontline health professionals working across the North East and North Cumbria. This session aims to support participants to connect with and deliver effective services to people across majority and minority ethnic communities. It provides an opportunity to gain knowledge and understanding of local BAME communities, their cultural needs and effective approaches to engagement.

### **8.4 Northern Cancer Alliance Bite-sized Learning Event**

In December 2020 the Northern Cancer Alliance hosted a bite sized learning event as an alternative to the annual face to face event. It consisted of a number of live webinar sessions and was attended by members of the cancer workforce, the public and voluntary organisations. Two of the live webinars delivered during the event related to patient experience and involvement:

- [“Cancer Doesn’t Stop Because of Coronavirus”](#) detailed the physical and psychological impact of lockdown on people living with cancer.
- [MDT Shared Decision Making – The Emperor’s New Clothes](#) explored the challenges that clinicians can face when involving patients in complex team decisions and how best to overcome these challenges.

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

Although the pandemic has impacted on the ability of the Cancer Alliance to carry out a full range of public involvement activities over the last year, it has been able to maintain a level of consistent involvement activity throughout.

It is hoped, that as the level of restrictions continue to reduce, the opportunities for involving people will widen. The Alliance welcomes the opportunity to engage with people on a face-to-face basis again, as there are times when this is, and should be, the preferred option. This is essential to ensure those with limited control over their life choices and with little or no access to digital resource have the opportunity to be involved.

Over the coming year the Cancer Alliance will continue to develop its approach to involving the public. It will take the learning from the past year 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. Recovery of urgent cancer referrals to pre pandemic rates.
2. Implementation of Rapid Diagnostic Centres.
3. Roll-out of personalised care agenda for cancer.
4. Roll-out of the Quality of Life patient survey.
5. Increased uptake of cancer screening programmes.
6. Non-surgical oncology and breast services review.