



# **Northern Cancer Alliance Public Involvement Report 2023-2024**

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**Date: September 2024**

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## 1 Introduction

We are delighted to introduce the 5th Northern Cancer Alliance Public Involvement Report covering the period April 2023 to March 2024.

The Northern Cancer Alliance recognises the value that involving people can bring to improving services; patient safety; patient experience; and health outcomes. The involvement of the public in the development and improvement of NHS cancer services is fundamental to our way of working.

This report clearly demonstrates the value that public involvement can bring to improving patient experience and outcomes.

On behalf of all members of the Alliance we would like to thank everybody who has been involved in our work, acting as our advocate and critical friend.

***Annie Dolphin and Karen Gannon***

***Lay Representatives  
Northern Cancer Alliance***

***Alison Featherstone***

***Managing Director  
Northern Cancer Alliance***



## 2 Purpose of the Report

Our commitment to understanding what matters most to people is set out in the [Northern Cancer Alliance Public Involvement Strategy](#) and is central to our ambition to embed meaningful involvement of the public into the development and improvement of NHS Cancer Services as a key part of improving patient experience and reducing health inequalities. This review highlights the progress we are making in delivering the strategy and forms part of the assurance processes overseen by our Public Involvement Accountability Forum (PIAF).

While involving people in developing health services is something we do regularly, we are continually exploring how we develop different ways to engage, embracing new innovations and approaches. However, we continue to listen to what matters most to people so we can better understand what is working well and what we need to change.

The report covers the period from 1 April 2023 to 31 March 2024. It describes our approach to Public Involvement and how we work with patient and public voice (PPV) partners and people with lived experience. 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 & North Cumbria to inform service change and improvements in patient experience working with members of the public, health professionals, the VCSE and organisations which commission and provide cancer services.

## 3 Who we are and what we do

The Northern Cancer Alliance (NCA) works to improve outcomes and experience for cancer patients in the North East and North Cumbria (NENC). Together with our partners, we want:

- Fewer people getting cancer through prevention, advice, and support.
- More people surviving cancer, diagnosed earlier, and given the best treatment.
- More people having a good experience of their treatment and care.
- More people supported to live as well as possible during and after treatment.

To help achieve this we bring together organisations, patients and others affected by cancer across the North East and North Cumbria to support the national ambition of improving cancer outcomes and services.

The focus of our work for 23/24 continued to be both nationally and locally driven. With a key focus on Awareness and Early Diagnosis; Cancer Diagnostics and Innovation; Treatment Pathways; and Personalised Care. Fundamental to our work is identifying the places and communities in the NENC that experience the greatest health inequalities and engaging with people in these communities to understand what matters to them and how we can work together to identify solutions. We know more cancers are diagnosed later in communities of inequality and there are also poorer outcomes from cancer in those communities.

The Alliance views patients and carers as equal partners in the design and delivery of their care and our vision for improvement and transformation puts the patient at the heart of the redesign of cancer services in every aspect of the cancer journey. We know that when patients feel involved in their care it can lead to improved patient outcomes and experience. Working

with the people who use services (and their families or carers) helps commissioners and providers to improve them and get it right first time. The primary aim of the NCA approach to involvement is to ensure the "right people are involved at the right time".

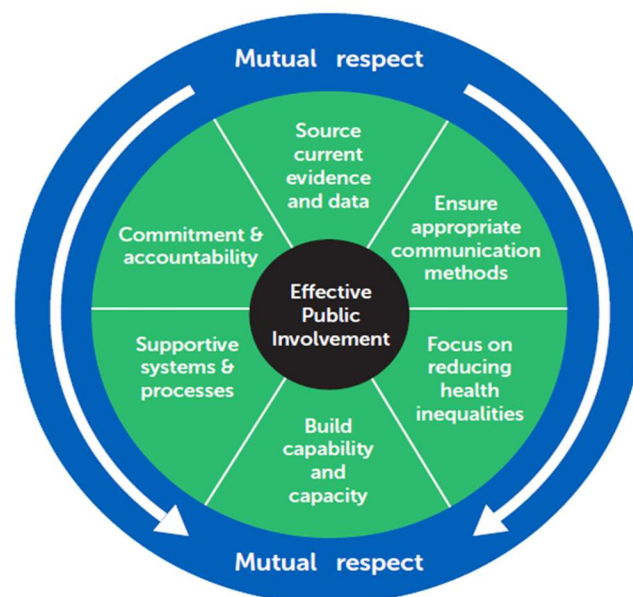
## 4 What do we mean by Public Involvement

'Public' describes everyone living in the Alliance area affected or potentially affected by cancer, whilst '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.

To support a partnership approach to working, the Northern Alliance Cancer produced a framework for public involvement. It was developed using a collaborative approach between members of the public and professionals from health, local authority and third sector organisations. The framework serves as a roadmap to building relationships that move from the 'them and us' to one where power is shared between all those involved in an environment of mutual respect. The Northern Cancer Alliance Framework for Public Involvement includes the values and principles for effective involvement that form the building blocks of our Public Involvement Strategy.

Figure 1: NCA Involvement Framework



Our Involvement Framework is underpinned by our Communication Strategy which sets out the way we will communicate and develop effective relationships with a wide range of diverse stakeholders. Who we communicate with and involve will vary depending on our goal. This

means involving a variety of people and organisations to enable us to achieve our ambitions as an Alliance.

## **5 Our Ways of Working**

### **5.1 Business as Usual**

The Cancer Alliance is committed to the involvement of patients and the public in all our work and has established good working practices whereby patient and public involvement within our programmes has become “business as usual”. We believe that it is the responsibility of everyone working with the Cancer Alliance, not just a named individual or team.

In our approach to ensuring the right people are involved at the right time we have divided the local population into 3 groups:

- Wider Public – provide insight and understanding into people and communities, help influence behaviour.
- People with Lived Experience – provide insight and understanding of patient experience to help shape pathways.
- Lay Representatives – champion the views and experiences of communities and provide strategic influence.

### **5.2 Our Partnerships**

We recognise building meaningful partnerships are central to good involvement. Our partners include individuals and stakeholders from health, social care, local authority and third sector organisations. Collaborative working with community leaders and organisations has enabled us to build trust and form mutually beneficial relationships - identifying community assets and developing alternative ways of working that create real opportunities for involvement even within the most vulnerable communities. Community members possess valuable knowledge, experiences, and perspectives that can inform and guide efforts to address cancer disparities. Actively partnering with communities helps ensure that interventions and strategies are culturally appropriate, relevant, and responsive to the unique needs of diverse populations. Two partnerships that have continued to grow during 23/24 are Cancern and Northern Cancer Voices building a network of support across the NENC.

### **5.3 Public Involvement Accountability Forum**

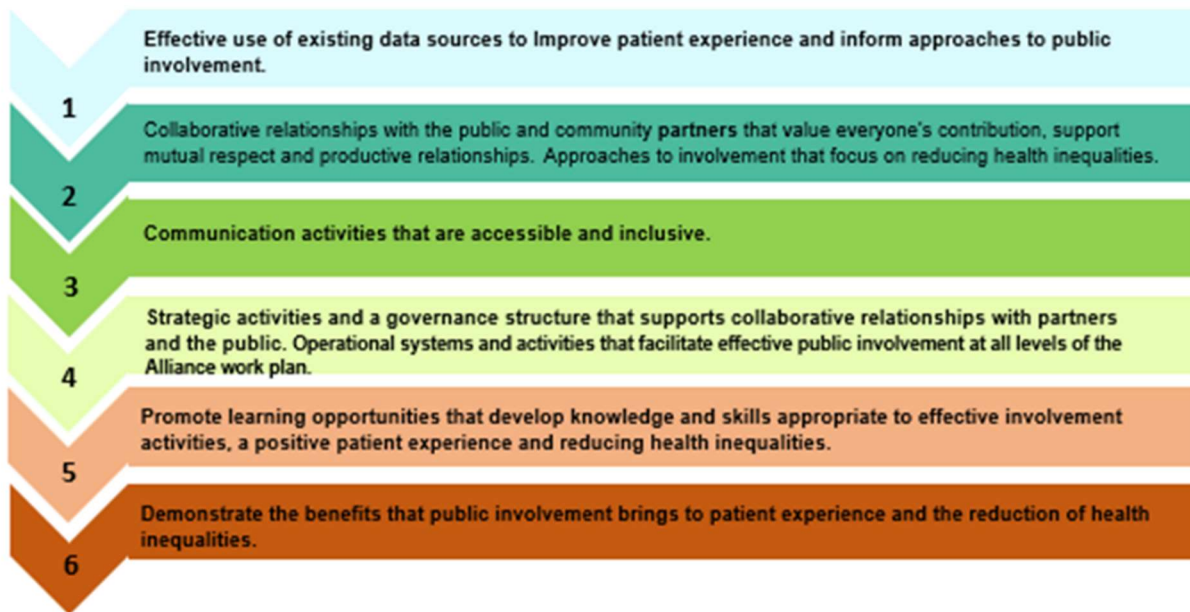
The NCA Public Involvement Accountability Forum (PIAF) forms part of our governance structures and is central to ensuring the Alliance's commitment to effective public involvement. The membership includes representation from the NCA, Healthwatch, VCSE organisations and Patient & Carer Groups (Appendix 1). It meets bimonthly providing opportunity to scrutinise the NCA workplan to ensure that the views of the public are considered and to support the development of collaborative relationships that facilitate effective and appropriate public involvement. PIAF provides a platform to learn, share and involve; building on each partners knowledge, assets and networks to support improvements in cancer outcomes, services and support.

## 6 The impact of involvement and engagement over the last year

### 6.1 Our Quality Standards

As part of the work co-producing its framework for public involvement the Alliance has defined what good public involvement should look like – identifying 6 Quality Standards (QS) against which to measure our effectiveness and impact.

Figure 2: NCA Involvement Quality Standards



### 6.2 Public Involvement Activities

Over the last 12 months the Alliance has worked with a range of communities and local partners across NENC to involve and engage people in local plans and service developments. The following examples of involvement activities have been collated with the support of both the Alliance core team and our partners and provide evidence of commitment to embedding public involvement within the heart of our programmes of work.

#### 6.2.1 Patient Experience & Quality of Life - Data Analysis

The NCA continues to encourage Trusts and partners to use the results of Cancer Patient Experience and Quality of Life Surveys to improve excellence in patient care. As well as undertaking local feedback such as friends & family test, complaints and patient reported outcome measures to understand patient experience and identify service improvements. Through analysis and triangulation of survey data we have produced Trust level data packs identifying areas for improvement, helping to ensure actions to improve patient experience are intelligence and insight driven at a provider level. We have also identified system wide opportunities for improvements that form part of our Personalised Care Work Programme.

#### Quality Standard 1

## 6.2.2 Personalised Care approach to involvement

The Northern Cancer Alliance is supported in delivering the Personalised Care Work Programme by the Public Involvement Accountability Forum (PIAF) and informed by the experiences of people affected by cancer from across the North East and North Cumbria. In 2023/24 the focus has been on developing community-based models and educational resources that improve access and availability to health and wellbeing information and support, with a focus on sleep and the menopause. Although our work has been directed by our intelligence from Patient Experience data, we have undertaken further involvement work including patient surveys and in patient workshops to inform the development of our work. Personalised Care is a standing item on our PIAF meetings so that members have ongoing involvement in the development of new support programmes and they have endorsed our approach to the development of models of care.

### Quality Standard 1

## 6.2.3 Community Based Cookery Classes for People Living with Cancer

Through previous work with Life Kitchen and through data gathered from patient engagement, a collaborative project was created to provide outreach cookery workshops with a cohesive community approach to reach areas of deprivation and people that otherwise may not engage with their voluntary offer.

The main premise of the workshops was affordability and addressing health inequalities. Seven workshops were held around the North East and North Cumbria and the locations were co-designed between Life Kitchen, the NCA Personalised Care Team and the local trust Macmillan Information and Support Teams. The details were considered with the NCA Patient and Public Involvement Forum.

Once the venues and dates were arranged the communications were shared with the local clinical teams, through both local social media channels and the NCA social media platforms. Posters were also devised for each local area to display in their clinical areas.

The immediate feedback from those that attended the events was overwhelmingly excellent but it was a challenge to encourage attendance in the first instance. This was due to the cost of travel and seemingly a reluctance to attend an event in person.

Learning has been taken from the above and we will now enhance the digital offer

as well as creating meal planners and recipe cards.

**Life Kitchen**  
BY RYAN RILEY

"Eye watering - first time I've tasted for years!"

"Good to hear other people's experiences...makes you feel less isolated"

"It has given me confidence to experiment more"

**FREE** cookery classes for people living with cancer

Touring the North-East  
February 2024

Thursday 15th February  
1pm - 3pm  
St Cuthbert's Hospice  
Park House Rd, Durham  
DH1 3QF

If you're living with cancer and experiencing a change to your taste, book on one of our classes today.

in partnership with  
northern cancer alliance

### Quality Standard 2

#### **6.2.4 Breast and bowel cancer screening learning disability health quality checker programme**

The North East and Cumbria Learning Disability Network cancer project group set up in 2015, works alongside the Northern Cancer Alliance and partners to specifically improve cancer services and experience for people with a learning disability, families, and carers. The group has taken the Health Quality Check format and developed new innovative resources to check if breast and bowel cancer screening services are accessible for people with a learning disability. Health Quality Checks enable services to improve the provision they provide; this has a direct impact on the people using those services and the staff providing services. This will help ensure we find more cancers early, providing the best possible outcomes for people with a learning disability. To coproduce the resources required for the Health Quality Checker project and complete the quality checks the network worked in partnership with: Skills for People; Your Voice Counts; People First Cumbria; Screening and Immunisations team NHSE; Northern Cancer Alliance; North of Tyne Bowel Cancer Screening; South of Tyne Bowel Cancer Screening; Newcastle Breast Screening Centre. For the project to be successful it needed to include people with lived experience at every stage. The Network was shortlisted as a finalist in the PEN National Awards 2023 Cancer Experience of Care Category Award.

**Quality Standard 2 & 6**

#### **6.2.5 Health & Wellbeing Project**

The Health & Wellbeing project is a collaboration with NCA and Macmillan working with the network of Macmillan Cancer Information Centres (MCIC) within North East and North Cumbria. The project has aimed to reduce the variation of support to patients in the region and align the MCIC's to their wider communities and VCSE to improve access and availability to health and wellbeing support. Achievements include:

- Completion of a detailed mapping exercise to understand the settings and infrastructure each centre works within – both internally and with other services/providers.
- An improved network of MCIC working collectively with better communication and NCA alignment.
- Analysis of patient data relating to those accessing MCIC to inform future service planning and consider better access to health and wellbeing through community support and outreach provision.

Engaging with the VCSE and working with Cancern North have been significant parts of the project achieving the following:

- Programme of engagement and consultation with Local Infrastructure Organisations (LIOs) on levels of cancer services and support locally - face to face visits and surveys.
- Supporting the strategic development of Cancern North which now represents the sector at ICB via VONNE and has NCA representation on steering group.

- Planning and participating in programme of VCSE engagement events promoting the importance of working in partnership with the sector - NENC wide event in Oct 23 and now place-based events based on feedback from VCSE partners.

The project has secured a further two-year funding from Macmillan to focus on health inequalities in relation to accessing information and support for anyone affected by cancer informed by the findings of the first phase. This includes connecting targeted approaches including the fisherman's mission and Bangladesh projects to share learning and develop more focused projects to make health and wellbeing support more accessible and widely available.

## Quality Standard 2

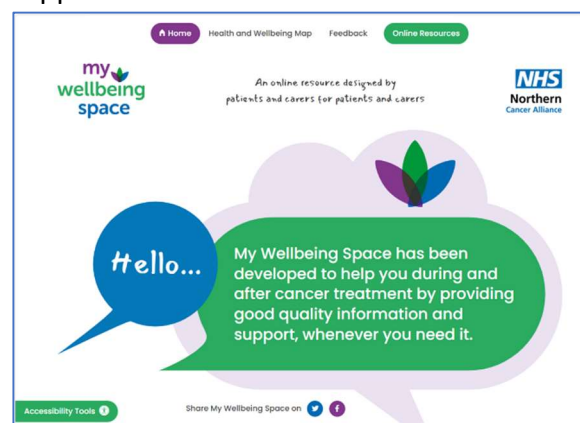
### 6.2.6 My Wellbeing Space [My Wellbeing Space \(mywellbeingspacenca.nhs.uk\)](http://mywellbeingspacenca.nhs.uk)

My Wellbeing Space launched in November 2023 providing helpful online links and resources to anyone affected by cancer to support their health and wellbeing. It provides content on topics identified by patients through the Quality of Life survey on areas they requires support with including sleep, finances, diet and exercise.

It was originally developed as an App by CDDFT with patients and user input throughout. Based on patient feedback of challenges in using the App and low levels of uptake it has progressed to a dedicated site for health and wellbeing support to improve access and availability of support.

Prior to the launch of My Wellbeing Space the Personalised Care team hosted four community engagement events to collect views and feedback from potential users on content, layout as well as other topics to include. The approach used small community venues with digital training rooms or access to IT facilities so the local community and other users could view the

site and provide us with direct feedback. This ensured the site was updated to make content more visible and identified additional topics to add, specifically support for carers which is now included.



*"Congratulations on the success of mywellbeingspacenca.nhs.uk! Your website has proven to be an invaluable resource on Cancer Care Map ([www.cancercaremap.org](http://www.cancercaremap.org)) and the feedback from our Content Team is that they find it exceptionally useful. Its intuitive design and clear, concise content make it effortless for visitors to access a wealth of resources on health, emotional wellbeing, nutrition, finances, fatigue, and the effects of treatment. It features on Cancer Care Map as both a local and national wellbeing resource, thanks to the breadth of resources and information." Cancer Care Map Team*

## Quality Standard 2 & 3

### **6.2.7 South Asian Community Breast Screening Self Checking Resource**

The Northern Cancer Alliance (NCA) have been working with NUR Fitness (NUR) in Middlesbrough to improve symptom awareness and access to services amongst the BME community. NUR is an award-winning community initiative that is dedicated to helping women and children become healthier, both physically and mentally, improving self-esteem and confidence. There is low uptake of breast screening in the South Asian Community and Nur Fitness has worked to coproduce self-checking resources in 4 languages and additionally a video to walk people through the screening unit at North Tees Hospital should they attend an appointment.

**Quality Standard 2**

### **6.2.8 Northern Radiotherapy Network (NRN)**

The Northern Cancer Alliance Public Involvement Accountability Forum provides an opportunity for partners to involve other members (or guests) in their programmes of work seeking their involvement, advice and support an example of which is the Northern Radiotherapy Network (NRN). The NRN engaged with PIAF members about their work to improve access to the most advanced and innovative treatments which improve outcomes for patients. This led to the co-production of an educational animation for people who are to be treated with Radiotherapy.

**Quality Standard 2 & 4**

### **6.2.9 Lay Representatives**

Our Lay Representatives continue to sit on all strategic groups within the Alliance governance structures. In 2023/24 they have contributed significantly to the Cancer Delivery Plan sitting on Tumour Pathway Boards. They have worked with Programme Managers and Delivery Leads on a number of key pathway developments including Breast Pain, Urology, Personalised Care, Non-Surgical Oncology and Targeted Lung Health Checks. The Lay Representatives chair the PIAF and are members on the Patient Experience and Quality of Life Forum and other NCA governance groups. They continue to keep our focus grounded in patient experience of care and their role as influencers and champions for patient experience in cancer care is recognised across partners who actively seek their advice and support.

**Quality Standard 4**

### **6.2.10 Quality of Life Share & Learn Event**

Supporting people to live better with and beyond cancer is a key focus of work recognising that receiving care that is tailored to our patient's needs can have a significant impact on patient experience and quality of life. The Cancer Alliance held a Quality of Life Share & Learn Event in November 2023. The session was well attended by both Cancer Nurse and Personalised Care leads from Trusts across the NE&NC and also patient representatives. As well as improving their knowledge and understanding of why quality of life and patient experience is so important, attendees got to hear perspectives from national and local leads

and learnt about initiatives supporting peoples physical, emotional and social well-being (including psychology, food, sleep, physical activity and menopause).

## Quality Standard 5

### 6.2.11 Community Cancer Awareness Workers Campaigns

The Northern Cancer Alliance has a network of 11 Cancer Community Awareness Workers (CCAW), across the region, as part of its continued commitment do address health inequalities in early cancer diagnosis. They are hosted in a range of different partner organisations from local health charities to GP Federations to ICB delivery teams, Local authority commissioned services. CCAWs adopt health community development approaches, (more recently) behavioural science messaging / nudges and collaborative working with communities, voluntary sector partners, to both develop and deliver a range of campaigns and engagement activities. As well as significant involvement in forums such as CANCEARN and Northern Cancer Voices. Over 2023/24 the Community Cancer Awareness team have supported a range of work streams and projects to deliver their key objectives here are a couple of examples:

#### Cervical Screening



Inner West Newcastle has some of the lowest cervical screening coverage rates in the region. Low engagement relates to areas of high deprivation and high cultural diversity. This multi-agency project aimed to test if the deployment of a mobile

cervical screening unit into key community venues offering drop-in appointments, will encourage women, who previously did not attend or were overdue screening, to attend. Delivering this project was heavily reliant on the local CCAW team and their ability to effectively work with local communities and listen to their views as to how the service should be delivered. Early evaluation findings have revealed women are attending from the target audiences – i.e. 80% of attendees from high deprivation postcode areas and in some cases, attendees have never been screened or not been screened for over 17 years.

#### Head & Neck Cancer

Regional data indicates that Head and Neck Cancers are predominantly diagnosed at a later stage and referrals have been slow to recovery post COVID. Men living in areas of high deprivation are less likely to present to health professionals/access healthcare services and be more likely to be diagnosed at a later stage.

The Northern Cancer Alliance aimed to develop a targeted Head and Neck cancer symptom awareness campaign. The target population being men aged 50yrs plus, living in areas of high deprivation who are heavy smokers and or drinkers, which increases the risk of developing these types of cancers.

To develop effective symptom awareness materials the NCA commissioned experts in Behavioural Science, Caja and sort the support of the CCAWs to engage with representatives of the target audience to help test the design concept and content of the posters.

The CCAWs in Newcastle played an integral role in devising the design thread based on *the Northern Sense of Humour* for a series of posters that focus on risk factors, symptoms and self-check advice. They set up test focus groups with men within the target population to test and refine the products. The materials were then displayed over an 8-week period within key trial sites, including pubs, clubs, pharmacies and one construction firm with over 386 post campaign surveys and conducted interviews to assess the impact of the campaign across the trial and the control sites.

Through effective joint work with communities, local businesses and health champions, the assets were refined.



The focus groups and surveys overwhelmingly indicated the campaign materials did lead to an increase in accurate symptom recall within the target audience and improved knowledge on how to self-examine. As a result, the campaign is going to be scaled up including specific work with primary care.

**Quality Standard 2, 3 & 6**



Continue to embed the use of coproduction; understanding what matters to people and communities within our programmes of work and codesigning solutions.



Continue to learn from what works and build on the assets of all partners – networks, relationships and activity across our places. Using our PIAF forum to support the development of collaborative relationships that facilitate effective and appropriate public involvement.



Use behavioural science principles to develop tailored messages and materials to influence engagement particularly across seldom heard communities.



Whilst remaining mindful of digital health inequalities, further develop our presence across social media channels to support the delivery of key areas of the Alliance annual workplan.



Utilise patient stories within our programmes of work and communications to focus the importance of our discussion on patient experience and inequalities.



Ensure the involvement of community members in the development and delivery of health campaigns and community focussed projects that support prevention, symptom awareness and the early detection of cancer.



Support the extension of our VCSE network these local charities are key to system working and particularly in addressing some of the support requirements identified through patient experience gap analysis.



Review of our communications strategy to ensure our messaging is clear and consistent, uses the right communication channels that are appropriate to our people and communities.



Review our involvement strategy to ensure that it remains fit for purpose and that we continue to put the voices of people and communities at the centre of our workplan, decision making and governance structures.

**PIAF STAKEHOLDER MAP:****PIAF MEMBERS 2023/2024:****CANCER ALLIANCE**

- NCA Managing Director
- NCA Head of Programmes
- NCA Clinical Lead for Nursing
- NCA Engagement & Involvement Lead
- NCA Lay Representatives
- NCA Clinical Lead for Personalised Care
- NCA Clinical Lead for Primary Care
- NCA Macmillan Health and Wellbeing Delivery Lead
- NCA Business Support Officer

**KEY CANCER CHARITY PARTNERS**

- Cancer North
- Coping with Cancer
- Macmillan Cancer Support
- Northern Cancer Voices

**VOLUNTARY, COMMUNITY AND SOCIAL ENTERPRISE (VCSE)**

- Age UK County Durham

- Healthwatch County Durham
- Middlesbrough & Stockton MIND
- North East and Cumbria Learning Disability Network
- Sunderland Bangladeshi International Centre
- Nur Fitness CIC

#### **PATIENT REPRESENTATIVES**

- Cumbria Patient & Carer Group
- South Tyneside and Sunderland Patient and Carer Group Rep
- Sunderland Patient & Carers
- North of Tyne and Gateshead Cancer Patient Collaborative, NCV

#### **NHS ORGANISATIONS**

- North Tees & Hartlepool FT
- Northumbria Healthcare NHSFT

#### **HEALTH NETWORKS**

- Northern Radiotherapy Network
- North East & Cumbria Learning Disability Network

#### **Statutory Bodies**

- NENC ICB (Involvement Lead)
- NENC ICB (County Durham)