

OFFICIAL



Northern Cancer Alliance Public Involvement Report

March 2019 to March 2020

Authors: Annie Dolphin - Northern Cancer Alliance Lay Representative
Karen Gannon - Northern Cancer Alliance Lay Representative
Jo Mackintosh – Northern Cancer Alliance Involvement Lead

Date: 26th May 2020

Contents

1.0 Introduction:	3
2.0 Background:	3
3.0 Purpose and scope:	3
4.0 Northern Cancer Alliance Public Involvement Accountability Forum:	4
5.0 Northern Cancer Lay Representatives:	4
6.0 The use of data to improve the cancer patient experience:	6
6.1 National Cancer Patient Experience Survey (NCPES):	6
6.2 Northern Cancer Alliance Health Inequalities Lead:	6
6.3 People with a learning disability:	7
7.0 Case Studies:	7
7.1 The Importance of Public Involvement – NCA Alliance Learn & Share Event	7
7.2 Developing animation films for people affected by cancer and the wider public..	7
7.3 Involving the public in the North Tyneside cancer locality plan	7
7.4 Involving patients in the development of the serious non-specific symptom’s pathway	8
8.0 How have we contributed to the development of knowledge and skills that support effective involvement:	8
8.1 Train the Trainer - 10 Steps to even better public engagement	8
8.2 North East Leadership Academy – Inclusion Carousel Event	8
8.3 Cancer Patient & Carer Groups	8
8.4 North Region Change Programme - Large Scale Change Event	9
8.5 Induction programme for the Alliance Pathway Board Clinical Leads	9
8.6 NHS England National Share & Learn Events	9
9.0 Plans for the year ahead:	9

1.0 Introduction:

The Northern Cancer Alliance (NCA) is one of 19 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 survival across the North East and North Cumbria. Key to the achievement of improved survival rates is a reduction in health inequalities, improvement in cancer outcomes and a positive patient experience.

National policy documents such as Achieving World Class Cancer Outcomes, the NHS Constitution and NHS Long Term Plan reinforce the importance of involving people in designing and delivering the changes necessary to drive forward improvements in 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.

2.0 Background:

In 2017, the Northern Cancer Alliance embarked on a two-year Macmillan funded project to develop a framework that would support and inform how it involved the public in its work plan. This project spanned 2 years and was led by a project steering group. Membership consisted of health professionals, members of the public and representatives from the third sector including Healthwatch, Macmillan and Cancer Research UK.

All aspects of the project were co-designed by the members of the steering group, as well as other key stakeholders including cancer patient support groups and members of local Healthwatch teams. As well as producing the framework, the steering group also identified ways in which it could be integrated across the Northern Cancer Alliance work plan. This included the introduction of the Public Involvement Accountability Forum (PIAF) to the NCA governance structure. The forum started its work in April 2019

The overall purpose of the forum is to review and scrutinise the public involvement activities across the Alliance work plan and provide assurance to the Alliance Board that the views of the public are taken into account in the planning, operation and evaluation of the Northern Cancer Alliance work programme. The forum also has the opportunity to review and influence the development of the Alliance work plan each year.

3.0 Purpose and scope:

This report forms part of the assurance process that the PIAF undertakes on an annual basis. It will be presented to the now established membership of the PIAF, with the purpose of detailing the public involvement activities undertaken by the Northern Cancer Alliance from 01/04/2019 to 31/03/2020. The report will then be presented to the Alliance Board along with feedback from the PIAF membership.

This will include the following:

1. Involvement activities that the Cancer Alliance has been directly responsible for.
2. The funding the Cancer Alliance has provided to other groups and organisations to support involvement activities.
3. How the Cancer Alliance has signposted and shared involvement opportunities with key stakeholders.

4.0 Northern Cancer Alliance Public Involvement Accountability Forum:

The overall purpose of the forum is to review and scrutinise the public involvement activities across the NCA work plan and provide assurance to the Board that the views of the public are taken into account in the planning, operation and evaluation of the Alliance work programme. The forum also has the opportunity to review and influence the development of the NCA work plan each year.

PIAF membership includes representatives from the Northern Cancer Alliance core team; people affected by cancer; NCA lay representatives; community groups and organisations; cancer commissioners; secondary care clinicians; cancer charities; and CCG communication leads. Each member of the forum is required to provide input from a wide discipline/specialism perspective and to influence their networks accordingly.

The forum met 4 times during the year to coordinate with NCA Board meetings. Initial focus was on establishing PIAF with the appropriate representation and defining member roles. The first main co-design task was developing performance metrics and a framework for evaluating involvement activity in delivering the work plan. This work has resulted in the format of this report that reflects the KPIs that were developed. The forum also developed the [Public Involvement Strategy](#) which is an important part of the NCA Communication and Engagement Strategy, and a work plan with annual objectives. This work combined with regular NCA work plan updates from the Alliance Programme Director, and case study presentations from members of the Alliance core team, provides the insight and information that PIAF members need to scrutinise the effectiveness of involvement activities.

5.0 Northern Cancer Lay Representatives:

The lay representative role is now well established as an essential and valued member of the Northern Cancer Alliance. The Alliance has four lay representatives that sit on the Alliance Board and other strategic groups within the Alliance governance structure, these include Clinical Leadership, Commissioning Forum and Pathway Boards. Lay representatives also chair the (PIAF).

Lay representatives bring a wide range of skills and personal attributes these include:

1. Awareness of the NHS strategy and policy agendas including local NHS structure.
2. Knowledge of current issues impacting on healthcare in the North East and North Cumbria.
3. Experience of working in a collective decision-making group such as a board or committee, or high-level awareness of 'board level' working.
4. Ability to listen and to express views in a constructive way, to be the critical friend.
5. The confidence to question information and explanations supplied by others, who may be experts in their field. Have the ability to express views and enter into constructive debate.
6. Ability to review programme plans and other associated documentation as requested, ensuring there is a focus on public involvement and patient experience.
7. Ability to work as part of a group with people from a wide range of different backgrounds.
8. Ability to understand and evaluate a range of information and evidence.
9. Understanding of Data Protection and diversity and equal opportunities issues and a commitment to applying these principles.
10. Comply with the Standards of Conduct, respecting the confidential nature of discussions when it is made clear by the Chair that this is a requirement.

A recent evaluation of the lay representative with other members of the strategic groups illustrated a high regard for the contribution they make to the work of the Alliance. Below is a selection of comments that were received as part of the evaluation process:

"I feel the lay representative role has had a positive effect, in that board members have experienced the value and expertise a lay rep' can give to the discussions. Seeing situations from a different lens can and does make a difference".

"Very effective, they are not afraid to challenge decisions but also bring a wide knowledge and experience to the Alliance".

"I think they have truly been a 'critical friend' - and a valuable resource in just sense checking that the patient/public is considered at all times, ensuring that decision making is more robust. They are the conscience of the Alliance".

The Cancer Alliance support team place a high value of the contributions of the lay representatives. Below are two quotes from members of the senior team:

I see our lay reps' as a critical friend, able to ask the questions others may overlook and to challenge where necessary without fear or favour. The best sort of friend to have – one that plays a key role in the development of all the work of the Alliance by being part of the conversation and being committed to our vision. They are key to supporting the work of the Alliance and because of their wide range of life experiences and their involvement in other communities they help to give a wider perspective on our day to day work.

Alison Featherstone – Northern Cancer Alliance Programme Director

They provide valuable perspective, challenge when needed and also positive feedback. Their increased involvement with clinicians has supported the visibility and

I hope has increased confidence in the role and value of public involvement in all our work.

Katie Elliot – Northern Cancer Alliance Clinical Director Primary Care

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

The use of appropriate data underpins all aspects of the work to improve cancer outcomes and the experience of cancer patients. The Northern Cancer Alliance uses a variety of data sources to inform the approach it has adopted to involve the public and improve patient experience. These sources include cancer patient experience surveys (National Cancer Patient Experience Survey) and health inequalities data (including one-year survival rates, poverty and deprivation indices and Right Care Learning Disability data pack). Over the last year the Alliance has utilised these data sources to improve the patient experience and involve people in the following ways:

6.1 National Cancer Patient Experience Survey (NCPES):

The NCPES is conducted on annual basis and results are published at the following levels, national, Trust, Clinical Commission Group and Cancer Alliance. The NCA analyses data and produces a report for the Alliance Board that details the following:

1. Comparison of NCA performance against national average scores.
2. Comparison of individual Trust performance against national average scores.
3. Identification of any areas for improvement across a number of Trusts that would benefit from a collaborative approach.

6.2 Northern Cancer Alliance Health Inequalities Lead:

In the Northern Cancer Alliance area too many people have their lives cut short or significantly affected by cancer. More cancers are being diagnosed early, when curative treatment is more likely, and patient reported experience of care is high (NCPES). However, cancer performance in the NCA stills lags behind many other Cancer Alliances in the country.

A key element of the [Northern Cancer Alliance Framework for Public Involvement](#) is the reduction of health inequalities. This involves ensuring that activities are targeted at and inclusive of those sections of the population who are more likely to experience poorer cancer outcomes and less likely to access health services.

In 2019 the Alliance Board approved a Clinical Lead for Health Inequalities. The focus of the work was to:

1. Raise awareness of health inequalities amongst the cancer workforce.
2. Support the development and implementation of Targeted Lung Health Checks.
3. Arrange an event to help reduce overweight and obesity to help prevent cancer.

In 2019, the Clinical Lead for Health Inequalities presented details of the cancer related inequalities in our region to the PIAF. The aim was to develop the knowledge and understanding of Health Inequalities to support the forum members in their

scrutiny of the NCA involvement activities. The Clinical Lead has also supported the development of the Cancer Alliance approach to involvement, providing valuable insight into the focus and targeting of interventions. It is hoped that the membership will draw on this learning opportunity to hold the Alliance to account in respect of how they seek to address health inequalities across their plan and through involvement.

6.3 People with a learning disability:

Data illustrates that people with a learning disability can; experience delays in a cancer diagnosis; are less likely to access cancer screening programmes; and face barriers to accessing health care. The North East & Cumbria Learning Disability Network has a programme of work in place with the aim of improving cancer outcomes for people with a learning disability. This work is led by a Macmillan funded project manager who has developed a number of innovative co designed interventions. The Cancer Alliance has provided support in the form of funding and manpower resources to the following interventions:

1. [Social care provider screening document](#) – Funding for design and print of the document.
2. Health Quality Checkers – Funding for the project to develop health quality checks for breast and bowel screening.
3. [Be Cancer Aware](#) – NCA staff support with training and delivery of the project.

7.0 Case Studies:

7.1 The Importance of Public Involvement – NCA Alliance Learn & Share Event

One of the principles of the [Northern Cancer Alliance Public Involvement Framework](#) is to build capability and capacity for effective public involvement across the Alliance “system”. This event provided attendees with the opportunity to learn new skills and hear about some examples of public involvement best practice from across the region. [Read more here.....](#)

7.2 Developing animation films for people affected by cancer and the wider public

Key objectives within the NCA work plan include improving screening uptake rates and the implementation of personalised follow up interventions e.g. the Holistic Needs Assessment. To support this work a set of patient information films were developed in partnership with Alliance lay representatives and people affected by cancer. [Read more here.....](#)

7.3 Involving the public in the North Tyneside cancer locality plan

North Tyneside Cancer Locality Group embarked on a project to involve the residents of North Tyneside in their cancer locality plan. Work aligned with the NCA strategy to involve the public at all levels of its work plan. This case study details the achievements of the group and how the Alliance supported this work. [Read more here.....](#)

7.4 Involving patients in the development of the serious non-specific symptom's pathway

A key objective within the NCA work plan is to increase early diagnosis rates. An element of this work has been the development of the serious non-specific symptom's pathway pilot. This provided a referral pathway for patients who present with non-specific but concerning symptoms that meet the criteria for a site-specific urgent referral pathway for cancer. This case study details how the experience of patients was measured to inform the development of the pathway. [Read more here.....](#)

8.0 How have we contributed to the development of knowledge and skills that support effective involvement:

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 values within the Northern Cancer Alliance Framework for Public Involvement is a commitment to build capability and capacity across the "system" to enable effective and meaningful public involvement activities to happen. Below are some examples of the support provided by the Cancer Alliance to develop involvement and skills:

8.1 Train the Trainer - 10 Steps to even better public engagement

Two members of the Alliance support team (Michelle Wren and Jo Mackintosh) have attended this course which means they can now provide the "10 Steps to even better public engagement" training sessions. This allows the Alliance to support our wider partners by sharing this best practice model of involvement.

8.2 North East Leadership Academy – Inclusion Carousel Event

The Cancer Alliance lead for public involvement ran a workshop at this NELEA event. Attendees were given the opportunity to understand the approach adopted by the Cancer Alliance to involve the public in their work plan and discuss how this might be applied within their own organisation/team. The workshop was well received by participants and discussions on the day indicated that attendees had gained learning that would inform their practice in the future.

8.3 Cancer Patient & Carer Groups

The Alliance lead for public involvement attends the cancer patient & carer group meetings across the region to provide regular updates from the Cancer Alliance. The Alliance also routinely shares learning and development opportunities with group Chairs via email. Over the past year this has included opportunities to be involved in:

1. Public Health England Cancer Data Event.

2. NHS England patient forum.
3. Planning for the Cancer Alliance Obesity Event.
4. Cancer Alliance Annual Event.

8.4 North Region Change Programme - Large Scale Change Event

Northern Cancer Alliance key stakeholders and lay representatives attended this regional event where they were able to learn the key principles of large-scale change. This was set within the context of partnership working to improve cancer outcomes and the patient experience. The Northern Cancer Alliance were closely involved along with lay representatives leading on the planning and delivery of this event along with other Cancer Alliances from the Northern region.

8.5 Induction programme for the Alliance Pathway Board Clinical Leads

The Alliance lead for public involvement and a lay representative attended the induction sessions for the Pathway Board Clinical Leads. This provided an opportunity to share the public involvement values of the Cancer Alliance and provide an overview of the Alliance approach to public involvement.

8.6 NHS England National Share & Learn Events

The Lead Cancer Nurse for South Tyneside & Sunderland NHS Foundation Trust and the Alliance lead for public involvement spoke at the Measuring Patient Experience and Acting on the Results Event to share their approach to understanding the patient experience and involving patients in the development of the vague symptom's pathway pilot.

9.0 Plans for the year ahead:

The start of a new year for public involvement activities saw the arrival of the COVID-19 pandemic. The measures introduced to protect the health of our nation and NHS services presents a number of challenges to some of the traditional methods of involving people in the work of the Cancer Alliance.

The Cancer Alliance remains committed to involving the public at all levels of its work plan. This has involved focussing on the "possible" in the early weeks and months, with a plan for identifying new and innovative ways of involving people in the year ahead. Below are some examples of the involvement activities that have been happening to date:

1. Lay representatives continue to be involved in all strategic clinical and management groups, participating remotely using Microsoft Teams.
2. The lay representative Advisory Group continues to meet using Microsoft Teams. The group agreed that they would have two priorities in the current situation; produce the Alliance annual involvement report and identify new

ways of involving people in the work of the Cancer Alliance during the pandemic.

3. Lay representatives now join the Alliance fortnightly team meeting which provides them with the opportunity to receive national and local updates and more importantly to participate in team discussions and plans.
4. Sources of information and support continue to be circulated with Healthwatch, cancer patient and carer groups and other key stakeholders. This has included sharing details of the COVID-19 section within the Alliance website which provides sources of information and support for people affected by cancer during the pandemic.
5. A number of people affected by cancer are involved in producing a set of short films to encourage people to attend their GP with cancer signs and symptoms and visit the hospital for essential cancer treatment and pandemic during the pandemic.

The next steps will involve identifying new ways of working in partnership with the public to improve cancer outcomes and the patient experience in the North East and North Cumbria. Whilst technology brings a range of possibilities for involvement, it is crucial that the Alliance is mindful that this approach can be just one element of how they involve people. To rely on this method alone could reinforce the very inequalities we seek to reduce as we will exclude those who do not have access to resources for virtual involvement.