

Executive summary

- The Humber and North Yorkshire Cancer Alliance patient and public engagement strategy (September 2023) has been developed in partnership with different stakeholders, including patient representatives, patient and public involvement professionals and representatives from the voluntary, community and social enterprise (VCSE) sector.
- The need for a refreshed strategy was identified following a review of the Cancer Alliance's approach to patient and public engagement in the summer of 2022, during which several areas were identified to improve the Cancer Alliance's patient and public engagement function.
- The patient and public engagement strategy aims to improve the Cancer Alliance's approach in this area during the remainder of 2023/24 and 2024/25, by establishing a robust and sustainable approach to involve cancer patients in the work the Cancer Alliance undertakes to transform the diagnosis, treatment and care for cancer patients. The strategy identifies ways to build on the improvements made over the past year following the conclusion of the review of the Cancer Alliance's existing patient and public engagement practices.
- The proposed changes in patient and public involvement practices include:
 - Ensuring that robust and sustainable patient and public involvement practices are threaded through each of the Cancer Alliance's programmes, and it is considered to be part of the Cancer Alliance's usual business.
 - Establishing and developing close relationships with local cancer charities and cancer support groups to ensure those people who are currently undergoing treatment for cancer are able to share their views on the cancer services and their experience of care, and that their views are used to improve outcomes for cancer patients.
 - Growing and diversifying the Cancer Alliance's patient and public representative group so it is fully representative of the Humber and North Yorkshire region, including representatives from areas and communities less likely to engage with healthcare services. Utilising and developing the skills of our patient representatives so they can contribute to the patient and public engagement function in more ways.
 - Working with partners to reach people, including those categorised as <u>Core20Plus5</u>, who experience the greatest health inequalities and deprivation but who may not often be part of the healthcare conversation or less likely to use healthcare services.

Humber and North Yorkshire Cancer Alliance patient and public engagement strategy – September 2023

1. Introduction

1.1 About this document

The Humber and North Yorkshire Cancer Alliance patient and public engagement strategy has been developed by Cancer Alliance staff and members of its public and patient representative group.

The views of other partners working in patient-focused roles and the volunteer, community and social enterprise (VCSE) sector have been sought in the development of this strategy.

This strategy was approved at the Cancer Alliance's System Board on 27th September 2023. The strategy will be reviewed by the end of September 2024.

1.2 About the Cancer Alliance

The Humber and North Yorkshire Cancer Alliance (HNY Cancer Alliance) consists of various NHS organisations; voluntary, community and social enterprise organisations; and patients and members of the public. It is one of 21 cancer alliances in England.

The HNY Cancer Alliance brings together organisations that pay for and provide cancer services, to transform the diagnosis, treatment and care for cancer patients in the Humber and North Yorkshire region.

The Cancer Alliance is part of the Humber and North Yorkshire Health and Care Partnership (HNY Partnership), the integrated care system (ICS) for our region. Integrated care systems were established on a legislative basis, inheriting responsibility for managing NHS services from clinical commissioning groups, when the Health and Care Act 2022 received Royal Assent in April 2022. Cancer is a strategic priority for the HNY Partnership (ICS).

The NHS Long Term Plan, which was published in 2019, set out <u>ambitious targets for cancer</u> in England. The two key ambitions are:

- By 2028, 55,000 more people each year will survive their cancer for five years or more.
- By 2028, the number of cancers caught early (stage one or two) will rise from around half to three-quarters (75%) of cancer patients.

To achieve this nationally the NHS is improving screening programmes, giving people faster access to diagnostic tests, investing in new treatments and technologies, and making sure more patients can quickly benefit from precise, highly personalised treatments.

The Cancer Alliance is committed to reducing health inequalities in cancer care. Central to our work is identifying the areas and communities in our region which experience greatest health inequalities and engaging with people in these communities to understand how we can work together to identify solutions to bridge the gap.

The Cancer Alliance is working hard to deliver on these targets, as well as many more, through its three main workstreams:

- Awareness and Early Diagnosis
- Cancer Diagnostics and Innovation
- Treatment, Pathways and Personalised Care

Integrated Care Boards (ICBs) are required to involve patients and the public in decision making and service development (see pages 4 and 5 for more information).

Improving practices around involving cancer patients and members of the public in the Cancer Alliance's work has been identified as a key communications and engagement priority for 2023/24.

Visit our website to find our more information about the Cancer Alliance and its work.

1.3 About the patient and public engagement strategy

Patients and the public have invaluable knowledge and experience which can help shape and improve local healthcare services. Humber and North Yorkshire Cancer Alliance is committed to ensuring that the voices of people affected by cancer are at the heart of service improvements.

The Cancer Alliance's patient and public engagement strategy aims to establish a robust and sustainable approach to involve cancer patients in the work the Cancer Alliance undertakes to transform the diagnosis, treatment and care for cancer patients in Humber and North Yorkshire.

This strategy describes the approach adopted by the Humber and North Yorkshire Cancer Alliance to involve cancer patients and members of the public in all areas of its work. It is aligned to, and forms part of, the Cancer Alliance's over-arching strategy.

This strategy outlines the vision, principles and methods the Cancer Alliance will employ to establish and maintain effective patient and public engagement within the different workstreams of the Cancer Alliance.

The Cancer Alliance recognises the patient and public engagement network across the entire Humber and North Yorkshire geography is integral to achieving improved outcomes for cancer patients. The Cancer Alliance recognises that it needs to work in partnership to engage with cancer patients, their carers, and cancer services staff across our region.

The objective is to ensure that high-quality engagement with cancer patients, carers of cancer patients, cancer staff and members of the public across Humber and North Yorkshire becomes business as usual.

High-quality engagement means that the engagement is authentic and is used by the organisations which make up the Cancer Alliance to transform cancer services to benefit the people using them.

We will do this by working closely with our partners across the Humber and North Yorkshire Integrated Care System and other relevant stakeholders. Therefore, understanding how we will work with key partners such as hospital trusts colleagues who have direct access to cancer patients to seek and understand their views is key to implementing this strategy.

2. About patient and public engagement

2.1 What do we mean by patient and public engagement?

There are many terms to describe working with people and communities to improve health outcomes – engagement, involvement, participation, co-production, patient public voice, lived experience partner, to name just a few. These words are used by different people to mean the same thing (and sometimes different things).

By patient and public engagement, we mean involving patients, carers and the public in the planning, delivery and evaluation of cancer services. Please note that is very separate to the community engagement activity carried out to raise awareness about cancer symptoms by the Communications and Engagement and Cancer Champions teams.

2.2 Why do we involve and engage with people?

Integrated Care Boards (ICBs) have a legal duty to involve patients and the public in decision making and service development. As part of the Humber and North Yorkshire ICB there are clear standards for patient and public engagement and involvement for the Cancer Alliance to meet.

These come from a wide variety of sources, including:

- Legislation, particularly the Health and Care Act (2022)
- The NHS Constitution

- NHS England guidance
- Integrated Care System guidance

Although we have a legal duty to involve people, the Cancer Alliance believes local people know their communities best; and by building relationships and trust by making sure everyone has a voice and that decision making is underpinned by robust evidence, we can make sure that services meet the needs of the local community.

By giving everyone an equal voice, listening to people who use services and empowering them to be part of the design and decision making about services, we become aware of ideas and aspects of service that may not have been considered, enabling us to make positive change.

2.3 The benefits of increasing patient and public engagement and involvement

There are clear benefits to working in partnership with people and communities. It means better decisions about service changes and how money is spent. It reduces risks of legal challenges and improves safety, experience and performance.

It helps address health inequalities by understanding communities' needs and developing solutions with them. It is about shaping a sustainable future for the NHS that meets people's needs and aspirations.

By working with people across the <u>six places in Humber and North Yorkshire</u> (Hull, East Yorkshire, York, North Yorkshire, North Lincolnshire and Nort East Lincolnshire) we can better tailor services to meet their needs and preferences, so that they are designed and delivered more effectively.

At an individual level, when patients feel involved in their care, listened to and informed, they are more likely to be satisfied with their care and have less anxiety, greater understanding of their own needs, improved trust and better relationships with the people providing their healthcare. Working with the people who use services helps those people charged with providing services or improving them get it right first time.

3. Setting the scene: where we are now

The Cancer Alliance has always aimed to put the patient at the heart of everything it does. Cancer Alliance leadership and programme boards have historically included patient/public representatives in their membership; however a robust framework is required to clarify how the Cancer Alliance ensures that:

- Patient and public reps can easily put forward their views, their views are acted upon wherever possible, with feedback provided where this is not possible
- Cancer Alliance staff are supported to engage the views of patients and the public when improving or redesigning existing cancer services, or creating new cancer services.
- There is accountability to ensure that meaningful patient and public engagement is carried out across all programmes of work.

In the summer of 2022, the Cancer Alliance carried out a review of its patient and public engagement approach to understand where it needed to improve. Cancer Alliance patient representatives were asked for their views. The consensus was that:

- The patient representative roles required enhancement to ensure they were involved in the work of the Cancer Alliance in a meaningful way.
- The Cancer Alliance did not always act on the feedback or views put forward by the patient representatives, and did not explain why this was the case.
- The Cancer Alliance could improve how it utilised the skills and experience of the patient representatives.
- The Cancer Alliance had not clearly communicated what it expected its patient representatives to do.

Since the summer 2022 review the Cancer Alliance has taken steps to improve its patient and public engagement approach.

Among the actions taken was to co-develop the vision and underpinning principles for the Cancer Alliance's patient and public engagement approach (see the next section for more details).

The patient representatives also worked closely with Cancer Alliance senior colleagues to agree the key themes, issues and guiding thoughts that would shape this engagement strategy.

Another way in which the Cancer Alliance has sought to improve its approach is by reinforcing commitment to patient and public engagement from senior leaders, to ensure it is threaded throughout the transformational work the Cancer Alliance does to improve cancer services and experience of care.

The results of the review of the Cancer Alliance's patient and public engagement function were presented to the Cancer Alliance System Board in August 2022, and the board unanimously approved a proposal to refresh the Cancer Alliance's patient and public engagement strategy to ensure cancer patients and the public are involved in the work of the Cancer Alliance in a meaningful way and this becomes normal practice.

Building on the improvement over the last year, further measures are required to ensure patient and public involvement is threaded through the different Cancer Alliance workstreams, and more training and support is provided to ensure that patient and public involvement is part of the Cancer Alliance's usual business. This strategy sets out some of the ways in which this change in approach will occur.

4. Objectives: where we want to be

In 2023/24 NHS England requested that cancer alliances establish and maintain a people and community engagement structure to enable coproduction throughout work programmes and in conjunction with local ICBs and hospital trusts responsible for providing cancer services.

4.1 Cancer Alliance vision

The Cancer Alliance's vision is to transform the treatment, diagnosis and care for cancer patients in Humber and North Yorkshire.

We aim to place the patient at the heart of everything we do, and acknowledge it's not just the people diagnosed with cancer who are affected by cancer.

4.2 Cancer Alliance vision for patient and public involvement

In terms of patient and public involvement, our over-arching objective is to proactively listen to the views of cancer patients and anyone else affected by cancer; and use these views to inform and influence its work with partners to improve cancer services in Humber and North Yorkshire.

We will go from this... Current engagement output

To this... Desired engagement output

Which will achieve this... Objectives

Uncoordinated, sporadic engagement which does not always directly lead to improved cancer services or experience

Planned, coordinated engagement activity with partners which leads to improved cancer services and / or improved experience of care

Utilise insight to determine how to make cancer patients' lives better

- To understand what matters to cancer patients most and identify where improvements to services can be made to improve patient experience.
- To work with cancer patients, cancer services providers and other partners to co-develop improvement plans based on feedback from patients around experience of care. To work in partnership with service providers to implement these improvement plans.
- To communicate how specific engagement has improved cancer services / patient outcomes to those who have taken part (closing the loop).

The Cancer Alliance and its patient and public representatives' group have agreed several principles to underpin the vision and help achieve the objectives to enhance its patient and public engagement approach.

The principles include, but are not limited to:

- The Cancer Alliance is fully committed to the involvement of patients and the public in all aspects of our work and is fully committed to establishing a working culture whereby patient and public involvement in our work becomes everyday practice or "business as usual".
- The Cancer Alliance believes that the involvement of patients and the public in our work is the responsibility of everyone working within the Cancer Alliance, not just a named individual or team.

- The Cancer Alliance is committed to establishing accountability in its plans to ensure that meaningful patient and public engagement is carried out in the necessary way and avoid tokenistic engagement activity.
- Where patients and/or the public have been involved in Cancer Alliance work, the outcome of this involvement will be communicated to them (also known as closing the loop). Where no action has been taken it will be explained why this is the case.

The principles can be found <u>here</u> in full.

We are moving away from a model where patient and public engagement is done sporadically and does not necessarily influence positive change, to a more joined-up approach with partners, one which ensures a proactive approach to patient and public engagement is taken and the insight captured is used to improve existing cancer services or develop new ones.

5. How the Cancer Alliance will do this



It is worth noting that the improvement of the Cancer Alliance's patient and public engagement function is a gradual process which requires us to work in different ways to how we have historically, and in partnership with many different stakeholders.

In recent years there has been a shift in views about what constitutes good engagement. Traditional engagement practice, where the NHS and other public sector organisations developed ideas behind closed doors before sharing them with the public for discussion is now regarded as poor practice. Best practice means involving the public at every stage and using their input to co-design solutions.

5.1 Adopt the 10 steps to Working with People and Communities model as a baseline approach

NHS England's 10 Steps to Working with People and Communities model advocates patient and public involvement from the outset and has therefore been adopted by the Cancer Alliance as its preferred patient and public engagement framework.

- 1. Centre decision-making and governance around the voices of people and communities.
- 2. Involve people and communities at every stage and feed back to them about how it has influenced activities and decisions.
- 3. Understand your community's needs, experiences, ideas and aspirations for health and care, using engagement to find out if change is working.
- 4. Build relationships based on trust, especially with marginalised groups and those affected by health inequalities.
- 5. Work with Healthwatch and the voluntary, community and social enterprise sector.

- 6. Provide clear and accessible public information.
- 7. Use community-centred approaches that empower people and communities, making connections to what works already.
- 8. Have a range of ways for people and communities to take part in health and care services.
- 9. Tackle system priorities and service reconfiguration in partnership with people and communities.
- 10. Learn from what works and build on the assets of all health and care partners networks, relationships and activity in local places.

The benefits of the 10 Steps model are plentiful. The Cancer Alliance has chosen to base its patient and public engagement approach on this model because it offers a comprehensive approach, yet its step-by-step guidance can be adopted by colleagues with little or no previous experience of patient and public involvement.

While implementing the 10 Steps model when involving patients and public in its work provides the Cancer Alliance with a solid foundation to build upon in the months and years ahead, there are plenty of other practical steps to be taken to ensure the Cancer Alliance's engagement activity is authentic and effective in leading to improvement to cancer services and patient experience of care.

5.2 Embedding robust engagement practices and establishing accountability

While following the 10 Steps model will provide the Cancer Alliance with a solid framework to build on, the Cancer Alliance will also establish other practices to further enhance our patient and public engagement function to achieve the objective of ensuring authentic engagement is threaded through all Cancer Alliance work programmes and it becomes business as usual.

These include, but are not limited to:

- Attaching the appropriate level of authority to the Cancer Alliance's patient and public representative group so it can hold the Cancer Alliance
 to account to deliver mandatory activity relating to patient and public involvement. Having a mechanism in place to escalate slippage in work
 relating to patient and public involvement so the appropriate mitigation and support can be put in place.
- Creating more dialogue between the Cancer Alliance's patient and public representatives and the Cancer Alliance's work programmes to foster closer working relationships to ensure the patient voice is central to our plans to improve outcomes for cancer patients. To necessitate the inclusion of patient and public engagement activity in mandatory programme reports.
- Develop a range of education and training resources to 1) support Cancer Alliance programme office staff to involve cancer patients and the public in their work and 2) support our patient and public representatives to function successfully in their roles.
- Patient and public involvement to be a standing item on the agendas (and given equal weighting) of the various leadership and delivery boards/groups operating within the Cancer Alliance; and its mandatory inclusion should be included in the board/group's governance documents - to demonstrate the subject is as important as headline subjects such as operational performance.
- The creation of yearly patient and public engagement plans for the Cancer Alliance's individual work programmes with defined activity expected to be delivered by the work programmes in collaboration with the Cancer Alliance communications and engagement team.
- The creation of a Cancer Alliance Communications and Engagement Programme Board to monitor progress to achieving milestones outlined in the Cancer Alliance programme communications and engagement plans. This group will report to the Cancer Alliance's Oversight and Assurance Board / System Board, and any slippage in meeting any patient and public engagement targets will be mitigated as best as possible.
- Patient and public engagement objectives to be included in Cancer Alliance programme office leads' personal development review (PDR) plans.

- Co-working between the Cancer Alliance programme office and partner organisations to develop improvement plans based on patient feedback on experience of care; and the requirement to involve those with lived experience in the design and development of cancer services is stipulated as mandatory in signed service level agreements.
- Leadership commitment to ensuring patient and public engagement is important at all levels of activity; involvement of patients and the public in our work is the responsibility of everyone working in the Cancer Alliance.

5.3 Working with people with lived experience

Collaboration is key to the Cancer Alliance's transformational work and because people with lived experience of cancer offer invaluable insight on what it's like to receive treatment and care for cancer, or care for someone with cancer, it stands to reason that they should be involved in planning and developing cancer services because of their knowledge and experience.

The Cancer Alliance currently has a small but dedicated group of patient and public representatives which is committed to using its collective experiences of cancer to influence the work we do. The Cancer Alliance is extremely grateful for the group's contributions to date and looks forward to working with the group in future.

Recognising that the Humber and North Yorkshire area is vast and contains communities with differing healthcare needs, the Cancer Alliance will embark on a recruitment drive to grow and diversify the membership of its patient and public representative group, so it reflects the diversity of our geography and we are confident that our engagement tells the diverse stories of all our cancer patients. We will ensure the group remains fully representative by actively recruiting from those areas and communities which may be less likely to participate.

Having a larger and more diverse patient representative group will enable the Cancer Alliance to match patient representatives to specific projects relating to their cancer experience and interest. The benefit of this approach is two-fold: firstly, it allows the Cancer Alliance to draw upon this valuable insight to enhance its work and, secondly, it ensures that the patient representatives have an opportunity to contribute in a meaningful way.

It is important to note that our engagement of cancer patients will not be limited to the Cancer Alliance's patient and public representative group. How we will widen our engagement circle is explained later in this chapter.

Our patient and public representatives have fed back that they wish to be involved in Cancer Alliance activity in several ways, so we will support them to contribute in these ways. For example, many of our current group have expressed an interest in volunteering to support our cancer

prevention activity in their local communities or speaking to cancer patients to understand their experience of care, so we will develop a volunteer programme which provides regular opportunities for involvement of this nature.

5.4 Joint working with key partners

There are many patient engagement networks operating within Humber and North Yorkshire. The Cancer Alliance will develop or reinforce relationships with these networks to advocate for the improvement of outcomes for cancer patients, rather than set up a new cancer-specific patient engagement network which duplicates what these networks already do.

The Cancer Alliance will also work with colleagues who work with cancer patients directly (e.g. Macmillan-funded and Cancer Alliance-funded staff in hospital trusts who work with cancer patients on a daily basis) to understand the real-time issues affecting these patients and develop work plans to improve outcomes for these patients in response.

The Cancer Alliance will work with ICB colleagues to identify stakeholders and undertake equality impact analysis to identify communities, people and organisations who could support the engagement and involvement it wishes to carry out. This enables the Cancer Alliance to make best use of existing knowledge and expertise, as well as make full use of existing relationships with communities, as well as help to build new ones.

See the Key Stakeholders section (P17) for more information about who the Cancer Alliance will work with to realise the ambitions of this strategy.

5.5 Working with the voluntary, community and social enterprise (VCSE) sector

The VCSE sector is an important partner for statutory health and social care organisations and plays a key role in improving health and care outcomes for its communities, not only by delivering services but also by shaping their design and advocating for, representing and amplifying the voice of service users, patients and carers.

The Cancer Alliance recognises that it needs to develop closer working relationships with the VCSE sector to ensure that the views of cancer patients in different communities are used to improve cancer services available in these communities.

The Cancer Alliance programme office has therefore created capacity to establish and maintain relationships with local cancer charities and cancer support groups to ensure their views about services and their experience of care influence the Cancer Alliance's work.

The value of insight from people who are being currently treated for cancer should not be underestimated as it provides a real-time picture of the standards of our region's cancer services. Building relationships with these groups opens opportunities for cancer patients involved in these charities and support groups to work with the Cancer Alliance and partners in their work to improve services and outcomes.

5.6 Working with existing groups and networks in local communities to gather insight

The Humber and North Yorkshire region is a vast landscape with rich and varied communities, each presenting very different opportunities and challenges. These communities want to be part of the conversation about health and care in their local area, so the Cancer Alliance's approach to engagement will be geared towards ensuring that involvement happens locally, in these neighbourhoods and communities.

We know there are robust relationships which exist in local communities which support effective approaches to engagement through partnership working across local partners.

The Cancer Alliance, in co-ordination with the ICB, will establish or enhance relationships with local partners to ensure effective engagement happens at local level. The goal is to work with local partners in a co-ordinated way to ensure that engagement activity is not duplicated unnecessarily.

The Cancer Alliance recognises the importance of working with local partners who have established trust in their communities, as it enables us to reach people and communities that are seldom heard or are not traditionally part of the healthcare conversation.

Making a concerted effort to engage with these people will help to address cancer health inequalities in Humber and North Yorkshire because insight demonstrates that these people are more likely to develop cancer or be diagnosed with cancer at a late stage when treatment and outcomes are less likely to be successful.

5.7 Use existing insight to plan how to improve experience of cancer care

While the Cancer Alliance will increase the engagement activity it carries out itself to find out what matters most to cancer patients, carers and the public, we will also utilise pre-existing insight relating to cancer services and experience of care to inform the work we carry out with partners to improve outcomes for cancer patients.

The Cancer Patient Experience Survey (CPES) results help organisations that commission and provide cancer services to understand what aspects of cancer services are working well and identify areas for improvement. The NHS survey asks questions such as how and when the

cancer was diagnosed, how involved patients felt in decisions about their care and treatment and how much information and support they were given.

Using the latest CPES results (published in July 2023), the Cancer Alliance and hospital trusts which provide cancer services in Humber and North Yorkshire work together with people with lived experience of cancer to develop and deliver action plans to improve experience of care.

The Cancer Quality of Life (QoL) Survey is a national survey run by NHS England. People who have been diagnosed with cancer are invited to complete the survey around 18 months after diagnosis. The aim of the survey is to find out how quality of life may have changed for people diagnosed with cancer. This helps NHS England, cancer alliances and partner organisations see where care is working well or not so well, and if any new services are needed.

As with the CPES, the QoL results will be used by the Cancer Alliance and partners to identify areas where cancer patients require further support and take appropriate action.

Cancer Alliance-area CPES results are an important mechanism with which to gauge patient satisfaction and provides a clear picture of where the Cancer Alliance and partner organisations need to focus their energy to improve cancer patient experience of care.

We will also work with partners (e.g. hospital trusts) to analyse the results of other surveys (e.g. the Friends and Family Test) and any organisation-specific patient satisfaction surveys to identify opportunities to work together to make further improvements to these services.

The Cancer Alliance and partner organisations which provides cancer services in Humber and North Yorkshire have reiterated their commitment to work together to improve cancer patient experience of care through their signed 2023/24 service level agreements.

Data will always drive the engagement work we do. Therefore we will work closely with partners from NHS England and UK Health Security Agency and Office for Health Improvement and Disparities (formerly Public Health England) to utilise pre-existing data around cancer to inform the conversations we wish to have about cancer with our people and communities.

5.8 Strengthening relationships with under-represented or seldom-heard groups

The Cancer Alliance will go to people and communities to speak to them about cancer, rather than expecting them to come to us. We will work with Healthwatch and other partners to reach people who may not often be part of the healthcare conversation or less likely to use healthcare services, including asking them what the best ways are to interact with them.

For example, we will work with community and religious leaders, and support them to speak to their communities about cancer prevention, cancer services and experience of care. Embracing the Core20Plus5 approach will help to drive meaningful engagement with the most deprived and under-represented groups in our region.

We will always look for ways to reach people who may not often be part of the healthcare conversation. We will work with these people to understand the best way(s) to reach them and understand what their barriers to involvement might be. Tailored materials and methods will create a relevant, relatable approach to empower these people to participate in the conversation. It is also crucial to demonstrate how their involvement informs decisions, priorities, and improvements to cancer services.

The Cancer Alliance recognises that it cannot establish and develop relationships with these people and communities on its own, and therefore needs to work with a wide range of partners.

5.9 Maximising opportunities for engagement (especially to address health inequalities)

Cancer Alliances are tasked with complementing national awareness campaigns with local activity. Humber and North Yorkshire Cancer Alliance uses data to identify in which communities it needs to target its awareness-raising about cancer symptoms and cancer screening programmes. For example, when raising awareness about a specific cancer screening programme, we identify the postcode areas in our region where take-up is lowest and focus much of our PR and engagement activity in these areas.

As part of this activity, the Cancer Alliance undertakes community engagement activity to raise awareness about cancer symptoms and cancer screening programmes as it is an important mechanism for improving cancer prevention in the community. The location of this activity has been driven by data, which has highlighted where there is most need to engage.

We need to build on this activity going forward, primarily by having conversations with people in these communities where screening take-up or early-stage cancer presentation is lowest to understand the barriers which are preventing people from taking these steps to identify cancer early, and using this insight to further refine our approach to cancer prevention awareness raising.

5.10 Feeding back outcomes from our engagement (closing the loop)

The final stage of any engagement is to close the loop - feeding back the findings of the engagement to decision makers to influence decisions made about cancer services; then informing those who took part in the engagement what impact their feedback had on decision making. We will also share and act on the learning discovered by the engagement to improve for the future.

The requirement to close the loop applies to all levels of engagement carried out by the Cancer Alliance, ranging from the high-level engagement undertaken to capture insight about specific issues with specific people or in specific communities, to explaining to patients who share their cancer story at Cancer Alliance board and delivery group meetings how their experiences have influence decisions made (or where they have not, explaining why this is the case).

This ensures that people who have taken the trouble to share their experiences see that their contribution was valued and meaningful, and that the engagement process was open, transparent and accountable.

6. Key stakeholders (i.e. who are we going to work with?)

Well-developed and maintained relationships with key stakeholders are crucial to ensuring the Cancer Alliance can foster positive change to cancer services, as they will help the Cancer Alliance reach those people affected by cancer to understand their experience of cancer services and take action to address the key issues identified by considered engagement activity.

This section explores the stakeholders who will play a role in the successful delivery of the engagement strategy and how the Cancer Alliance will ensure they are aware of our new way of working in this regard, and how we will join up with them much more closely going forward.

The Cancer Alliance's involvement of patients, the public and carers could be better, and it is our intention to improve our practice, especially in communities where people experience the greatest health inequalities.

Earlier in this strategy the importance of working with members of the voluntary, community and social enterprise (VCSE) sector was highlighted, as they have reach into the local communities we need to engage with to understand their experiences of cancer services and experience of care.

6.1 List of stakeholders

We will work with a number of people, groups and communities, including, but not limited to:

- Cancer patients, carers and the public
- Cancer Alliance patient and public representative group members

- Cancer Alliance colleagues, including:
 - Cancer Alliance programmes
 - Associated leadership boards and delivery groups
 - Clinical delivery groups
 - Lay representatives
- Key cancer charity partners (such as Macmillan Cancer Support and Cancer Research UK)
- Members of the Humber and North Yorkshire voluntary, community and social enterprise (VCSE) sector, including:
 - Local cancer charities
 - Local cancer support groups
 - Healthwatch
 - Community leaders (particularly in deprived areas and from seldom-heard groups)
- Staff working for organisations which commission and provide cancer services, including:
 - Hospital trusts
 - Place health and care partnerships (replacing clinical commissioning groups)
 - GP practices and other primary care partners
 - Community integrated care organisations
- NHS England, UK Health Security Agency and Office for Health Improvement and Disparities (formerly Public Health England)
- Humber and North Yorkshire Integrated Care System patient and public engagement colleagues

The Cancer Alliance undertook an extensive review of its stakeholders last year and will review them annually to ensure we are keeping our large number of stakeholders informed and involved in our work as appropriate.

7. Engagement methods

This section explores the different methods the Cancer Alliance will use to engage with cancer patients and the public. The Cancer Alliance is committed to utilising the most appropriate method of engagement to suit the people, groups or communities it wishes to engage with.

Generally speaking, when choosing the engagement approach, we will trial in the first instance, allow it to evolve, and amend if necessary to ensure it works. Engagement evaluation and monitoring is therefore extremely important.

The methods adopted for the engagement are dependent on many factors, including:

- Creating an inclusive approach, which takes inequalities into consideration, to ensure patients and public can contribute should they wish to.
- Capacity (i.e. availability of resources).
- The objectives of programme of work the engagement is being carried out to contribute to.

Moreover, patient and public engagement cannot be done as a 'one size fits all' activity. The chosen level of engagement must be appropriate to the audience, the circumstances and the issues concerned.

There are many ways in which people might participate in health and the Ladder of Engagement and Participation is widely recognised model for understanding different forms and degrees of patient and public.

All activity on the ladder is valuable but the participation activity becomes most meaningful towards the top of the ladder.

7.1 Ladder of participation

A ladder of participation for the Cancer Alliance has been created. It has been adapted from the <u>Ladder of Engagement and Participation Model</u> and NHS England's <u>guide to community-centred approaches for health and wellbeing</u>, which itself is adapted from <u>David Wilcox's guide to effective participation</u>.

Level	What does it entail?	Stance
Supporting local initiatives (devolving)	Community development: Placing decision making in the hands of the community and individuals. For example, personal health budgets or a community development approach.	'We can help you achieve what you want, within guidelines'
Acting together (collaborating)	Partnership building: Working in partnership with communities and patients in each aspect of the	'We want to carry out joint decisions together'

	decision, including the development of alternatives, and the identification of a preferred solution.	
Deciding Together (involving)	Consensus building: Working directly with communities and patients to ensure that concerns and aspirations are consistently understood and considered. For example, partnership boards, reference groups, and service users participating in policy groups.	'We want to develop options and decide together'
Consultation (consulting)	Communication and feedback: Obtaining community and individual feedback on analysis, alternatives, and / or decisions. For example, surveys, door-knocking, citizens' panels and focus groups.	'These are the options what do you think?'
Information (informing)	Presentation and promotion: Providing communities and individuals with balanced and objective information to assist them in understanding problems, alternatives, opportunities and solutions. For example, websites, newsletters and press releases.	'Here's what we are going to do'

7.2 List of engagement methods

Some of the traditional methods the Cancer Alliance will use to engage with cancer patients and the public include, but are not limited to:

- Surveys: paper, online, telephone or face-to-face. The Cancer Alliance can develop and manage online surveys via Tractivity, our stakeholder
 management platform, which is managed by the Communications and Engagement team. Equally, community organisations could be asked
 to carry out this activity on the Cancer Alliance's behalf, either voluntarily or if commissioned to do so.
- Focus groups and one-on-one interviews: these can be held in person or online (via MS Teams or Zoom). These are useful when you require detailed information about feelings, thoughts, perceptions and opinions. Focus groups would be delivered by the Cancer Alliance directly or community organisations could be asked to carry out this activity on the Cancer Alliance's behalf. There will be occasions where we would cofacilitate with professional facilitators or community leaders due to their expertise, knowledge or relationships in a particular area or wit certain stakeholders.
- Community pop-up stalls: Engage with people and distribute information at public venues using pop up stalls. For example, at shopping centres or at town marketplace days. Really useful to raise awareness about cancer prevention initiatives such as Lung Health Checks and gaining insight about potential barriers to access.

- Stalls at health events: Engage with people and distribute information at public events specifically focused on health and wellbeing. A really good way to engage with people from deprived areas or seldom-heard groups.
- Co-production events: These workshop-style events are a good opportunity to involve the public and stakeholders in developing service design, e.g. the Humber and North Yorkshire non-surgical oncology workforce review.
- Listening activities: Less structured conversation which ensures that cancer patients and the public are not restricted in what they wish to discuss, which helps to discover issues and / or concerns which might not initially be obvious. These are drop-in by nature and could be added into larger-scale community roadshow events.
- Case studies and patient stories: Although these are used to raise awareness about cancer symptoms and promote vigilance to support early detection, they can also be used at leadership boards and delivery groups to help members link the discussion around transforming cancer services back to the patient voice.
- Other methods: Leaflets and posters distributed to community venues, GP surgeries and pharmacies, at public events, or through on-street distribution methods with a specific call to action together insight about cancer services and experience of care from patients and the public. Social media is also a very useful tool to encourage two-way dialogue, but you must be mindful not to exclude those with low digital literacy and non-social media users from the conversation (see next section).

There are other factors to consider and best-practice to follow when considering your engagement approach...

7.3 Embracing digital methods of engagement

The Cancer Alliance will utilise digital channels to engage with the people, groups or communities it wishes to engage with, recognising that we can use technology and social media to reach a wider population as part of our engagement activities.

These opportunities will also be promoted across the Cancer Alliance's digital communication channels and its partners' communication channels (e.g. website, e-newsletters and social media channels). Real-time engagement platforms such as Mentimeter and Jamboard will be used routinely, and the Cancer Alliance will develop best practice around their usage.

But, recognising that there are several groups, communities and areas in Humber and North Yorkshire where digital literacy is low, we will not neglect traditional engagement methods to ensure their voices are heard and their views help to transform cancer services and improve patient experience of care.

We will also use digital technology to aid in the analysis of feedback, which can identify themes and trends in greater detail.

7.4 Using existing insight

As mentioned earlier in this strategy, the results from national surveys such as the Cancer Patient Experience Survey and the Quality of Life Survey will be used to inform our work to improve outcomes for cancer patients. The Cancer Alliance will explore whether we can also use patient experience feedback collated by partner organisations which provide cancer services, such as the <u>Friends and Family Test</u> results, to inform this work.

7.5 Working with experts by experience

As part of its stakeholder relationship building activity outlined earlier in this strategy, the Cancer Alliance will build a 'bank' of patients, families and carers as 'experts by experience' to contribute to service improvement and redesign work. These participants would not necessarily become part of the Cancer Alliance's patient and public representative group (unless they were keen to be involved this way), but asked to provide feedback into work projects specifically relating to their lived experience.

Those local cancer charities which are specific to a tumour site, for example, would play a key role in putting the Cancer Alliance in touch with patients and their families to feed into specific Cancer Alliance work.

An example of this would be the Cancer Alliance's work to understand the psychosocial support available to cancer patients with pre-existing mental health conditions, dementia or autism.

The Cancer Alliance is working with charities in Humber and North Yorkshire such as Mind, Dementia Forward and the National Autistic Society to ensure patient voice is threaded through the work being carried out to tailor mental health services to cancer patients also affected by these conditions.

7.6 Closing the loop

Regardless of the engagement method employed, the Cancer Alliance will always ensure it 'closes the loop' by communicating with those people who have participated in engagement activity to let them know the outcome of the engagement activity.

It is a vital part of the engagement process because it requires the Cancer Alliance to show what information we have gathered and the impact it has had on the way we carry out our work. From the patient and member of the public's perspective, it helps them to feel valued and encourage them to be involved.

Some of the ways the Cancer Alliance will close the loop include:

- Personal feedback: Letters and emails to those who have taken part to round up key points and answer further questions.
- Website: Survey results, verbatim comments and formal consultation documents, you said, we did information is regularly posted on our website in a timely manner. This includes information about recent surveys or engagement events.
- Newsletters: Providing updates about how the public has influenced the Cancer Alliance's work, including links to outcomes of surveys.
- Reports: We will create short reports collating the main feedback on topics where we have asked for patient and/or public feedback.
- Inviting in patients / public to find out how their feedback has made a difference: Inviting people with concerns about cancer services to meetings to hear their perspective and work with them to identify solutions.
- Patient stories: We will present a patient story as a regular item at the start of the various Cancer Alliance leadership boards, with the preference for the patient to tell their story themselves. each Quality and Patient Experience Committee (QPEC). We already follow this practice with some of our leadership boards and will continue to do so going forward and feed back to them the difference their story has made.
- Social media: We will use our social media channels to provide feedback and updates about surveys, strategies and plans.
- Presentations at forums: We will attend patient forum meetings and VCSE sector network meetings to provide an update on how their feedback has influenced the work we have done
- Board meetings: We will regularly update the Cancer Alliance's leadership boards to feedback what people have told us through our various patient and public engagement activity.

8. Evaluating and monitoring

The Communications and Engagement team will also work with the Cancer Alliance's patient and public engagement group and other stakeholders to develop a patient and public involvement dashboard with relevant metrics to measure the success of engagement activity against KPIs to ensure objectives are met. This insight will be gathered on a regular and ad hoc basis and circulated to stakeholders.

The tables below provide an overview of the general objectives to improve the Cancer Alliance's patient and public engagement function. See the responsible, accountable, consulted and informed (RACI) table in section nine for more detail about specific objectives.

Objective:

To understand what matters to cancer patients most and identify where improvements to services can be made to improve patient experience.

KPIs:

- Improved dialogue of patients, carers and the public that are involved in activities and people's satisfaction in getting involved.
- Robust yearly Cancer Alliance programme engagement plans which include authentic involvement opportunities to improve service and experience of care.
- Identify themes and trends from secondary engagement activity (CPES, QoL etc) and formulate actions plans to address issues highlighted.
- The above activity will become business as usual.

Objective:

To work in collaboration with cancer patients and the organisations which provide cancer services to co-develop improvement plans based on feedback from patients around experience of care.

KPIs:

- Increased instances of authentic patient and public engagement activity co-ordinated across the different Cancer Alliance work programmes.
- Improved outcomes from programme projects where there has been significant patient and/or public involvement.
- The way patient and public engagement is carried out with partners will be well co-ordinated and evaluated, which will help to improve the how we share insight and intelligence across the local health and care system.
- Improvement in CPES results per trust/Cancer Alliance area.
- The above activity will become business as usual.

Objective:

To communicate how specific engagement has improved cancer services / patient outcomes to those who have taken part (closing the loop).

KPIs:

- Improved dialogue of patients, carers and the public that are involved in activities and people's satisfaction in getting involved.
- Outcome of patient engagement activity communicated via following mechanisms (board meetings, reports, follow-up communications).
- Communication to illustrate how their involvement has led to service improvement will be proactively carried out with those who have provided feedback via planned Cancer Alliance engagement activity.
- The above activity will become business as usual.

8.1 Strategy outcomes

The outcomes that this strategy will deliver are:

- There will be an improved culture of understanding and commitment to patient and public engagement within the Cancer Alliance work programme teams.
- With support from the Communications and Engagement team, the Cancer Alliance programme teams will undertake more meaningful patient and public engagement which will authentically influence the work the programme carries out.
- Communication to illustrate how their involvement has led to service improvement will be proactively carried out with those who have provided feedback via planned Cancer Alliance engagement activity.
- Increased confidence in the Cancer Alliance colleagues to undertake patient and public engagement.
- Patients and public will receive timely communications about the different ways in which they can be involved in Cancer Alliance work.
- The way patient and public engagement is carried out with partners will be well co-ordinated and evaluated, which will help to improve how we share insight and intelligence across the local health and care system.
- Patients and the public, especially those from deprived communities where health inequalities are greatest, will be more aware of how they can be with Cancer Alliance engagement activity to influence improvements in cancer services in Humber and North Yorkshire.
- The above activity will become business as usual.

8.2 Evaluation measures

The Cancer Alliance will know we have achieved the above because we will be able to demonstrate the following:

• Increased instances of authentic patient and public engagement activity co-ordinated across the different Cancer Alliance work programmes.

- Increased confidence in Cancer Alliance programme office colleagues to undertake patient and public engagement, which leads to improvement to cancer services and cancer patient experience of care.
- Improved dialogue with patients, carers and the public that are involved in activities and people's satisfaction in getting involved.
- Improved outcomes from programme projects where there has been significant patient and/or public involvement.
- Increased co-ordination of patient and public engagement activity with partners across the local health and care system.
- Increased interaction to communicate how the views of patients and the public we have engaged with have influenced outcomes in specific work of the Cancer Alliance. Where their views have not influenced outcomes, we will explain why this is the case.

9. Next steps: roles, responsibilities and accountability

Who's doing what and when are they doing this during the 2023/24. Responsibilities have been determined for each element of patient and public engagement.

	RACI and next steps: 23/24 Cancer Alliance patient and public engagement milestones						
Objective	Action	Responsible	Accountable	Consulted	Informed	Deadline	
To develop and communicate new Cancer Alliance engagement strategy	 Hold workshop with senior Cancer Alliance colleagues, patient representatives and patient and public involvement professionals to identify and co-develop main themes of strategy. (April 2023) Use insight from April workshop to develop the strategy. (May to July 2023) 	Communications and Engagement Lead	Communications and Engagement Lead	 Cancer Alliance Managing Director Cancer Alliance Programme Leads Cancer Alliance Patient and public representatives 	 Cancer Alliance Chair Cancer Alliance Clinical Lead Cancer Alliance Communications and Engagement team Individual Cancer Alliance programme teams Integrated Care Board (ICB) communications 	August 2023	

	Share the strategy for comment, carry out amends as necessary. (August and September 2023)				and engagement directorate	
To agree 23/24 patient and public engagement work activity for each Cancer Alliance programme	 23/24 programme communications and engagement plans developed for programme leads and teams to comment on and contribute to. (May to June 2023) Individual programme 23/24 communications and engagement plans agreed between respective programme leads and communications and engagement lead. (August to September 2023) 	 Programme Leads Communications and Engagement Lead 	Programme Leads Communications and Engagement Lead	Patient and Public Representatives	 Managing Director Individual CA programme teams Communications and Engagement team ICB Communications and Engagement Directorate 	September 2023
To gain System Board approval to implement new Cancer Alliance engagement strategy	 Strategy submitted for System Board papers. (18th September 2023) Strategy presented to the System Board. (27th September 2023) 	Communications and Engagement Lead	Communications and Engagement Lead	System Board (including: Managing Director, Chair Clinical Lead)	 Communications and Engagement team Patient and Public Representatives Individual CA programme teams ICB Communications and Engagement Directorate 	September 2023
To create an engagement dashboard with relevant metrics to measure the success of the engagement	Scoping work to identify dashboards in use at ICB or at other cancer alliances and evaluate whether any features should be incorporated	Senior Patient and Public Engagement Co-ordinator	Communications and Engagement Lead	 Programme Leads Patient and Public Representatives 	 Managing Director Chair Clinical Lead Patient and Public Representatives 	Q3 (October to December 2023)

against KPIs to ensure objectives are met	 into Cancer Alliance dashboard. (November 2023) Work with patient representative group, Cancer Alliance programmes and other stakeholders to identify what metrics should be included on the dashboard (November 2023) Develop dashboard and test during some relevant engagement activity. (December 2023) Training for Cancer Alliance colleagues on dashboard use and 			•	ICB Communications and Engagement Directorate	•	Individual CA programme teams	
To set up the Cancer Alliance Communications and Engagement Programme Board to deliver individual programme's agreed 23/24 engagement activity	purpose. (December 2023) Identify Board members Board. (October 2023) Set meeting schedule for remainder of 23/24, with inaugural meeting scheduled in October or November 2023. (October 2023) Develop Terms of Reference and other governance docs. (November 2023)	Communications and Engagement Lead	Communications and Engagement Lead	•	Programme Leads Patient and Public Representatives	•	Managing Director Chair Clinical Lead Patient and Public Representatives Individual CA programme teams ICB Communications and Engagement Directorate	Q3 (October – December 2023) Meeting bi- monthly so schedule might be: October 2023 December 2023 February 2024 April 2024

To deliver individual programme's agreed 23/24 engagement activity	 Monthly meetings with individual programmes teams to develop work plans to carry out patient and public engagement activity outlined in 23/24 programme communications and engagement plans. (First meetings from October 2023) Identification and the setting up of task and finish groups where necessary to deliver specific PPE engagement activity. (From October 2023) 	Programme Leads (and team) and Communications and Engagement Lead (and team)	Programme Leads and Communications and Engagement Lead	Patient and Public Representatives	 Managing Director Chair Clinical Lead Patient and Public Representatives Individual CA programme teams ICB Communications and Engagement Directorate 	Throughout year (Progress monitored at bi- monthly comms and engagement Programme Board meetings (see above schedule)
To establish and maintain relationships with cancer support groups, cancer charities and other key stakeholders (i.e. from VCSE sector)	Relationship building via one-to-one meetings with cancer support group leaders, cancer charity PPE colleagues and other stakeholders with PPE interests. (October to December 2023) Establish a cancer support group directory to improve communications and involvement activity with these groups (October to December 2023) Develop a Humber and North Yorkshire cancer support group network	Senior Patient and Public Engagement Coordinator Personalised Care (Living With and Beyond Cancer) programme	Senior Patient and Public Engagement Coordinator Personalised Care (Living With and Beyond Cancer) programme	 Communications and Engagement Lead Personalised Care (LWBC) Programme Lead Patient and Public Representatives 	Communications and Engagement team Other CA programme leads Individual CA programme teams	Q3 and Q4 (and beyond)

	to facilitate joint- working opportunities. (October to December 2023) • Develop a plan for incorporating these groups into the PPE work of the Cancer Alliance. (January to March 2023)					
To expand and diversify the patient and public partnership (representative) group	 Identify patient groups and other partners the Cancer Alliance wants to work with. (October 2023) Further develop the patient representative induction process. (October to November 2023) Enhance patient representative training programme. (November and December 2023) Plan patient representative recruitment campaign. (November and December 2023) Deliver patient representative recruitment campaign. (January to March 2024) 	Senior Patient and Public Engagement Co-ordinator	Communications and Engagement Lead	Communications and Engagement Lead Programme Leads Patient and Public Representatives	Communications and Engagement team Other CA programme leads Individual CA programme teams ICB Communications and Engagement Directorate	Q4 (January to March 2023)
To evaluating and	Collate all patient and	Communications and	Communications and	Programme	Managing Director	End of Q4 (i.e.
monitoring success of	public engagement	Engagement Lead	Engagement Lead	Leads	Chair	March 2024)

new approach to patient and public engagement	reports since new approach adopted. (March 2024)	Patient and Public Representatives	Clinical LeadCommunications and Engagement
	Review activity relating to improving the		team Individual CA programme teams
	Cancer Alliance's function for effectiveness. (March 2024)		ICB Communications and Engagement Directorate

10. Further reading

- Link to full ICB working with people and communities engagement strategy: www.hny-working-with-people-and-communities-engagement-strategy-june-2022.pdf (hullccg.nhs.uk)
- Link to ICB working with people and communities engagement strategy (summary): www.humberandnorthyorkshire.icb.nhs.uk/wp-content/uploads/2022/07/HNY-Working-With-People-and-Communities-Public-Facing.pdf
- 10 Steps model: <u>NHS England's 10 Steps to Working with People and Communities model</u>
- NHSE patient and public involvement: www.england.nhs.uk/aac/what-we-do/patient-and-public-involvement
- NHSE ladder of engagement and participation model: www.ngage.england.nhs.uk/survey/strengthening-ppp/supporting-documents/ppppolicy.pdf#page=14
- National Cancer Patient Experience Survey: <u>www.ncpes.co.uk</u>
- Humber and North Yorkshire (Cancer Alliance) Cancer Patient Experience Survey results: www.hnycanceralliance.org.uk/wp-content/uploads/2019/06/CPES-2022-Alliance-Humber-and-North-Yorkshire-Cancer-Alliance-E56000026-1-3.pdf
- Quality of Life Survey: <u>www.cancerqol.england.nhs.uk</u>
- The Gunning Principles (for public consultation): www.local.gov.uk/sites/default/files/documents/The%20Gunning%20Principles.pdf

- The NHS Long Term Plan: www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf
- The NHS Long Term Plan for Cancer: www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/better-care-for-major-health-conditions/cancer
- The Humber and North Yorkshire Health and Care Partnership Long Term Plan: www.humberandnorthyorkshire.org.uk/wp-content/uploads/2020/03/FINAL-REVISED-HCV-Partnership-Long-Term-Plan-v5.0.pdf