Llais response to the National Cancer Strategy for Wales

October 2026

Submit to: qualityandnursing@gov.wales

About Llais

Llais is the independent statutory body that reflects the views and represents the interests of people living in Wales in their NHS and social care services. We have operated since 1 April 2023, working locally, regionally and nationally to give people a strong voice in the planning, design, development and delivery of health and social care services.

We listen to people and communities across Wales through our public engagement activities, including visits to places where people receive care. We use what people tell us to make representations to NHS bodies and local authorities, so that their views and experiences inform decisions and improvements to services. We also work to make sure people can have their say from the start when changes to services are being considered.

We provide a free, independent and confidential complaints advocacy service, supporting people to raise concerns or complaints about NHS and social care services. Through our partnership with Tenovus Cancer Care, we have a dedicated cancer complaints advocate available to support people living in Wales to raise concerns about their cancer care and treatment.

What our response is based on

Our response to the call for evidence on a National Cancer Strategy for Wales draws on what we've heard from people about their experiences of health and social care, including cancer diagnosis, treatment, follow-up and support.

It brings together the views and experiences shared through our public engagement work, what we hear from others, including our work with

partners, and the concerns raised by people we support through our complaints advocacy service.

We use this evidence to highlight what matters to people and where their experiences point to a need for improvement. Our response offers a people's perspective on cancer services and the wider support people, families and carers need, rather than a clinical or technical assessment of cancer treatment.

1. How should the national cancer strategy improve outcomes?

The aim of the strategy is to improve population outcomes for cancer. This includes:

- **reducing the number of people per 100,000 who develop cancer**
- **improving survival after a cancer diagnosis**
- **reducing the number of people per 100,000 who die from cancer each year**
- **improving people's experience of NHS services**

There are many ways to improve cancer outcomes. We want to know how you think the Welsh Government can make the greatest difference.

Llais welcomes the development of a National Cancer Strategy for Wales.

From what people tell us, improving cancer outcomes is about more than preventing cancer, diagnosing it earlier and helping people live longer. These things matter greatly, but people also judge their experience by how easy it is to access help, how well services work together, whether they feel listened to and supported, and how cancer affects their day-to-day lives.

People often speak highly of the care they receive from cancer teams and the compassion shown by staff. Many describe excellent treatment once they enter the system.

We also hear about long waits for appointments, tests and results; difficulties getting clear information; and the stress of finding their way around different services during an already challenging time.

Our insights highlight concerns about delayed or missed diagnoses, cancellations, delays in treatment, gaps in follow-up care and poor communication between services. People tell us that these experiences can leave them feeling anxious, uncertain and unsupported. For some, the struggle is not only the cancer itself, but the effort required to find answers, chase appointments or understand what is happening next.

Our **People's Principles** provide a useful framework for understanding what good care looks like from the public's perspective. People want services that are accessible, timely, joined up and compassionate. They want clear information, honest conversations and confidence that services understand their individual needs. Above all, they want to be treated as a whole person rather than a condition or diagnosis.

To make the greatest difference, the strategy should focus on improving people's experience throughout the entire cancer journey. This includes supporting prevention and early diagnosis, reducing delays, improving coordination between services, making sure people know who to contact when they need help, and providing practical, emotional and psychological support when it is needed. It should also strengthen rehabilitation, recovery support, palliative care and support for families and carers.

Attention should be given to reducing inequalities. Everyone should be able to access high-quality cancer care regardless of where they live, the language they speak, whether they have a disability, their background or the type of cancer they have.

We have heard from people who face additional challenges because they live in rural areas or need to travel significant distances for treatment. These barriers can affect both access to care and quality of life and should be reflected in the strategy's approach.

Success should not be measured only through survival rates and waiting-time targets. These remain important, but they should be considered alongside what people tell us about their experiences. This

includes whether they felt listened to, informed and supported; whether care was joined up; whether they could access help when they needed it; and whether their quality of life was improved.

People's experiences should be treated as a key measure of success. The strategy should demonstrate how feedback from patients, families and carers is used to shape services and drive improvement, and how those improvements have made a difference to people's lives.

2. How can more cancers be detected at earlier stages?

Most cancers can be staged based on how far they have progressed. Earlier-stage cancers are often easier to treat but can be harder to detect.

We want to know what factors, developments, approaches or innovations could help more cancers be detected at earlier stages in Wales.

People tell us that earlier diagnosis starts with feeling able to seek help and being confident that concerns will be taken seriously.

When people are diagnosed early, they often describe a straightforward journey where symptoms were recognised, investigations happened quickly, and they knew what was happening next.

However, we also hear from people whose diagnosis was delayed because symptoms were not recognised, were attributed to another condition, or because they experienced long waits between appointments, tests and results.

A recurring theme in what we hear is that people often know when something does not feel right. When symptoms persist, worsen or do not improve, they want to feel listened to and involved in decisions about what happens next. People can become frustrated and distressed when they feel they have to repeatedly seek help, explain their symptoms several times, or push for further investigation.

Detecting more cancers earlier will require action at every stage of a person's journey. This includes helping people understand potential symptoms, making it easy to access advice and support, taking concerns seriously at first contact, providing timely access to tests and reducing delays between referral, diagnosis and treatment.

People also tell us that uncertainty can be one of the hardest parts of the process. Waiting for appointments, tests or results can cause significant anxiety, particularly when people do not know how long they will wait or who to contact if they have concerns. Clear communication and regular updates can make a significant difference to people's experience, even when they are waiting.

We know that not everyone experiences the healthcare system in the same way. Some people face additional barriers because of language, disability, culture, geography, digital exclusion, transport difficulties or financial pressures.

Others may be less likely to recognise symptoms or seek help. The strategy should take these differences into account and make sure information, screening programmes and diagnostic services are accessible to everyone.

We have also heard from people living in rural and cross-border communities who face additional challenges accessing appointments, investigations and specialist services. Efforts to improve early diagnosis should make sure that where people live does not affect their ability to access timely assessment and care.

Screening programmes have an important role to play in detecting cancer earlier. Encouraging participation will require clear communication, accessible information and public confidence in the process. People should be involved in the design and development of new approaches so that services work for the communities they are intended to serve.

Technology, innovation and new ways of working may help detect cancers earlier, but these developments should improve access rather than create new barriers. New approaches should be designed around

people's needs and introduced in ways that are fair, inclusive and easy to navigate.

Through our complaints advocacy service and engagement activities we have heard about the impact of missed follow-up appointments, delayed investigations and failures in ongoing monitoring after treatment.

Earlier detection is not only about identifying cancer for the first time; it also includes recognising recurrence or deterioration as quickly as possible. Strong follow-up arrangements and clear communication are therefore essential.

Improving early diagnosis is not just about meeting targets. It is about creating a system that people can access easily, understand clearly and trust to respond when they need help.

3. How should the NHS prepare to deliver future cancer treatments?

Healthcare services are constantly changing as new evidence about cancer treatment emerges. This means the NHS needs to prepare for new and innovative ways of treating cancer.

We want to know what major changes the NHS should prepare for over the next 10 years to ensure it can deliver future cancer treatments.

People affected by cancer often see research, new treatments and innovation as a source of hope. They want reassurance that advances will be available fairly and consistently across Wales and the UK.

From what we hear, preparing for future cancer treatments is about much more than introducing new medicines or technologies. People want confidence that services will be ready to deliver new treatments safely, fairly and in a way that works for them.

Many people tell us that access to treatment should not depend on geography. We hear concerns from people who travel long distances for appointments and treatment, particularly those living in rural communities or receiving care across the Wales-England border.

Long journeys, transport difficulties, parking costs and time away from work or family can all add to the burden of cancer. As new treatments are introduced, the NHS should consider how care can be delivered closer to home wherever possible and make sure that people can access treatment without facing unnecessary barriers.

People also want clear information so they can make informed decisions about their care. New treatments often bring new choices, but choice is only meaningful when people understand the options available to them.

We regularly hear how important it is for information to be explained in plain language, with opportunities to ask questions and discuss what different treatments might mean for their quality of life, recovery and future wellbeing.

A recurring message from people is the importance of feeling supported throughout their cancer journey. Many value having a trusted professional who understands their circumstances and can help them navigate complex services.

As treatments become more specialised and personalised, this need is likely to become even more important. People should know who to contact when they need advice, information or support.

People also tell us that good care depends on services working well together. Too often, individuals and families feel responsible for joining the dots between different teams, appointments and organisations.

Future developments in cancer treatment should be supported by systems that allow information to be shared effectively so that care feels coordinated from the person's perspective.

Innovation should benefit everyone. The strategy should consider the needs of people who face additional barriers in accessing care, including disabled people, Welsh speakers, people from minority communities, those who are digitally excluded, and people living in rural areas.

New technologies and digital approaches may improve access for some people, but they should increase choice rather than replace face-to-face support where this is needed or preferred.

People affected by cancer, their families and carers should be involved in shaping priorities for how new treatments and services are developed, introduced and evaluated.

Co-production helps ensure that innovation reflects what matters most to people, not only what matters to the system. It can help identify potential barriers early, improve communication and accessibility, and build confidence in new approaches to care.

We also hear about the wider impact of cancer on people's lives. Treatment can affect people's ability to work, travel, care for others and manage financially. As new treatments are introduced, consideration should be given to the practical, emotional and financial support people may need alongside their clinical care.

Workforce planning will also be critical. People consistently tell us that compassionate, knowledgeable staff make a huge difference to their experience. The NHS will need enough trained staff with the time and support to deliver new treatments safely, explain complex information clearly and provide personalised care.

People want confidence that advances in cancer treatment will lead to real improvements in their experience and outcomes. They want to have high-quality care when they need it, understand their options and receive joined-up support.

4. What support should individuals, carers and families receive during and after cancer treatment?

Healthcare services do more than treat cancer. They also provide advice, support and care during diagnosis, treatment and recovery.

We want to know what the NHS and other organisations should provide to improve the experience of people affected by cancer.

People tell us that support should not begin and end with treatment. Cancer can affect every part of a person's life, and the need for support often continues long after appointments become less frequent or treatment has finished.

A consistent message we hear is that people want to feel supported, informed and connected throughout their cancer journey. While many people describe excellent care and compassionate support from professionals, others tell us they felt uncertain about what would happen next, who to contact for help, or where to turn when problems arose.

Many people value having a trusted point of contact who understands their circumstances and can provide advice, reassurance and practical support. Clinical Nurse Specialists and other key workers are often described as making a significant difference to people's experiences.

However, access to this support is not always consistent. Everyone affected by cancer should have a named contact who can help them navigate services, answer questions and act as a source of continuity throughout their care.

People have shared with us how important clear information is, particularly at diagnosis and during periods of uncertainty. Information should be easy to understand, available in Welsh and English, and provided in formats that meet people's communication needs.

People should know what to expect, what support is available, who is responsible for their care, and where to go for help if their circumstances change. Recognising that diagnosis and treatment can be overwhelming, information should be provided more than once and in ways that people can refer back to later.

Support should reflect the fact that cancer affects more than physical health. People describe the emotional impact of diagnosis, treatment and uncertainty about the future, as well as worries about family life, work, finances and maintaining independence.

We have heard from people who felt well supported emotionally, but also from others who felt left to cope alone. Access to psychological and emotional support should be available throughout the cancer pathway and not only when someone reaches crisis point.

We also hear that the impact of cancer does not end when treatment finishes. Many people continue to live with fatigue, pain, reduced mobility, anxiety, changes to relationships, financial pressures and other long-term effects.

People often tell us that recovery can be much longer and more complex than they expected. Ongoing support should include rehabilitation, therapies, practical advice and help to manage the longer-term consequences of cancer and its treatment.

Families and carers play a vital role in supporting people affected by cancer. They often provide emotional support, attend appointments, help with day-to-day care, organise transport, manage information and advocate on behalf of loved ones.

While many willingly take on these responsibilities, they can be demanding and have a significant impact on carers' own wellbeing.

Carers and families need information, advice and support in their own right. Where appropriate, they should be involved in discussions and decisions, while also having access to carer assessments, emotional support, respite and bereavement support. Services should recognise the contribution carers make and avoid assumptions that families can take on increasing responsibilities without support.

A recurring concern raised with us is that people and families can feel responsible for holding care together themselves. We hear about people chasing appointments, following up test results, repeating information to different teams and trying to coordinate services.

At a time when people should be focusing on their health and wellbeing, this can create unnecessary stress and anxiety. Support should include better coordination between services so that people experience care as joined up and seamless.

The transition points in care are particularly important. People often feel most vulnerable when moving from diagnosis to treatment, from hospital to home, from active treatment to follow-up, or when entering palliative and end-of-life care. Extra support, clear communication and well-coordinated planning are essential during these periods.

We also recognise the important role played by charities and community organisations in supporting people affected by cancer. Many people value these services greatly. Access to support should not depend on knowing where to look or being confident enough to seek help

independently. Everyone should be able to access consistent support when they need it.

People want support that recognises them as individuals, not just as patients. They want to feel informed, listened to and supported throughout their cancer journey, and confident that help will continue to be available for as long as they need it.

5. What opportunities exist to strengthen cancer research, clinical trials and innovation in Wales?

Improving cancer care, treatment and outcomes requires a strong focus on research.

This includes:

- **population studies**
- **laboratory-based research**
- **clinical trials of new treatments and tests**
- **adopting new and innovative practices**

We want to know what developments, opportunities and approaches could strengthen cancer research and innovation in Wales

People strongly support research and the development of new treatment options. However, they are often concerned about whether they will be able to access those advances in practice.

From what we hear, many people are supportive of research and want to contribute to improving cancer care for future generations. Awareness of research opportunities can vary, and not everyone feels they have the same chance to take part.

People should not miss out on opportunities because of where they live, the type of cancer they have, or because they were never told that a study or trial existed.

Information about research should be clear, accessible and easy to understand. People need honest information about what taking part

involves, the possible benefits and risks, what support is available, and what will happen during and after the study.

Participation should always be a genuine choice, and people should feel able to ask questions and make informed decisions about whether a particular opportunity is right for them.

We have heard from people living in rural and cross-border communities about the challenges of travelling for appointments and treatment. Similar barriers can affect participation in research and clinical trials.

Consideration should be given to how people can take part without facing significant travel, financial or practical burdens. Where appropriate, opportunities to participate closer to home or through more flexible approaches should be explored.

People also tell us that cancer research should focus on the issues that have the greatest impact on their lives. This includes improving early diagnosis, understanding and reducing treatment side effects, supporting recovery, improving quality of life, addressing inequalities in access and outcomes, and improving support for people living with and beyond cancer.

Research into rare cancers and the experiences of groups who may face additional barriers to care is also important.

A strong message from our work is that people want to be involved in shaping the future of cancer services, not just consulted once decisions have already been made.

People affected by cancer, families, carers and communities should be involved in identifying research priorities, designing studies, developing innovations and evaluating whether new approaches are making a meaningful difference. Co-production can help make sure research reflects what matters most to people and leads to improvements that are practical, accessible and relevant to their everyday lives.

Innovation should not be seen as an end in itself. New tests, treatments, technologies and ways of working should improve people's experiences as well as clinical outcomes. People want services that are easier to navigate, more joined up, and better able to meet their individual needs.

New approaches should be introduced in ways that reduce inequalities rather than create new barriers for those who are already disadvantaged.

We hear how frustrating it is for people when promising treatments and innovations are not adopted consistently, or when people see new options becoming available elsewhere in the UK before they are available in Wales.

This can create uncertainty and undermine confidence in the system. The Strategy should support timely, evidence-based decisions about new treatments, with clear communication about availability, eligibility and the reasons behind those decisions. Where research demonstrates clear benefits, there should be a clear route to implementing effective innovations consistently across Wales.

Where research demonstrates clear benefits, there should be transparent processes for deciding how effective innovations will be implemented and made available across Wales.

People who take part in research often want to know what difference their contribution has made. Providing accessible feedback, sharing findings in plain language and demonstrating how research has influenced practice can help build trust and encourage future participation.

Ultimately, people want cancer research and innovation to lead to real improvements in people's lives. Success should be reflected not only in the number of studies taking place, but in whether more people have an opportunity to participate, whether research addresses the issues that matter most to them, and whether it results in better experiences and outcomes for people affected by cancer.

6. What future workforce, equipment and facilities will be needed to deliver high-quality cancer care in Wales?

The NHS delivers cancer treatment and care in a range of settings, including people's homes, GP surgeries, hospitals and specialist cancer centres.

Many clinical teams play a role in caring for people affected by cancer. For some specialist teams, such as oncology services and cancer specialist nurses, this is their primary role.

The quality of people's cancer care is shaped by the people they meet, the support they receive and how well services work together. Many speak highly of the compassion, skill and dedication of staff across Wales.

We also hear about delays, difficulties accessing support and the challenges people face when different parts of the system do not work together as seamlessly as they should.

The success of the strategy will depend on having sufficient workforce capacity, facilities and infrastructure to deliver high-quality care.

Future workforce planning should start with the experience people need and expect from cancer services. People want timely care, clear communication, continuity of support and confidence that services will work together around them. The workforce, equipment and facilities needed in the future should be planned with these outcomes in mind.

A strong and sustainable workforce will be very important. This includes not only specialist cancer teams, but also primary care, diagnostics, radiology, pathology, pharmacy, rehabilitation, community services, psychological support, social care and palliative care.

People's experiences are shaped by everyone involved in their care, from the person arranging appointments to the clinical staff delivering treatment and ongoing support.

We regularly hear how valuable it is for people to have a trusted point of contact who understands their circumstances and can help them navigate the system. Clinical Nurse Specialists and other key workers are often described as making a significant difference to people's experience. Future workforce planning should make sure that everyone affected by cancer has access to this kind of support.

People also tell us about the anxiety they feel when appointments are delayed, follow-up arrangements are unclear, or they are unsure who to

contact with concerns. Good cancer care relies on more than clinical staff alone.

Administrative, coordination and support roles are equally important in making sure appointments happen when they should, information is shared effectively and people do not feel lost or alone within the system.

As cancer treatments continue to develop, staff will need the skills, time and support to adapt to new approaches and technologies. Investment in training and development will be essential, alongside efforts to recruit, retain and support the workforce.

People value not only clinical expertise but also the ability of staff to explain information clearly and compassionately, answer questions and support decision-making.

We also hear from people about the practical challenges of accessing care. Long journeys for appointments and treatment can be physically demanding, expensive and stressful, particularly for those living in rural communities or accessing specialist services far from home.

Where it is safe and appropriate, services should be delivered closer to home through community provision, outreach services, remote monitoring or satellite clinics. This can help reduce the burden on people and their families while maintaining access to specialist care when needed.

Facilities should be designed around people's needs. People tell us they want environments that are welcoming, accessible and easy to get around. Privacy, dignity and comfort matter, particularly during difficult conversations, treatment and end-of-life care. Facilities should also meet the needs of people with disabilities, sensory impairments and different communication requirements.

Technology and equipment will continue to play an important role in improving diagnosis, treatment and monitoring. However, investment in buildings and equipment alone will not improve people's experiences. New facilities and technologies must be supported by sufficient staffing, effective coordination and clear pathways of care.

We also know that people's needs do not always fit organisational boundaries. Future planning should recognise the realities of rural and

cross-border care and make sure that services are designed around people rather than organisations. This includes considering travel, transport, appointment scheduling and the support people may need to access care.

People want cancer services that are reliable, accessible and compassionate. The future workforce, facilities and equipment should support timely care, reduce avoidable delays and improve coordination between services.

7. What improvements in digital systems and cancer data will support improved care and outcomes?

Data plays an important role in supporting individual care and helping the NHS plan services.

More accurate, integrated and accessible data can improve patient care, service delivery and planning.

We want to know how improvements in digital systems, technology and cancer data could support better care, service planning and outcomes.

People generally do not talk to us about digital systems or datasets. They talk about whether services communicate with each other, whether they have to repeat their story, whether they know what is happening next, and whether they can get the information and support they need when they need it.

From a person's perspective, digital systems should make cancer care feel more joined up and easier to navigate. They should help services work together behind the scenes so that people do not have to act as the link between different teams, organisations or appointments.

A recurring concern in what we hear is the effort people sometimes have to make to follow up test results, chase appointments or find out next steps in their care. People tell us that this can create unnecessary stress and uncertainty at an already difficult time.

Better digital systems should help make sure that referrals, test results, follow-up appointments and ongoing monitoring are tracked effectively so that people do not feel lost in the system.

People also want confidence that the professionals involved in their care have access to the information they need. Too often, people describe having to repeat their medical history, explain their situation multiple times or carry information between services themselves.

Better information sharing between primary care, hospitals, specialist services, community care and palliative care could help improve continuity of care and reduce frustration for patients and families.

Digital services can make it easier for people to access information about appointments, care plans, test results and support. However, digital access should increase choice rather than replace other ways of communicating.

Not everyone is able, willing or confident to use digital services. People should still be able to access information and support by telephone, in person and through other accessible routes. This is particularly important for people with disabilities, sensory impairments, communication needs, limited digital confidence or poor internet access.

We also hear from people about the anxiety that can come with receiving information without support or explanation. Digital systems should be designed around people's needs, making sure that important or distressing information is shared sensitively and that people know who to contact if they have questions or concerns.

People also tell us that access to their own information can be difficult and inconsistent. Through our work, we hear from individuals seeking access to medical records and personal information who can experience delays, fragmented processes or uncertainty about how to obtain information relating to their care. Access to personal information is important not only for transparency and trust but also because it can help people understand their diagnosis, treatment and decisions about their care. Digital improvements should make it easier for people to access their own information in a timely, accessible and understandable

way, with clear support available where records are complex or difficult to interpret.

Good cancer data should help services understand the whole journey people take, from their first concern through diagnosis, treatment, follow-up and ongoing support. It should help identify where delays occur, where people are experiencing poorer outcomes or access, and where particular groups or communities may be facing barriers.

Performance figures can show where variation exists, but people's experiences help explain what that variation means and why it occurs. This information is important in helping services target improvement efforts and reduce inequalities in cancer care.

Alongside clinical and performance data, organisations should use feedback, engagement findings, complaints and patient-reported outcomes to build a fuller picture of where services are working well and where improvements are needed.

People want services to learn from their experiences. This means collecting and using information not only about waiting times and activity levels, but also about communication, coordination, access, quality of life and the support people receive throughout their cancer journey.

We would also encourage people affected by cancer, families and carers to be involved in shaping how information is collected, used and reported. Co-production can help make sure that systems measure what matters most to people and present information in ways that are meaningful and easy to understand.

Better digital systems should mean people are having a smoother experience, receiving information more quickly, feeling better informed, and having confidence that services are working together to provide safe, timely and personalised care.

8. What actions will help address differences in outcomes between people with protected characteristics, people living in different health board areas, or people affected by different types of cancer?

People affected by cancer can experience differences in:

- **risk factors**
- **access to care**
- **the type of cancer they are diagnosed with**
- **outcomes following treatment**

We want to know what the NHS can do to reduce these differences.

People tell us that everyone should have the same opportunity to receive high-quality cancer care, regardless of who they are, where they live or the type of cancer they have. We know that this is not always people's experience.

From what we hear, barriers to care can take many forms. Some people face challenges because of disability, sensory loss, language needs, transport difficulties, caring responsibilities, financial pressures or digital exclusion.

Others may find it harder to access information, appointments or support that meets their individual needs. These barriers can affect people's experience of care and, ultimately, their outcomes.

Reducing these differences should be a core part of the strategy rather than a separate piece of work. Equality should be considered in the design, delivery and evaluation of services from the outset. The key question should be whether services work for everyone, not only for those who find it easiest to access and navigate the system.

A recurring theme in our work is the importance of recognising people as individuals. Services should routinely ask about communication, language and accessibility needs and make sure those needs are met throughout the cancer pathway.

People should not have to repeatedly explain their requirements or advocate for adjustments that enable them to access care safely and

effectively. Welsh-language services and information should be proactively offered and readily available.

We have also heard examples of the consequences when communication needs are not met. One British Sign Language (BSL) user told us that she received devastating news about her cancer through her daughter because a BSL interpreter was not available.

Experiences such as these highlight the importance of making sure that communication needs are identified early and consistently met throughout the cancer pathway. No one should have to rely on family members to receive, interpret or relay life-changing information about their health.

We also hear about the additional challenges faced by people living in rural and cross-border communities. Long journeys, limited transport options and the need to move between services or organisations can create additional stress, cost and inconvenience for people affected by cancer.

These challenges can have a real impact on people's ability to access care and support. The strategy should recognise these issues and consider practical solutions that reduce unnecessary travel and improve coordination across services.

People often tell us that understanding and navigating cancer services can be difficult, particularly at times of stress and uncertainty. This can be even harder for those who face additional barriers or whose voices are less often heard.

It is important that services actively engage with diverse communities and work with trusted local organisations to understand people's experiences and identify where improvements are needed.

We would also encourage a stronger focus on co-production. People affected by cancer, carers and communities should be involved in identifying inequalities, designing solutions and evaluating whether changes are making a difference. Those most affected by inequality often have the clearest insights into what needs to change.

The strategy should also recognise that people with rarer cancers can face particular challenges, including delays in diagnosis, limited

information and fewer opportunities to connect with others who share similar experiences.

Efforts to reduce inequalities should consider differences between cancer types as well as differences between population groups and geographical areas.

Reducing inequalities means making sure that every person can access care, understand information, receive appropriate support and move through the cancer pathway with dignity and confidence.

Understanding inequalities requires direct engagement with those affected. Particular attention should be given to communities that currently experience poorer access, poorer experiences or poorer outcomes so that improvements are felt by everyone.

9. How can success in improving cancer services and outcomes be measured?

There are many different ways to measure cancer care and the success of this strategy.

We want to know how best to measure improvements over time and how the success of the strategy should be assessed.

For people affected by cancer, success is not measured in numbers. It is reflected in whether they feel listened to, supported and confident in the care they receive.

While measures such as survival rates and waiting times are important, they do not always reflect what it is like to live with cancer or navigate cancer services.

From our conversations with people affected by cancer, success means being diagnosed and treated in a timely way, knowing what is happening, feeling informed and supported, and having confidence that services are working together. It also means receiving care that reflects individual needs and circumstances.

Quantitative information can identify where differences exist, but people's experiences can help explain why those differences occur.

For this reason, success should be measured using a combination of clinical outcomes and people's experiences. Looking at only one type of measure risks missing important aspects of care that matter to people, their families and carers.

Measures should include how many people are diagnosed early, how many people survive cancer, and how quickly people move through the system from referral to diagnosis and treatment. They should also look at what happens between those points.

People tell us that waiting for appointments, tests and results can be one of the most difficult parts of their cancer journey, so it is important to understand where delays occur and how they affect people's experiences.

People also want cancer care to feel joined up. We regularly hear from people who are unsure who to contact, who have to repeat information, or who feel responsible for chasing appointments and results.

Measures of success should therefore include whether people know who is responsible for their care, whether they feel supported while waiting, and whether services are communicating and working together effectively.

The People's Principles provide a useful framework for understanding what good care looks like from the public's perspective. Success should include whether people can access services in ways that work for them, whether they are treated with dignity and respect, whether communication is clear and honest, and whether care feels coordinated and personalised.

It is also important to measure the things that matter beyond treatment itself. People tell us about the long-term impact of cancer on their physical health, emotional wellbeing, family life, work and finances.

Measures should therefore consider quality of life, access to rehabilitation and psychological support, support for carers, and people's experiences of living with and beyond cancer.

We know that averages can hide important differences. A service may appear to be performing well overall while some communities continue to experience poorer access or outcomes. Data should be used to understand whether experiences and outcomes differ between health board areas, cancer types and different groups of people.

Research, innovation and service improvement should also form part of the picture. Success should include whether people are able to access research opportunities, whether effective innovations are adopted consistently across Wales, and whether improvements are making a meaningful difference to people's lives.

People affected by cancer, carers and communities should have an ongoing role in shaping how success is measured. Co-production can help make sure that services focus on what matters most to the people who use them, rather than only on what is easiest to measure.

People want to know that sharing their experiences leads to change. Through our complaints advocacy service, people often tell us they are raising concerns not just for themselves, but because they do not want anyone else to go through the same experience.

Services should demonstrate how feedback, concerns and lived experience have been used to improve care. Clear and accessible reporting on "what we heard, what we changed and the difference it made" can help build trust and show people that their voices are making a difference.

10. Are there any other comments or suggestions you would like to make?

Are there any comments or suggestions that have not been covered by the previous questions?

For example:

- **how services are commissioned or planned in Wales**
- **how NHS organisations can best work together**
- **what should happen to services that can only be provided in England**

People affected by cancer want assurance that the strategy will lead to visible and meaningful improvements. Delivering this will require clear accountability, strong partnership working and ongoing involvement of people with lived experience.

People experience cancer as a single journey. They do not distinguish between health boards, hospitals, community services, local authorities, charities or providers in England. What matters is whether care feels joined up, timely and supportive.

Access to personal information and medical records is an important aspect of person-centred care. Difficulties obtaining information can add to distress during an already challenging period and may undermine confidence in services. Improving access to personal information should form part of wider efforts to improve transparency, communication and patient involvement.

Throughout this response, we have highlighted what people affected by cancer tell us matters most. While individual aspects of care are important, people experience cancer as a single journey. What matters to them is whether care feels joined up, timely and supportive.

People consistently tell us that good communication and coordination make a significant difference to their experience. When services work well together, people feel more confident and supported.

When they do not, people can find themselves repeating information, chasing appointments, navigating different systems and trying to work out who is responsible for their care.

The strategy should promote closer working between organisations and make sure that services are designed around people's needs rather than organisational boundaries.

We would encourage greater focus on learning from people's experiences. Through our partnership with Tenovus Cancer Care, we have seen how valuable independent complaints advocacy can be in

helping people raise concerns, understand their rights and have their voices heard.

People who contact our complaints advocacy service often tell us they do so because they do not want others to experience the same difficulties they faced. This insight is an important source of learning and should be used alongside other forms of feedback and engagement to drive improvement.

Cross-border care should be given particular consideration within the strategy. For many people, especially those living in rural and border communities, receiving aspects of their care in England is a normal part of their cancer journey.

People want services to work together seamlessly, regardless of organisational or national boundaries. They should not have to find their way through differences in systems, processes or responsibilities at a time when they are already coping with a cancer diagnosis and treatment.

We have heard about the practical impact cancer can have on daily life. Travel costs, parking charges, accommodation costs, time away from work and reliance on family and friends can all add to the burden of cancer.

These realities should be considered when planning and commissioning services. Decisions about how and where services are delivered should take account of the impact on patients, families and carers, particularly in rural communities.

We would also encourage greater recognition of the needs of people receiving urgent or emergency care while undergoing cancer treatment.

Some people have told us about long waits, difficulties accessing appropriate support and concerns about being in environments that they feel put them at risk when they are immunocompromised. People should have confidence that they can access safe and appropriate care when their condition changes unexpectedly.

Finally, people affected by cancer, their families and carers should have an ongoing role in shaping, reviewing and evaluating delivery of the

strategy. Their experiences provide vital insight into whether changes are making a meaningful difference in practice.

We would encourage the Welsh Government and NHS organisations to establish clear mechanisms for involving people throughout implementation, rather than only during consultation and design phases.

The People's Principles could provide a practical framework for assessing whether services are delivering what matters most to people affected by cancer and for testing whether improvements are being experienced consistently across Wales.