

Wales Cancer Alliance's response to the National Wales Cancer Strategy call for evidence

1. How should the national cancer strategy improve outcomes?

The Wales Cancer Alliance (the Alliance) is a coalition of 35 charities working to prevent cancer, promote earlier diagnosis, improve care, fund research, and influence policy in Wales. Together, we fund research and roles including nurses, allied health professionals and social workers, and provide information and support. Our members aim to ensure everyone facing a cancer diagnosis can access what they need, when they need it.

What follows are high level positions that the WCA has collectively agreed through the work of its subgroups and in development of its manifesto for the Senedd elections in May 2026. For specific cancer charity calls, please refer to individual charity contributions which have been submitted separately.

Cancer outcomes only improve overall when action is taken across all the way across the cancer pathway. This means acting to:

- Reduce future cancer cases through prevention
- Reduce the rate of late-stage diagnosis and emergency presentation
- Give every patient in Wales the best treatment for them
- Invest in research and innovation
- Improve patient experience of care

The cancer strategy is an important opportunity to set ambitions, address inequalities across the pathway, and join up action across the NHS to meet these goals.

We believe it is important to prevent cancer, where possible, and diagnose it earlier and faster, where it is not. For those who are diagnosed, we want to see better survival rates and more people living well with and beyond cancer, and for those who sadly die of cancer, we want them to have as good a death as possible. We are aware that delivering on all of these outcomes is complex and that achieving them will look different for different demographics of people and cancer types; we want to see this accounted for in the strategy, with a focus on groups and cancer types which have not had attention in previous plans for example, children and young people, those who get less survivable or rarer cancers and those who are diagnosed with blood cancers.

We have consistently called for focus to be given to children and young people because, overwhelming majority of cancers they are diagnosed with stem from genetic errors and preventing these is not possible. At the same time, they are ineligible for screening programmes that are focused on adults, and so the primary way they are

diagnosed is through identifying signs and symptoms as being possibly cancer. As such, awareness of how cancer most often tends to present amongst children and young people is vital for it to be diagnosed faster and earlier when it is more treatable and patients are likely to have fewer long-lasting effects of cancer and/or its treatments. Healthcare professionals, and particularly those who on the frontline, such as GPs and those in A&E, must therefore be trained and equipped to detect and refer effectively.

Positively, once diagnosed, those under 25 rarely experience delays in starting their treatment, yet it is essential that diagnosis delays are addressed so treatment can be given as soon as possible. This maximises the treatment's effectiveness, reduces long-term effects, and supports achieving the best possible outcome for each child and young person.

To drive improvements here, and also in relation to cancers affecting adults, we want to see the strategy commit to providing effective education, training and resourcing of frontline healthcare professionals, including GPs, to detect and diagnose cancer earlier.

Without a tailored focus on improving outcomes for rare and less survivable cancers, it will be challenging for Wales to meet overarching outcome targets for cancer. To support improvement here, we want to see the effective implementation of the Rare Cancers Act 2026 as it applies to Wales, and for the strategy to commit to appointing a named Government lead for rare cancers with a responsibility to support research and innovation. The Act commits to this in England, and we want to see parity here in Wales, along with improved research funding and improved access to clinical trials.

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

As detailed in our answer to question one, the Alliance believes that healthcare professionals, and particularly those on the frontline, should be better equipped to identify the signs and symptoms of cancer, particularly in children and young people or those whose cancer where it is imperative that a more prompt diagnosis is made, such as those categorised as less survivable, where a person may present at their GP with vague symptoms that might warrant referral onto the vague symptom pathway.

Yet receiving a diagnosis also requires a properly resourced workforce to, for example, review patients presenting with symptoms, undertake tests, and process results. At present, however, we are aware there are shortages that could be impacting on earlier diagnosis ambitions. For example, it is the experience of one of our members, from speaking with experts, that there is not enough diagnostic capacity in Wales to meet the needs of the bowel screening programme and that this is causing delays in further investigative tests. Further to this, there is an insufficient number of screening

colonoscopists in Wales, and our membership understands there is also a shortage of sonographers which is contributing to a diagnosis bottleneck and impacting on the timely diagnosis of gynaecological cancers.

For many years, the Alliance has called for a specific Cancer Workforce Strategy and whilst we are understanding of the difficulties in separating out the cancer workforce from the general workforce, our current arrangements do not provide a comprehensive view of the gaps that need to be addressed to mitigate resourcing challenges which lead to system challenges and therefore – later diagnosis within the patient population.

Whilst the Cancer Improvement Plan put an action on Health Education and Improvement Wales to develop a more strategic approach to workforce planning – no clear framework was ever produced. We would expect to see the cancer strategy reading across to other workforce development plans to ensure there is a coherent and well-resourced approach to tackle the workforce challenges that exist across the cancer pathway, but particularly at the diagnostic interval. Please see Q6 below for more information on this.

We want to see the strategy commit to measuring the success of interventions introduced to detect cancers at an earlier stage, and ideally through a dataset on routes to diagnosis as the focusing just on stage of diagnosis is too simplistic to fully understand patient journeys.

The Alliance would also like to the strategy commit to rapidly adopting proven technology and science that supports earlier diagnosis through ensuring there is the necessary infrastructure, policies and processes in place to do so. This is essential if as many people as possible across Wales are to benefit from breakthroughs, yet Wales is not presently meeting its potential which can lead to later diagnoses and poorer outcomes.

For example, the UK National Screening Committee recommended in 2022 that nations roll out targeted low-dose CT lung cancer screening. While the 2025 Welsh Government commitments towards this screening are welcomed, delays have meant that people in Wales will benefit from the new programme from 2028. With the prediction that the implementation of this programme could save up to 190 lives a year, Wales cannot afford for that rollout date to slip any further. For context, people across large parts of England have had access to this form of screening for several years and lung cancers are being diagnosed earlier. The strategy must help us understand and address these delays at a fundamental level and ensure that proven early diagnosis interventions are adopted and implemented at pace, so that patients across Wales can benefit from advances sooner.

Finally, more cancers would be detected at an earlier stage through encouraging more people to take up their screening invitations. We want the strategy to commit to

improving screening participation, including through focused work with groups that are presently underrepresented in screening programmes to help reduce health inequalities.

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

It is essential that Wales has the necessary infrastructure in place to deliver recommended treatment standards immediately, and to rapidly introduce and roll out new cancer treatments. The Alliance wants to see the strategy commit to developing this and across all parts of the system so that everyone can benefit regardless of where they live.

National Cancer Clinical Audits, hosted by NATCAN, are a key source of information on whether Wales is delivering recommended treatment standards for everyone. Recent audits show both that Wales is not meeting many best practice treatment standards, and that there is considerable variation in the care people receive across Wales. The strategy must set out how cancer service and data teams will be supported to submit high-quality data for NATCAN audit, as poor quality and completeness is currently hampering confidence in findings. It must also set out support for quality improvement projects where NATCAN audits identify unwarranted variation in delivery of best practice treatment.

The strategy must meet the reality that new cancer cases will grow over the next 10 years, as well as a growing number of people living with cancer and requiring ongoing treatment and care. International evidence suggests already that Wales delivers less treatment than nations where cancer outcomes are better. Increased investment is therefore vital in workforce and equipment to deliver cancer treatment. It must also respond to changes in demand as new services are established, for example with Lung screening rollout expected to create an increase in demand for surgery and SABR. Lastly, it must create a framework for reconfiguration of services, balancing the extremely important needs of patients to receive treatment near to home or with travel options, with the improved productivity and outputs typically seen at more specialist centres.

Genomics is key within modern cancer treatment, and its role will undoubtedly continue to expand. In light of this, the strategy should prioritise equitable access to genomic testing across Wales, ensuring that every patient can benefit from the right diagnostic test at the right time, irrespective of geography. This will not only support optimal patient care and targeted treatment selection but also enable greater participation in genomically stratified clinical trials and research, helping Wales to harness the full potential of precision medicine. Alongside this, the strategy must ensure Wales has the necessary data infrastructure to support the growing use of

genomics in routine cancer care — and to fully harness the research opportunities that this presents.

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

Alliance members support people with cancer, along with their families and carers, through a range of services – from information and peer support, through to funding expert roles including social workers, nurses and physical activity specialists. Our experience demonstrates the importance of providing wraparound support to help those affected by cancer to journey through it with the best possible health and wellbeing. This includes tailored and responsive prehabilitation and rehabilitation support.

To support this, it is essential that everyone with cancer has a care plan, based on a needs assessment. This should surface where they could benefit from accessing support outside of cancer treatment to help them with their health and mental wellbeing along with practical issues such as money and work. Ideally, this should be delivered by a named point of contact, such as a clinical nurse specialist or support worker, who can provide consistent support to the patient. Need assessments should be repeated at appropriate points in the care pathway, including at transition points, to account for any changes in circumstance, and patients should be referred or signposted as needed. Their families and carers should also be provided with information on relevant support services.

To do this effectively, it is key that those who undertake needs assessments, as well as healthcare professionals who support patients day to day, are well aware of what services are accessible within the community and at a national level, such as local support groups and helplines. Resources, such as a directory, could be developed to support them with this and to ensure that all healthcare professionals are properly equipped to signpost.

For those who sadly face incurable cancer, we would like to see the strategy ensure they receive timely, coordinated support. This should include earlier identification of palliative care needs and referral alongside cancer treatment, better integration across health and social care, and reliable access to 24/7 clinical advice.

We are pleased that the 2014 Health Circular focussing on the requirements of the Key Worker has been reviewed and, in its place, new Quality Standards for Person Centred Care are being developed. It is vital that these are fully integrated within the new Strategy and subsequently rolled out at pace. Health Boards should be expected to consistently deliver to these standards. We would expect to see clear directives to health boards to ensure these are adopted to ensure people's needs are met,

particularly around being able to access emotional and higher-level mental health support and also access financial advice – two areas which are flagged to us as charities through the work we do on a day-to-day basis in support of colleagues within the NHS.

With regard to children and young people, cancer has a significant impact on their mental and emotional health, along with that of their family. Research has consistently highlighted this group is more likely to experience depression, anxiety and loneliness as a result of having cancer, and that the mental impacts can endure years beyond treatment ending. It also shows a lack of consistently available emotional and mental health support, often due to the poor availability and an absence of age-specific support, both during and beyond treatment.

It is essential that all under 25s and their families have consistent, equitable access to specialist mental health support throughout treatment and beyond, in both Welsh and English.

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

Despite vital progress in recent years, Wales is not meeting its full potential in cancer research. The Alliance wants change here so that Wales has a thriving research environment that attracts investment, provides more patients with opportunities to participate in and benefit from research, and generates valuable insights to help address the global cancer challenge. We want the strategy to reflect this vision through ambitious commitments on research.

On academic cancer research, we want the strategy to commit to greater investment in this area. Different forms of academic research play essential roles; discovery research generates knowledge to increase our understanding of the disease, and translational and clinical research use this insight to help develop and evaluate improved diagnostic tools and treatments. Overall, academic cancer research is a vital part of the research ecosystem, and particularly in advancing areas that offer significant clinical or societal value but may struggle to attract commercial investment.

Despite its importance, Welsh academic research receives comparatively low levels of investment, which hinders its potential. Crucial here is the Welsh Government's quality-related (QR) institutional funding. This is critical for universities to maintain and build their research capabilities, while also helping them secure competitive funding from other sources. At present, Wales invests less QR funding per capita when compared to other UK nations, with this funding not keeping pace with inflation. The Alliance wants the strategy to address this by reviewing how academic research is



funded in Wales with the aim of supporting its growth. As part of this, we want to see Sêr Cymru reintroduced for cancer research, to support this ambition.

We also want the strategy to commit to strengthening and building on existing efforts to increase clinical trial activity and participation across Wales.

Firstly, we want more clinical trials taking place in Wales, across different cancer types, including rare cancers, and all stages of disease, including metastatic cancer. Our membership also highlights that there is scope to improve the number and distribution of late-phase (Phase III) cancer trials across Wales. Streamlining the process of establishing trials would support more trial activity. In light of this, we would welcome a review of the effectiveness and consistency of the Once for Wales approach across Health Boards, to identify opportunities to further streamline trial set-up and strengthen Wales' attractiveness as a location for research.

Secondly, we want to increase trial participation by addressing structural and eligibility barriers. We know geography can prevent some people from participating in trials. Some face practical, physical or financial challenges in traveling, and so spreading them out across Wales, and delivering elements of them close to home where possible, would increase access. Furthermore, we understand that organisational and study delivery arrangements across Health Board boundaries can contribute to differences in access. We would welcome a review of any remaining barriers to ensure that patients are not unduly prevented from participating in research because of where they live.

Eligibility can also hinder participation. Despite teenagers and young adults often being underrepresented in trials, age cut-offs can exclude those aged 17 or younger from adult trials, or those aged 18 and above from paediatric trials — even where there is no clear medical or clinical reason and they may have benefited from taking part. We would welcome work to address this.

Thirdly, we want the strategy to ensure NHS staff are fully equipped to support patients with trials – whether through specific research posts or making research a part of all relevant contracts. It is vital that NHS staff have the time and capacity to engage in clinical trials, and the skills to communicate these opportunities with patients and/or their parents or carers.

We welcome existing work to strengthen clinical trial activity and participation, including the Tackling Cancer Through Research initiative. It is vital that this work is strengthened and built upon to ensure that all forms of clinical trials, including commercial and non-commercial, are supported to flourish.

On innovation, the Alliance would like to see stronger national coordination in this area. Previously, the rollout of innovations such as capsule sponge testing and digital and AI-assisted pathology has highlighted the challenges of slow and fragmented adoption

across Wales. If a new approach is developed to address this, such as the Cancer Innovation Adoption Pathway, it is vital it has the mandate and mechanisms to effectively horizon scan for, prioritise, and support, the equitable adoption of proven innovations at pace.

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

It is essential that Wales has the right workforce with the right skills in place to provide high-quality cancer care to its growing number of cancer patients – whoever they are and wherever they live. Yet, as it stands, workforce gaps are leaving too many patients to endure long waits for tests, results and treatment. It additionally places the present workforce under pressure and at risk of burnout and stress. It is vital the strategy seeks to rapidly address these issues if it is to overcome present challenges and deliver against its ambitions.

As mentioned in a previous section, workforce planning is vital and more specifically we are aware there are a number of gaps within the workforce which may be exacerbated by current healthcare professionals either reducing their hours or resigning or retiring from their roles. For example, the Royal College of Radiologists' 2025 Wales census found there was a 28 percent shortfall in clinical radiologists, expected to rise to 34 percent in 2030. Yet, at the same time, 57 percent of radiology departments reported recruitment freezes imposed on them in 2025. In addition, a recent review of the haematology workforce found that 60.6 percent of consultant haematologists in Wales, who provide vital care to those with blood cancer, intend on retiring by the end of 2028.

With both current and upstream issues, the strategy must take urgent action. The Alliance wants to see HEIW developing a dedicated strategic workforce plan for cancer. Within this, it should design and plan – and then deliver – the cancer care workforce of the future with clear, actionable, steps as to how it can be achieved, including a focus on both retaining current healthcare professionals and developing a steady pipeline of new ones.

As a starting point, the plan should formally define what roles the cancer workforce comprises of; this was discussed at our 2025 roundtable with politicians and senior NHS leaders on the potential of cancer strategy, where it was raised that, without a definition in place, it is hard to comprehensively plan or budget for cancer services. This should include roles delivering services from screening and diagnosis through to end of life care, as well as cross cutting roles such as those in research.

It should use data and modelling to project the size of the workforce and the skills it needs to support the growing numbers of people being diagnosed with cancer and their evolving needs. For example, it should account for the growing need of cancer teams to

rapidly draw on other specialisms to treat novel side effects from immunotherapies and training to deliver new treatments.

Such a plan would support Health Boards with their own cancer workforce planning. This is a clear need; Audit Wales is presently looking at each Health Board's approach to managing cancer services, and the first two reports published state that, while the Health Boards understand their cancer workforce pressures, their present focuses have been on addressing short-term need despite gaps in capacity being expected to continue.

The Alliance would like to see the strategy commit to taking immediate action in the shorter-term to support addressing capacity issues where there are possible solutions. For example, in looking into the possibility of expanding the number of specialist endoscopy nurses to provide more diagnostic capacity. The strategy should also commit to ending recruitment freezes for roles where this impacts on critical cancer services. With pressure on genomics services to expand to meet the demand for more personalised cancer treatments, it should also address the urgent need to recruit and train clinical genomics fellows to bridge the gap between clinic, diagnostics and research.

The Alliance would also note that the development of Regional solutions to both detect and treat cancer is vital. The new Community Diagnostic Hub being developed in Llantrisant to support patients in Southeast Wales will go a long way to alleviate pressures and centralise diagnostic capacity creating efficiency within the system and benefitting people affected by cancer. It is vital that these approaches to regional working are developed more quickly in the future to help create a system fit for the future.

Finally, the strategy should support the cancer workforce to develop the foundational competencies in the All Wales Competency Framework for Adult Palliative and End of Life Care. Those frequently supporting people with palliative care needs would also benefit from the middle-tier ("some") profession-specific competencies to help strengthen their understanding of palliative care and the value of early referral.

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

The Alliance believes it is essential that robust and comprehensive data on cancer services, patient experience and outcomes is routinely collected, analysed and acted upon in Wales. Where possible, this should include real-time data. High-quality data has both strategic and operational value, providing the evidence needed to assess whether current approaches to service delivery are achieving their intended outcomes and where improvement is needed.

Data is critical for understanding demand across the cancer pathway, monitoring waiting times, evaluating patient outcomes and experiences, and supporting effective service and workforce planning. It also helps identify inequalities, emerging trends and opportunities to improve care, while enabling best practice to be shared across Wales.

As Wales becomes increasingly reliant on data to inform cancer policy, service delivery and personalised treatment decisions, it is essential that the information used is accurate, complete and validated. However, the current landscape remains fragmented. Multiple data collection systems contribute to a lack of clarity around the cancer data pathway, including responsibility for data collection, validation, quality assurance and oversight.

As a result, important information is being lost or inconsistently captured. This includes data on metastatic disease, cancers that cannot be classified using the traditional TNM staging system, patient experience measures and protected characteristics. These gaps limit our ability to understand patient needs, evaluate services, identify inequalities and target improvement activity.

Limited resources for data management and validation also risk reducing data quality. Coding decisions and category selections may not always be consistently reviewed, potentially leading to variation in interpretation and recording between health boards, organisations and individual users. This undermines confidence in the data and limits its usefulness for service improvement, research and policy development.

The strategy should therefore set out a clear cancer data framework for Wales, defining responsibilities for data collection, coding, validation, analysis and governance. It should ensure sufficient investment in the workforce, systems and infrastructure required to deliver high-quality cancer data, with clear standards for the collection of clinical, demographic, equality, experience and outcome data.

There are also concerns about how data is currently presented. For example, grouping everyone under 30 years of age within SCP waiting time data limits understanding of trends affecting children and young people. Data collection and reporting arrangements should be designed to provide meaningful insight into population groups and inequalities.

The Alliance wants to see the strategy urgently address these issues. As a first step, it should commit to establishing a task and finish group to review current data provision and identify the data requirements of a modern, high-quality cancer service. This should examine the entire pathway, including data on prevalence, service demand, treatment, outcomes, patient experience and demographics. It should also consider how technology can support real-time insight through patient-reported outcome measures (PROMs), electronic patient-reported experience measures (PREMs) and

other digital solutions. Particular attention should be given to children and young people to ensure appropriate data is routinely available.

The group should identify the gaps, barriers and actions required to create a more coherent and comprehensive cancer data framework, ensuring data is consistent across Wales and, where possible, comparable with other UK nations. It should also consider how Wales can improve the completeness, accuracy and timeliness of submissions to the National Cancer Audit Collaborating Centre (NATCAN). High-quality NATCAN data is essential for benchmarking services against best practice standards, identifying unwarranted variation in care and supporting targeted quality improvement initiatives.

To maximise the benefits of improved data infrastructure, the Alliance also believes that increased investment in Wales's national cancer registry, WCISU, is essential. Reporting of key cancer metrics, including incidence, mortality and staging data, often lags behind that of other UK nations, limiting the ability of policymakers, clinicians and researchers to make timely evidence-based decisions.

The strategy should therefore commit to strengthening and adequately resourcing WCISU's analytical and reporting capacity, bringing it more in line with that of Scotland and Northern Ireland. This would enable more timely, comprehensive and actionable cancer intelligence to support service planning, performance monitoring, research and continuous improvement across the cancer system.

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?

We believe that improved data collection, linkage and analysis, as outlined in our response to Question 7, is fundamental to understanding and addressing inequalities in cancer outcomes. While there is relatively strong evidence on deprivation-related inequalities, with around 1,400 cancer deaths in Wales attributed to deprivation, there remains a significant lack of data on outcomes for other underserved groups, including people with disabilities, people from different ethnic backgrounds, and children and young people. Without this information, it is difficult to develop robust, evidence-based plans to reduce inequalities.

Screening participation is a major driver of cancer inequalities. People living in more deprived areas of Wales are less likely to participate in bowel, breast and cervical screening programmes, despite evidence that relatively simple interventions such as telephone follow-up and community outreach can improve uptake. The strategy should therefore set out clear actions, responsibilities and accountability across Public Health



Wales and health boards to implement proven interventions and reduce participation gaps. This approach should be embedded from the outset of targeted lung cancer screening, given that lung cancer remains the leading cause of deprivation-related cancer deaths in Wales.

To support targeted action and measure progress, the strategy should also improve data collection and reporting on screening participation among underserved groups, including ethnic minority communities, in line with the Screening Equity Strategy. Further research is also needed to understand why some groups are less likely to engage with screening and how barriers to participation can be overcome.

The Alliance welcomes the ambition to reduce unwarranted variation in cancer care across Wales. However, meaningful action requires a clearer understanding of the services available to patients and the outcomes they achieve. Several structural factors are likely to contribute to variation, including differences in commissioning arrangements across Wales' three tertiary cancer centres. The strategy should therefore commit to developing a comprehensive national picture of cancer service provision, access, quality and outcomes.

The programme of work undertaken by Audit Wales provides an important foundation for this. National and health board-level reviews have identified significant variation in pathway performance, service delivery and outcomes across Wales. While some organisations have managed increasing demand relatively effectively, others have experienced deterioration in performance. The Welsh Government should use the cancer strategy as a mechanism to ensure Audit Wales recommendations are implemented consistently and monitored nationally, helping to reduce unwarranted variation and improve equitable access to high-quality care.

The Alliance would therefore like to see the strategy commit to improving the early diagnosis and rapid treatment of less survivable cancers through disease-specific action plans. This should include support for research and innovation, particularly the development of diagnostic tools that can identify cancers presenting with vague or non-specific symptoms. The strategy should also support the full rollout of targeted lung cancer screening and ensure Wales benefits from wider initiatives aimed at improving outcomes for rare and less survivable cancers, including implementation of the Rare Cancers Act.

While inequalities within Wales must remain a priority, it is also important to recognise the significant reliance on cross-border cancer care. Many Welsh patients receive treatment in England, particularly those with rarer or less survivable cancers and children and young people. The strategy should therefore take a broader, UK-wide perspective when considering equitable access to care.

Differences in access to services can arise between patients treated in Wales and those treated in England. The strategy should include a commitment to ensuring Wales keeps pace with developments elsewhere in the UK so that Welsh patients have access to the same core services, support and standards of care regardless of where they are treated. This is particularly important for specialist and long-term support services. For example, children and young people treated in England are understood to have greater access to late-effects services and follow-up care than those treated in Wales. The strategy should identify and address such disparities to ensure all Welsh patients have equitable access to high-quality care throughout their cancer journey.

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

The Alliance believes that success should be measured across the whole cancer pathway, from prevention and diagnosis through to treatment, patient experience and outcomes. However, particular emphasis should be placed on whether the strategy is succeeding in reducing the rates of late-stage diagnoses, reducing inequalities, and ensuring that patients can access the right care at the right time.

A key measure of success should be changes in ratios of routes to diagnosis. We do not currently report the proportion of cancers which are diagnosed through screening, primary care referral and emergency presentation. A strong measure of success of any intervention would be a reduction in the percent of cancers which are diagnosed following a medical emergency, which are associated with poorer outcomes and more advanced disease, and an increase in the proportion of cancers detected through screening programmes and timely referral pathways.

Currently, it is estimated that approximately 1 in 4 cancers in Wales are diagnosed as a result of a medical emergency. Monitoring routes to diagnosis would provide an effective way of evaluating the impact of public awareness campaigns, screening programmes, diagnostic centres and targeted interventions aimed at underserved populations. Crucially, it could provide a more timely indicator of outcomes and survival for all cancers, even those which fall outside of traditional Tumour/Nodes/Metastasis (TNM) staging system. Not only should routes to diagnosis data be validated and regularly published, but mandated quarterly reporting, with the necessary accountability would help improve data quality and reliability at all stages.

The Alliance believes that the 62-day waiting times data, does not always accurately reflect patient experience, or provides insight into the period before cancer was suspected. Whilst adherence to a 62-day waiting time does influence how patients perceive their care, there is little correlation between waiting times and patient outcomes. Emergency presentation rates through a regularly reported routes-to-diagnosis dataset would help to identify geographical regions or communities in which

symptom recognition is poor, there is a lack of engagement with primary health care or there is simply a failure in referral.

By utilising additional metrics such as the emergency presentation rates, we can target the use of the Suspected Cancer Pathway data to explore delays in treatment delivery, with a special focus on the number of patients experiencing exceptionally long waiting times. By exploring waiting times as a whole rather than limiting ourselves to the binary of reaching the 62-day target or not, we would be able to understand much more about how long most people are actually waiting for their cancer treatment in Wales.

Quality of care should be assessed through national audits and benchmarking. Success should include improved completeness and quality of Welsh submissions to the National Cancer Audit Collaborating Centre (NATCAN), improved performance against audit standards, and a reduction in unwarranted variation identified through audit findings. Audit recommendations should be routinely monitored and acted upon.

Patient experience and quality of life must be given equal importance alongside clinical outcomes. Success should include routine collection and publication of Patient Reported Outcome Measures (PROMs) and Patient Reported Experience Measures (PREMs), enabling services to understand whether care is meeting patients' needs and improving what matters most to them.

Reducing inequalities should be another key measure of success. Progress should be assessed through narrowing differences in screening participation, routes to diagnosis, stage at diagnosis, treatment access, patient experience and outcomes between different population groups. This will require improved collection of data on ethnicity, disability and other protected characteristics. Initial success should be demonstrated by improved coverage of data collection which will further enable us to monitor how other improvements to cancer care are shared equitably across Wales.

Ultimately, the success of the strategy should be reflected in improved survival, reduced mortality and better quality of life for people affected by cancer. However, these are long-term outcomes. In the shorter term, improvements in routes to diagnosis, earlier stage at diagnosis, reduced variation, better patient experience, and more equitable access to services will provide important indicators that the strategy is delivering meaningful change and is on course to improve cancer outcomes for the people of Wales.

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?

Strategic approach and governance



The Alliance has been clear for some years that Wales needs a long term, strategic approach to planning and delivering cancer services, and that this should be through a cancer strategy. As such, we strongly welcome this strategy's development and hope it will marshal a much-needed focus on driving up cancer outcomes and equity so that everyone in Wales has access to high-quality treatment and care.

Yet evidence demonstrates that if a cancer strategy is not sufficiently supported, it will not lead to transformative change or improved outcomes. As such, how it is developed and implemented is vital and we are keen to see due process in both the strategy's development and implementation to give it the best possible chance of achieving its ambitions.

Evidence gathered by the International Cancer Benchmarking Programme, Cancer Research UK has highlighted the elements of successful national cancer planning that are vital to cancer strategy's success. These include: bold and comprehensive long-term ambitions; strong leadership with dedicated governance and oversight structures; steady implementation plans; robust monitoring and evaluation, and the funding and capacity to deliver a strategy. The Alliance believes the ICBP's evidence is compelling and calls on the Welsh Government to apply Cancer Research UK's associated tests when developing and implementing the strategy.

A standalone section for children and young people

Children and young people have a unique experience of cancer because of their age and life stage and require care from healthcare professionals who are experts in paediatric oncology. For example, the cancers they most commonly develop differ from those of adults, and there are additional considerations when determining treatment for them as children are still growing and may have to live with late effects for many decades. Furthermore, there can be considerations around their education and supporting the child's family.

As such, the Alliance believes the new cancer strategy must contain ambitions and commitments that are specific to them and, to mirror how services for them are commissioned and delivered, we want to see these in a standalone chapter that is focused on their needs. This should also explore alignment with services in England where patients from Wales travel across border to access specialist services.

Without this approach, we are concerned that the needs of this particularly vulnerable group of patients, along with those of their families who support and advocate for them, may be lost amongst those of adults who make up the majority of cancer diagnoses in Wales. Furthermore, we believe this would make it more straightforward for those who implement the recommendations for children and young people.



In addition to this, the Alliance strongly supports the Welsh Government's announcement that it is developing a travel and accommodation fund for those impacted by childhood cancer. Families must often travel long distances for their child's care at specialist centres, with evidence from Young Lives vs Cancer highlighting that they can travel of up to 530 miles a month, costing up to £280 a month. This places them under significant financial pressure at a point where incomes can be reduced.

We want to see this fund formally adopted and rolled out swiftly and will support the scoping work however we can through our members which have relevant insight from working with these families and supporting them financially.

Third sector and patient involvement

To ensure that services truly meet the needs of patients – whoever they are and wherever they live – it is imperative that people with lived experience of cancer are engaged and involved with how services are designed and implemented. This approach improves accessibility and supports services to embed a person-centred lens to care, amongst other benefits. Despite this, the Bevan Commission found there are opportunities to improve how health providers engage with people with lived experience in this way.

Further to this, the third sector in Wales has considerable insight and expertise from work with and within cancer services, including specialist knowledge in relation to some groups, such as children and young people. As a result, we would like to more routinely be enabled to use this to contribute to how cancer services are designed.

As such, the Alliance would like to see the strategy commit to involving both patients and the third sector routinely and meaningfully within cancer services and governance so that the opportunity for these groups to support the development of better policy and practice is not lost.