

SCOTTISH CANCER STRATEGY

Submission from The Brain Tumour Charity

Introduction

The Brain Tumour Charity is the world's leading brain tumour charity and the largest dedicated funder of research into brain tumours globally. As well as investing around £38million in world-class research over the last five years, we provide specialist support services for those diagnosed with a brain tumour, as well as their families and friends. **Our goal is twofold; to double survival and halve the harm that brain tumours have on quality of life in the UK.**

We strongly welcome the opportunity to feed into the development of the Scottish Cancer Strategy. Brain tumours remain the biggest cancer killer of children and adults under 40 and so much more needs to be done.

Questions

Overall

1.

- a. **What are the most important aspects of the cancer journey you would like to see included in a long-term strategy? Think about, for example, prevention, screening, diagnosis, treatment, support for people with or affected by cancer, other care.**

Unfortunately, survival rates in brain cancer remain very poor. Just 40% of people aged over 15, who are diagnosed with a high grade brain tumour in Scotland, will survive beyond one year and just 15% of people will survive beyond five years. Brain tumours are uniquely complex and require a different approach in many areas of care to other cancers. Our response highlights some key areas that the plan needs to address so that outcomes for brain tumours do not fall woefully behind progress being made in other cancers over the duration of this strategy and beyond.

Recommendations

1. Clarity should be provided on how the welcome £130 million investment set out in the 2022 National Workforce Strategy will be spent, including specifically for the cancer workforce. By ensuring the cancer workforce is well funded to support, retain and recruit vital staff in the long-term, this would allow us to move towards the target of every brain tumour patient (with high or low grade tumours) having access to a Clinical Nurse Specialist (CNS) or key worker.
2. Action to ensure Holistic Needs Assessments (HNAs) are being routinely offered to all brain tumour patients at diagnosis and any key changes in care, with resulting care plans put in place, is essential in ensuring that all patients receive personalised care and sufficient support.
3. A target on early diagnosis should be introduced, which addresses early detection for cancers that aren't staged, such as brain tumours and blood cancers, including developing proxy measures to monitor progress.
4. The Scottish Government should commit to exploring whether emerging triage tools, such as the [Dxcover blood test](#) or the [Verbal Fluency Test](#), could speed up the diagnosis of brain tumours and to establishing them in primary care across Scotland as soon as possible as the evidence emerges.
5. The Scottish Government should commit to multi-year funding for continued cancer awareness campaigns - including working with NHS Scotland and The Brain Tumour Charity to promote a brain tumour signs and symptoms awareness campaign.

6. The Scottish Government should support brain tumour research in the Scotland by setting out a long-term commitment to prioritise and fund world-class brain tumour research as soon as possible.
7. Every brain tumour patient in Scotland should be informed about research and given the opportunity to participate in research wherever possible.

b. Are there particular groups of cancers which should be focused on over the next 3 or 10-years? Examples of groups may include secondary cancers or less survivable cancers.

We urge the Government to use this Cancer Strategy to outline specific commitments and targets for less survivable cancers, including brain cancer, to drive forward the transformational changes we need to see in diagnosis, treatments and care.

As members of the Less Survivable Cancer Taskforce, we are really encouraged that less survivable cancers have been a focus for action in the Government's current Recovery and Redesign Action Plan, and are also highlighted as a potential focus for action in this consultation. We believe it is crucial that less survivable cancers are a focus for action in the upcoming Strategy.

Further to the worrying five-year survival statistics outlined for brain cancer, only 16% of people diagnosed with one of the six less survivable cancers will survive for 5 years or more and, whilst some cancers have seen huge breakthroughs and improvements in outcomes in recent years, survival rates for these six cancers have not significantly improved in decades. They account for a quarter of all cancer diagnoses each year in Scotland and, because of their poor outcomes, around 44% of cancer deaths. In Scotland, 78% of pancreatic patients die within a year and for cancers of the brain, lung, oesophagus, liver and stomach, around 60% die within one year.

The development and publication of the new 'Collaborative and Compassionate Cancer Care: cancer strategy for children and young people 2021-2026' last year was really welcome and we would like to see the new Cancer Strategy consider how it will work with the 'Collaborative and Compassionate Cancer Care: cancer strategy for children and young people 2021-2026' to best support those transitioning between children and adult's services.

c. What do you think we should prioritise over the short-term? Consider what needs addressed within the first 3 years.

The answers throughout this response highlight immediate key areas that we believe the plan needs to address to improve outcomes for patients with brain cancer in Scotland. However, it is also important these actions are addressed alongside specific interventions to ensure recovery from the impacts of the COVID-19 pandemic on diagnosis, treatment and care.

The pandemic has created both a backlog of cancer patients in the system and patients who are 'missing' because they have been put off presenting to the NHS during the pandemic. Our analysis of the Scottish Cancer Registry data suggests the extent of these missing diagnoses for brain tumours to be 67 people in Scotland in 2020 compared to 2019 diagnosis levels. This equates to an 18.5% decline in the number of people diagnosed with a brain tumour via pathological sample in Scotland. It is hugely important that the Scottish Cancer Strategy builds on ambitions committed to in the 'National Cancer Plan and Recovery and Redesign: an action plan for cancer services', and sets out a clear and innovative approach to addressing the lasting impacts of the pandemic on cancer care. A way in which the Scottish government can help ensure the "missing" brain tumour diagnosis are found is by working in partnership with The Brain Tumour Charity on a campaign to raise awareness of the signs and symptoms of a brain tumour and encouraging people to come forward.

One aspect of brain cancer diagnosis and care that falls behind progress in other cancers is early detection and triage tools. There are currently no screening options for brain cancers and we know there are often delays in brain tumour patients being diagnosed because of the vague and non-specific symptoms, such as headaches or nausea. Therefore, the development of any promising triage tools for brain cancer patients should be prioritised. Currently there are two – a blood test that has had

promising outcomes in being able to detect potential brain tumours, [Dxcover](#), and a [Verbal Fluency Test](#).

Dxcover, a low-cost blood test developed in Scotland, has shown promise in improving the diagnostic pathway, and was recently found to identify more than 90% of glioblastomas (the most common type of brain tumour) and more than 80% of all other brain tumours in a study in NHS Lothian. The Verbal Fluency Test is a simple language test which asks people to name as many animals as they can in 60 seconds. Both these tests could help GPs identify people with common but vague symptoms, such as headaches, who are more likely to have a brain tumour. These triage tests could be valuable additions to clinical assessments to help GPs identify patients in need of an urgent brain scan, while providing reassurance that a period of observation may be appropriate for others. Further research is needed to validate and optimise use of both tests.

In the next three years, the Scottish Government should prioritise investing to develop emerging brain tumour triage tools in Scotland, such as the Dxcover blood test and the Verbal Fluency Test, and establishing them in primary care across Scotland as soon as possible as the evidence emerges.

Type of Document

The options considered for this new strategy are:

- i. Extending or renewing the current recovery plan taking into account the ongoing impacts of the COVID-19 pandemic.**
- ii. A 5-year strategic plan to indicate that the short-term recovery plan was interim and that we are shifting back to a more normal approach.**
- iii. A longer-term strategy with short-term action plans which will evolve with changing landscape but remain consistent with the overarching ambitions.**

They are proposing option 3.

2.

- a. Do you agree with this proposal? Do you agree with a 10-year high-level strategy which will be underpinned by three shorter-term action plans? Please respond yes or no.**

Yes.

- b. Please explain your answer and provide any additional suggestions. Please explain your answer to Question 2a.**

It is important that the Scottish Cancer Strategy has a long-term approach and ambitious targets to ensure that significant improvements are made to survival and quality of life for brain cancer patients; but that progress is still accountable. It is also essential that the plan does not lose sight of the continuing impact and backlog in care brought about by the pandemic and how this may impact on cancer services over the next ten years.

Vision, Aims and Principles

Vision

The proposed Vision is: "A compassionate and consistent cancer service that provides improved support, outcomes and survival for people at risk of, and affected by, cancer in Scotland".

3.

- a. Do you agree with this vision? Please respond yes or no.**

Yes.

- b. Please explain your answer and provide any additional suggestions.**

In order for a cancer service to be compassionate and consistent, we believe it is essential that it is person-centred and holistic. This is addressed clearly in the principles and framing themes, which is really welcome, but we feel including this wording in the vision could provide even greater clarity of the importance of putting patients at the centre to the Scottish Government's vision. This would help ensure all brain cancer patients feel they are going to be supported by wrap around care throughout their diagnosis, treatment and following after or palliative care. By providing care that is more tailored to the individual and their needs rather than a "one size fits all" approach, it could improve the support provided and help to address any disparities by both geographical area and protected characteristics.

It is also key that, when considering outcomes and survival, the strategy also includes improvements to an individual's quality of life. Survival outcomes for brain cancer patients remain very poor with just 15% of adults in Scotland diagnosed surviving five years or more. Therefore, quality of life improvements for brain cancer patients are imperative.

Aims

The Aims of the strategy set out more-specific goals that we will prioritise and that can be measured. The proposed aims are:

- a. Slowing down the increasing incidence of cancer.**
- b. Earlier stage at diagnosis.**
- c. Shorter time to treatment.**
- d. Lower recurrent rates.**
- e. Higher survival rates.**
- f. High quality, consistent experience of the health service for people affected by cancer.**
- g. An enabling environment for research and innovation in diagnosis and treatment.**
- h. Reduced inequalities in all these areas.**

4.

a. Do you agree with these goals? Please respond yes or no.

Yes.

b. Please explain your answer and provide any additional suggestions.

These aims are all important to achieve for cancer patients in Scotland and we support these aims; however, there are two important points to flag. Firstly, we would urge for a specific aim to be included to improve quality of life for patients. This would be distinct from ensuring a high-quality and consistent experience of NHS care and would instead be focused on helping reduce the impacts of cancer and its treatment on patients' quality of life in the short- and long-term. Survival rates for brain cancer will be mainly improved from investment in research to ultimately find breakthrough new treatments; however, patients are also in need of significant improvements in quality of life during their care and treatment.

Secondly, brain tumours are not staged in the same way that other cancers are. This means that prioritising an aim or measure that looks at diagnosis at an earlier 'stage' alone will not be relevant to or include brain cancers and others that are not staged, such as blood cancers. **In order to ensure brain cancers are included in this target, a measure for early diagnosis that can include non-staged cancers needs to be introduced, for example using proxy measures.**

Principles

The proposed principles are:

- Putting patients at the centre of the approach.**
- Actively involve communities and users of services.**
- Be inclusive.**
- Provide high quality, compassionate care.**

- **Ensure services are sustainable.**
- **Collaborate across all sectors.**
- **Use an evidence-based approach and make the best use of emerging data/research/technology.**
- **Strive for consistency through a 'Once for Scotland' approach.**

5.

a. Do you agree with these principles? Please respond yes or no.

Yes.

b. Please explain your answer and provide any additional suggestions.

We very much support these principles and it is important that all of these principles are taken forward in the development and delivery of the plan. It is important that the Scottish Government collaborate with charities in the production of the Cancer Strategy and in facilitating the plan. For example collaboration between charities and the Scottish Government on signs and symptoms awareness campaigns can be hugely beneficial. **The Brain Tumour Charity would be very willing to play an active role in any collaboration on the further development and delivery of this plan.**

Scope and Framing

They are proposing that themes are used consistently in the overarching strategy and 3 year action plans, these currently include:

- **Person-centred care.**
- **Prevention.**
- **Timely access to care.**
- **High quality care.**
- **Safe, effective treatments.**
- **Improving quality of life and wellbeing.**
- **Data, technology and measurement.**
- **Outcomes.**

6.

a. Do you agree with these themes? Please respond yes or no.

Yes.

b. Please explain your answer and provide any additional suggestions.

We're encouraged to see these important themes identified as needing to be used consistently throughout by the plan. It is good to see improving quality of life and wellbeing identified, which we believe also needs to be reflected as a key area in the previous proposed aims of the strategy.

Person-centred care

Person-centred care means 'mutually beneficial partnerships between people diagnosed with cancer, their families and those delivering healthcare services which respect individual needs and values and which demonstrate compassion, continuity, clear communication and shared decision-making'. Care focuses on the individual and their particular health and care needs, ensuring people's preferences and values are taken into account.

Under person-centred care they are considering:

- **Individual experience (by responding to Scotland Cancer Patient Experience Survey 2022 (SCPES); and by working with Third Sector and key partners on projects such as Care Opinion).**

- **Co-production of some actions with people affected by cancer.**
- **Wider support for people living with and beyond cancer and their supporters (for example Single Point of Contact, Transforming Cancer Care, Prehabilitation).**

7.

a. Do you agree with these areas of focus? Please respond yes or no.

Yes.

b. In your experience, what aims or actions would you like to see under any of these areas?

As part of the wider support for people living with and beyond cancer, we would like to see action to ensure Holistic Needs Assessments (HNAs) are offered to all brain tumour patients at diagnosis and key changes in their care or condition. We also believe that all brain tumour patients should have good access to a Clinical Nurse Specialist (CNS) or keyworker, which we know is unfortunately not yet the case.

c. Please explain your answer and provide any additional suggestions.

Person-centred care is vital for improving patients' quality of life and outcomes. A key aspect of this for brain tumour patients, specifically, are Holistic Needs Assessments (HNAs).

Action to ensure HNAs are being routinely offered to brain tumour patients at the point of diagnosis, and any key changes in care, with resulting care plans put in place, **is essential in ensuring that all patients receive person-centred care and sufficient wider support.**

HNAs are extremely important tools for ensuring that patients' needs are met and identifying areas where extra support is required. One respondent to The Brain Tumour Charity's Improving Brain Tumour Care Survey said "We only had one virtual consultation, but in that hour we had such a holistic consultation covering a range of topics, followed up by the CNS referring us to palliative care, accessing physio and occupational health and also referring us for some help with finances." This activity is often carried out by a CNS, making the importance of access to a CNS or keyworker linked with the provision of HNAs and, as such, access to wider support.

The provision of a HNA and resulting care plan is essential for good patient experience, and in ensuring that the patient is supported in all aspects of their treatment and care, particularly through signposting and referring to other services. This can include interventions such as access to counselling, financial support and signposting to other charities for support. This can be especially important for brain tumour patients who, due to the location of their tumour, can experience personality and cognition changes.

However, we have found that many brain tumour patients are missing out on such a crucial element of successful after-care and support services. The Brain Tumour Charity's Improving Brain Tumour Care (IBTC) survey showed that only 37% of Scottish respondents were offered an HNA, and only 5% of respondents who did have a resulting care plan, felt that it was working well. This is extremely concerning, and shows that many brain cancer patients have needs that are not being identified or addressed and lack the signposting to the support they require. Many patients are unsure of where to go to receive specialist support, and what support they may even be entitled to, **making a regularly reviewed HNA a vital part of ongoing and consistent person-centred care for patients.**

Prevention

They propose to look at Prevention in relation to risk factors for cancer that can be modified at the population level and at the individual level. They are considering, for example:

- **Alcohol minimum unit pricing.**
- **Smoke-free zones.**
- **Restricting promotion and advertising of foods high in fats, sugar and salt.**
- **Mandatory calorie labelling.**

- **Raising awareness of weight management services.**
- **Healthy eating advice.**
- **Smoke cessation services.**

8.

- a. In your experience, what actions do you think would be most effective for helping to stop people getting cancer and reducing inequalities in cancer incidence? Please focus your response on the prevention of cancer and inequalities in cancer incidence.**

Unfortunately, the current scientific consensus suggests the vast majority of brain tumours are not preventable. Of the factors known to increase the risk of a brain tumour, just two are thought to be 'preventable' – being overweight and exposure to ionising radiation. Not just that, but these are thought to only cause a very small number of cases: it is thought that just 3% of brain tumours in the UK are preventable¹.

While this is a small proportion, if we can act to tackle the increase in risk that being overweight can bring, we could still prevent hundreds of cases per year. When it comes to the devastating impact a brain tumour diagnosis can have, anything we can do to bring down the overall number is worthwhile.

We would therefore support measures to tackle obesity and encourage healthy lifestyles with regards to cancer prevention programmes.

- b. Please explain your answer and provide any additional suggestions.**

The lack of understanding around the causes of brain tumours can be incredibly difficult for those who are diagnosed to accept. Because we cannot prevent most cases, or predict or screen for the onset of brain tumours, understanding the signs and symptoms is incredibly important in ensuring more people are diagnosed promptly and can receive the support they need as soon as possible following the onset of symptoms.

With the vast majority of cases not being preventable, it is so important that funding is invested in world-class research to develop our understanding of how brain tumours develop, grow and behave, and find better ways of detecting, treating and ultimately curing them. While we have seen significant advancements in knowledge about how other cancers develop and grow to develop effective and targeted treatments, **we have just not seen the same progress for brain tumours – and we need government to act.** We would like to see a commitment in the Scottish Cancer Strategy **for the Scottish Government to invest in world-class brain tumour research in Scotland.**

Timely access to care

Timely access to care means trying to identify cancer as early as possible. Actions include, for example, education for the public and health professionals, screening programmes (general and targeted), getting the right tests quickly, and being referred and seen at the right time by the right people.

Under Timely access to care, they are considering:

- **Screening (such as national programmes and genetics).**
- **Early detection and diagnosis (looking at genetic tests/molecular pathology; diagnostic tests (haematology, pathology, radiology, endoscopy); Detecting Cancer Early programmes; and Early Cancer Diagnostic Centres).**
- **Primary Care (including direct access to investigations, referrals and opinions; and education and engagement with communities).**

¹ <https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-other-cns-and-intracranial-tumours#heading-Three>

9.

a. Do you agree with these areas of focus? Please respond yes or no.

Yes.

b. In your experience, what aims or actions would you like to see under any of these areas?
Please focus your response on timely access to care.

We would like to see further research and support for the development of triage tools for GPs to help with faster diagnosis of brain tumours, such as the [Dxcover blood test](#) or the [Verbal Fluency Test](#) (see question 1c).

Greater understanding of how these two triage tools could be used by doctors and patients, and then establishing them in primary care across Scotland as the evidence emerges could really make a difference to faster diagnosis times for brain tumour patients – while ensuring only those most in need of a scan are referred for imaging, so action from the Scottish Government to support this will be key.

We would also like to see Early Diagnosis Progress/Strategy Groups for each of the six less survivable cancers, including brain cancer. These groups should explore and invest in better tools, tests and analysis of data to help with making progress on faster and earlier diagnoses of these cancers. As brain tumours (and other cancers such as blood cancers) cannot be staged, we must see proxy measures developed to track progress. This will mean brain cancer can be included in efforts to diagnose people earlier such as in overall targets to increase the percentage of people diagnosed with cancer at stage 1 or 2.

c. Please explain your answer and provide any additional suggestions.

As mentioned above, triage tools to support primary care professionals identify those presenting with vague or non-specific symptoms for urgent scans are not currently available. We do not have the routes to diagnosis data publically available for Scotland, but fewer than 2% of patients in England referred from GPs for rapid access brain imaging to rule out more serious diseases, such as a brain tumour, actually have one, yet, 39% of brain tumour patients in England² are diagnosed via an Emergency Department. Brain tumour emergency presentations are the 4th highest in England out of the 24 cancer groups. Eight of these 24 cancers reported have emergency presentation diagnoses of less than 10%. This data is not available for Scotland, but we expect it to be similarly significant.

Some of this will be down to the fact that for some brain tumour patients, the first symptom may be very serious or severe, such as a seizure, which takes them to Accident and Emergency. However, for those who are presenting symptoms, no matter how vague, we need to see action to bring emerging triage tools to primary care.

The two emerging triage tools (see question 1c), [Dxcover](#) and the [Verbal Fluency Test](#), have shown promise in helping GPs identify patients who may need to be referred for an urgent brain scan.

We are calling on the Scottish Government to commit to (establishing and) **reducing the proportion of brain tumours diagnosed via an emergency presentation**, and commit to developing brain tumour triage tests including **the Dxcover blood test and Verbal Fluency Test and to establishing them in primary care across Scotland as soon as possible as the evidence emerges.**

High quality care

Under High quality care, they want to think about actions outside of direct treatment that affect the care given to those affected by cancer. They are considering:

² NHS Digital (2022) Routes to Diagnosis, 2018. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/routes-to-diagnosis/2018#>

- **Workforce (thinking, for example, about requirements and modelling for oncology and other workforce, including specialist nurses; leadership).**
- **Service delivery (thinking about national, regional and local services; flexible use of workforce; role of cancer network; strategic alliances and working across health boards, for example).**
- **Inequalities (thinking about how to make sure everyone is included, and targeting those who may be at a disadvantage).**
- **Accessibility (breaking down barriers such as geographical, cultural or language)**
- **Integrated support services between NHS and Third Sector.**

10.

a. Do you agree with these areas of focus? Please respond yes or no.

Yes.

b. In your experience, what aims or actions would you like to see under any of these areas? Please focus your response on quality of care.

We would like to see action to improve signposting to after-care and support services, provide greater long-term support in managing later effects of treatment including through access to HNAs (see question 7), and greater access to a CNS or keyworker for all brain tumour patients. This should include signposting to specific charity services.

c. Please explain your answer and provide any additional suggestions.

If we are to achieve consistent and high-quality care for all cancer patients, it is clear that a long-term commitment to growing, retaining and supporting the cancer workforce will be key. The commitment to publish regular workforce projections is very much welcomed, and we look forward to seeing these in future and working with the Scottish government to ensure the workforce adequately provides for brain cancer patients.

A high standard of care should include signposting to after-care and support services for brain tumour patients, which at present is worryingly lacking. The Brain Tumour Charity's Improving Brain Tumour Care Surveys showed that only 50% of respondents were signposted to emotional support, only 32% were signposted to financial help, and 22% of respondents were not connected to any support by a healthcare professional³. These numbers are UK wide, as we do not have the breakdown for this particular question down by nation; however, we believe Scotland would reflect similar. We know that so many people affected by brain tumours have significant unmet needs during and after their treatment, and this needs to be addressed through the signposting of, and provision of, necessary holistic support and care.

Brain tumours are incredibly complex and treatments can be gruelling. Where an individual does receive curative treatment, the impact of the disease often unfortunately does not end when their treatment ends. Later effects such as learning and cognitive difficulties, or permanent disabilities can occur, that the individual and their family often need support managing. These late effects need to be considered early in a person's treatment, and access to support and care packages should be in place for as long as necessary in that individual's life.

When it comes to improving the experiences of treatment and care, a CNS or key worker can be essential in helping patients better understand, coordinate and advocate for their care needs. The Scottish Government should commit to everyone with a brain tumour having a named healthcare professional or CNS who coordinates their health and social care support. This is especially necessary because the care surrounding brain tumours is incredibly complex to coordinate.

³ Sample: 1257 adults diagnosed or in active treatment for a brain tumour during the last 2 years (up to October 2021).

Unfortunately, we know that access to a CNS can vary. According to the Scottish Adult Neuro Oncology Network (SANON) Audit, for 2020 (published in January 2022) under a third (31.8%) of patients with brain/CNS cancer had an identified key worker by the time of their first MDT meeting. In addition, our own Improving Brain Tumour Care (IBTC) survey showed that of those who did have access, only 38% felt they were able to speak to their CNS or keyworker whenever they needed to. It is crucial to improving care that every brain tumour patient has access to a Clinical Nurse Specialist (CNS) or key worker, no matter where they live, who is able to explain treatments and answer any ongoing questions.

In order for this to happen, **there needs to be clarity on how the welcome £130 million investment set out in the 2022 National Workforce Strategy will be spent on the different cancer workforce areas and roles.**

We are calling on **the Scottish Government to apply a 'Once for Scotland' approach to delivering brain tumour services – ensuring everyone diagnosed with a brain tumour can access support from a Clinical Nurse Specialist or key worker**, regardless of their tumour type or where they live in Scotland.

Safe, effective treatments

Safe, effective treatments are the cornerstone of managing cancer. The majority of cancer treatments have continued throughout the pandemic but there are noted variations around the country. Treatment may come with side effects – or even a negative outcome: realistic medicine means encouraging people using healthcare services and their families to discuss their treatment fully with healthcare professionals, understanding the potential benefits and risks.

Under Safe, effective treatments, they are considering:

- **Surgery.**
- **Radiotherapy.**
- **Systemic anti-cancer treatment.**
- **Acute oncology.**
- **Realistic medicine.**
- **Consent.**

11.

a. Do you agree with these areas of focus? Please respond yes or no.

Yes.

**b. In your experience, what aims or actions would you like to see under any of these areas?
Please focus your response on treatment.**

We would like to see a focus on research in the cancer strategy, including facilitating innovative treatments to come to the clinical trial stage in Scotland, and increasing the participation rate of brain cancer patients in research.

c. Please explain your answer and provide any additional suggestions.

All brain tumour patients should have access to the best and most appropriate treatment and care for them, including receiving holistic support tailored to their needs before, during and after treatment.

For many brain cancer patients, however, the treatment options remain limited – and survival rates overall are still worryingly low with just 15% of adults in Scotland diagnosed with brain cancer surviving five years or more. So as well as improving access to existing treatments and care for brain tumour patients, it is critical we focus on developing the new innovative treatments we need to improve survival.

Research is absolutely essential to enable developments in improving brain cancer prevention, diagnosis and treatment; but it is also key in achieving the goal of meeting the needs of those affected

by brain tumours. Accessing clinical trials gives patients the opportunity to access potentially helpful or life prolonging treatments they wouldn't otherwise have access to.

However, we know from The Brain Tumour Charity's IBTC survey that many patients are not informed about research participation opportunities, with only 21% of Scottish respondents stating they had been informed about potential opportunities. Increasing the proportion of brain tumour patients who are given the opportunity to participate in research could not only help benefit those currently undergoing treatment, but could accelerate progress into prevention, diagnosis and treatment. That's why widening access to research, so that people with brain tumours have the opportunity to be involved across the care whole pathway, is so important. **People diagnosed with a brain tumour should be given the opportunity to take part in clinical trials wherever possible.**

Improving quality of life and wellbeing

Treatment may not be the solution and, alone, is not sufficient. There is also the need to consider the overall quality of life and wellbeing of people living with and affected by cancer. This can be influenced by where a person lives and other social factors. Wellbeing and quality of life can be improved by strategies such as prehabilitation (helping people prepare for cancer treatment), psychological support and support for families and carers. Patients' experience of cancer is affected by how quickly and smoothly they move through the 'patient pathway' from symptoms to diagnosis to treatment and care. And care beyond surgery, radiotherapy and chemotherapy is important too, including palliative and end-of-life care.

Under improving quality of life and wellbeing, they are considering:

- **Prehabilitation and rehabilitation.**
- **Psychological support.**
- **Patient pathways (including quality of care, waiting times, less survivable cancers).**
- **Palliative medicine, Best Supportive Care and End of Life care.**
- **Support to family/carers.**

12.

a. Do you agree with these areas of focus? Please respond yes or no.

Yes.

b. In your experience, what aims or actions would you like to see under any of these areas? Please focus your response on quality of life and wellbeing.

Earlier conversations and information surrounding palliative care, support for carers with the psychological impact of a loved ones' brain tumour diagnosis, and access to appropriate rehabilitation services.

c. Please explain your answer and provide any additional suggestions.

We absolutely agree with these areas of focus. Many people with a less survivable cancer will not have treatment options available to them and we need to see holistic support given to every patient, meeting their psychological and wellbeing needs, and those of their families and carers. It is important that the plan has a focus on less survivable cancer patient pathways, to ensure these patients are diagnosed as quickly as possible and have as many treatment options available to them as possible.

Ensuring conversations and information around palliative care are introduced earlier for patients is important to help support patients and their families holistically at a very difficult time. End of life care is often provided at a GP or local authority level, after patients have been discharged from their consultant. This means that the patient can lose access to the disease-specific specialist support and the healthcare professionals who have coordinated their care up to that point, which can be challenging to navigate. **A patient's multidisciplinary team should work better together to ensure that the disease-specific care is not lost in the transition to specialist palliative care support.**

Support for carers (family and friends) is absolutely vital, particularly in regards to psychological support and counselling. Not only does brain cancer often have a devastatingly short prognosis, it can also change the personality of the patient, which can be extremely challenging for family and friends to understand and deal with. **Every patient and their family must have access to the full range of psychological services, including those provided by NHS, social care and third sector organisations.**

Rehabilitation services can be difficult for patients to access, particularly when they have large waiting lists. It is important to recognise that recovery from a brain tumour is different to other cancers. There may be significant long lasting disabilities and impacts of treatment that require holistic support to help patients adapt.

Data, technology and measurement

Data (knowledge, information and statistics) are important to help manage cancer care as well as for measuring how well they are doing. There continue to be new innovations and technology that can help with diagnosis and more precise treatment. And research is important to stay up-to-date and know what works best. They want to make the best use of Data, technology and measurement, and are considering:

- **Data, for example:**
 - **Outcomes e.g. recurrence, benchmarking.**
 - **Scottish Cancer Registry and Intelligence Service (SCRIS).**
 - **Quality Performance Indicators (QPIs).**
 - **Cancer Waiting Times (CWTs).**
 - **Cancer Medicines Outcome Programme (CMOP).**
 - **Patient Reported Outcome Measures (PROM).**
 - **Multi-disciplinary teams (MDTs)**
- **Research, technology and innovation (including regulation/quality/safety):**
 - **Clinical trials.**
 - **Precision medicine.**
 - **Genetics/genomics/molecular pathology (screening, diagnostics, treatment).**
 - **Robotics.**
 - **E-health, for example, Near Me and Connect Me.**

13.

a. Do you agree with these areas of focus? Please respond yes or no.

Yes.

**b. In your experience, what aims or actions would you like to see under any of these areas?
Please focus your response on data, technology and measurement.**

We would encourage 31 day waiting time data and 62 day waiting time data by month to be measured and reported for brain/CNS cancer. A greater provision of publically available data around routes to diagnosis for brain cancer patients would also be very useful in understanding how this might be improved. This would provide an understanding of the current situation for brain tumour patients in regards to the experience of patients and how long they may be waiting for their treatment to begin following diagnosis.

We would also like to see a greater role of the BRIAN App (Brain tumouR Information and Analysis Network) in supporting brain tumour patients in Scotland. **We would also like to see a greater provision of and access to data about brain tumours in Scotland, an enhancement of the research landscape to promote innovation and collaboration, and increased funding for research.**

c. Is there any technology that you would like to see introduced to improve access to cancer care? Please consider access to screening, diagnostics, results, tracking of your pathway.

Tools like the [BRIAN App](#) (Brain tumouR Information and Analysis Network) have a major role to play in harnessing the power of medical and clinical data and patient-reported quality of life information. It is therefore important that these tools and the generated datasets are available in a safe, ethical and responsible manner to researchers, clinicians and patients, in order to help drive improvements in quality of life and accelerate progress towards cures. It would be beneficial for Trusted Research Environments (TRE) that hold NHS data in Scotland to allow for federation with other datasets. Having a federated identity service, along with standardised terms in government and NHS contracts, would drive forward standards for federation of TREs and allow easier access of data while still maintaining safety and confidentiality. **The Scottish Government should work to federate Trusted Research Environments that hold NHS data in Scotland and work with The Brain Tumour Charity to allow NHS Scotland data to be used within BRIAN.**

Please explain your answer and provide any additional suggestions.

As stated above, **we would encourage 31 day waiting time data and 62 day waiting time data by month to be reported for brain/CNS cancer.** This would provide an understanding of the current situation for brain tumour patients in regards to the experience of patients and how long they may be waiting to be diagnosed and for their treatment to begin following diagnosis. Being able to access comprehensive and consistent data will provide crucial insights to both move towards and measure progress on the Scottish Government's goals on early detection.

Patient data is also crucial in providing insights to advance medical research and holds significant potential to deliver benefit to patients, as well as measure progress. We need an increase in good-quality research and data in order to further the knowledge and understanding of brain tumours, accelerate new treatments, and enhance quality of life through evidence-based supportive care. This data needs to be granular to be meaningful, as the impact of brain tumours is so varied depending on type and location in the brain.

In our experience, accessing national healthcare datasets is currently costly for charities and researchers and can be time-consuming. There are often errors, poor coverage of certain information and inconsistencies in clinical coding and reporting practices between trusts, which makes trends harder to understand. Access to data and assurance of data quality are key, alongside ensuring accurate linkage of complimentary datasets and making it easier to request additional aspects of data. Greater transparency over the outcomes of every clinical encounter as well as over the technology and services employed in different hospitals would enhance the research value of the data.

It is also essential to improve the process for collecting data, giving consideration to the information required for research.

There is also a disparity between the genomic medicine service in England and Scotland, as there are fewer patients to support this kind of work in Scotland. Molecular (whole genomic sequencing) testing is not currently offered in Scotland, making it harder for patients to be included in trial platforms such as [BRAIN MATRIX](#). **We'd encourage the Scottish Government and NHS Scotland to consider whether adopting long-read genomic sequencing would help address these concerns in the future, and ensure all patients can access the right clinical trial opportunities. Genomic-wide methylation testing should be included in the standard of care for all patients.**

Being able to pool data from across the whole of Scotland is also particularly important when looking at relatively rare diseases such as brain tumours, where there are over 130 different types, as it can be the only way to obtain statistically significant results. Thanks to collaborations with Public Health England, NHS Digital and the SAIL databank in Wales, anonymised data in England and Wales will soon be available to patients and researchers alike, maintaining the highest levels of privacy and confidentiality. But the current barriers to data access in Scotland – including high costs and significant length of time it can take for data to be released – could lead to delays in research progress. It can mean delays in

Scottish patients accessing relevant insights which could ultimately limit the information they have on treatment options and alternative patient pathways.

It is essential that research funding into brain tumours is increased in order to grow our knowledge and understanding of brain tumours, accelerate new treatments, and enhance quality of life through evidence-based supportive care. And that's exactly what The Brain Tumour Charity's new research strategy, [Accelerating a Cure](#), looks to achieve. **We would like the Scottish Government to support brain tumour research by setting out a commitment in the Cancer Strategy to prioritise and fund world-class, brain tumour research as soon as possible.**

Scotland's cancer charities have a key role to play at the interface of research, healthcare and patient support – and we must urgently harness the power of data to deliver progress and best serve our communities. We are calling on the **Scottish Government to commit to accelerating access to real-world data for Scottish brain tumour patients, researchers and charities, including through our app BRIAN, by addressing the current barriers to accessing the best data.**

Outcomes

14. What suggestions do you have for what we should measure to make sure we are achieving what we want to in improving cancer care and outcomes? Please focus your response on cancer care and outcomes.

There are some key areas which should be measured to ensure patients are being provided with the most appropriate support, and observe progress made on outcomes. These include:

- Percentage of patients being offered a Holistic Needs Assessment; this should aim to be 100%.
- Money invested into brain tumour research by the Scottish Government, with the aim for continued and increased funding to find treatments and better understand brain tumours.
- Time to diagnosis, measured from the onset of first symptoms. It is also important to know a patients' route to diagnosis, and how many healthcare professionals were seen before diagnosis. The aim should be to have a better coordinated system with improved cross-departmental communications.
- Percentage of patients having access to a Clinical Nurse Specialist; this should aim to be 100%.
- Percentage of patients being informed about their potential opportunities to participate in research; this should aim to be 100%.

Early Diagnosis Vision

The Detect Cancer Early Programme was launched in 2012. Its main purpose was to raise the public's awareness of the national cancer screening programmes and the early signs and symptoms of cancer to encourage them to seek help earlier.

They plan to continue the programme, and the new Cancer Strategy will include an Earlier Diagnosis Vision, shaping the earlier diagnosis programmes in Scotland over the period of the new strategy. Earlier diagnosis of cancer means detecting cancer in people with symptoms as soon as possible when there are more treatment options and a better chance of cure.

15.

- a. What would you like to see an Earlier Diagnosis Vision achieve? Think ahead to the next 10 years, think big picture – what change(s) should we be aiming to influence when it comes to earlier cancer diagnosis? Consider access to care/cancer screening/primary care/diagnostics and awareness of cancer signs and symptoms.**

Early diagnosis is a unique challenge for brain tumours, due to their varied and often non-specific symptoms, as well as their location in the body. Presenting symptoms, such as headaches, or cognitive and personality symptoms, may also be more commonly attributable to other conditions, such as migraines, depression or dementia. This contributes to delayed diagnosis. Patients often only present

when they develop more severe symptoms such as a seizure or loss of limb mobility. This means that diagnosis following an emergency presentation is still relatively common for brain tumour patients.

Data on emergency presentations leading to brain tumour diagnosis is not available for Scotland. But in England, diagnoses of brain tumours for emergency presentations are the 4th highest of the 24 cancer groups⁴. **Data on emergency presentations and routes to diagnosis for all cancers, including brain tumours, should be collected and made available in Scotland.**

As part of a long-term vision, **we would like to see the Scottish government commit to reducing emergency presentations for brain tumours.** If data on emergency presentations and routes to diagnosis were made available, they could be used as trackers of progress and a target to reduce emergency presentations for brain tumour diagnoses could be set.

We also see **national signs and symptom awareness raising campaigns and the emerging triage tools as important in improving early diagnoses for brain cancer patients.**

Over ten years ago, The Brain Tumour Charity established [HeadSmart](#). Launched in partnership with the Children's Brain Tumour Research Centre at the University of Nottingham and the Royal College of Paediatrics and Child Health, and accredited by NICE, the HeadSmart campaign aimed to raise awareness of the signs and symptoms of brain tumours in children and young people. It did this by providing tools to support and equip parents, healthcare professionals and the public to recognise symptoms as soon as possible. The campaign used a combination of tools including posters, symptom cards, campaigners writing to their MPs, and a symptom diary. The HeadSmart campaign has been a success helping to reduce childhood time diagnosis from over 13 weeks to 6.5 weeks⁵.

The Brain Tumour Charity will be re-launching a new signs and symptoms campaign for both adults and children over summer 2022 and **would welcome the Government's support in promoting this and helping more people to come forward to visit a doctor** if they have concerns about symptoms.

The awareness of the signs and symptoms needs continued efforts and investment to be maintained over time in order to see sustained and persistent improvements in diagnosis times. **The government should commit to multi-year funding for continued cancer awareness campaigns** – including working with the NHS and The Brain Tumour Charity to promote a brain tumour signs and symptoms awareness campaign.

As mentioned in earlier answers, funding to develop diagnostic and triage tools specifically for brain tumours will also be vital and is desperately needed. Moreover, GPs may see just four or five brain tumour patients in their working lifetime making it challenging to develop expertise and demonstrates how important quick and easy triage tools could be for GPs. The Scottish government should **commit to establishing triage tools (such as Dxcover blood test or the Verbal Fluency Test – see question 1c) in primary care across Scotland as soon as possible, as the evidence emerges.**

Providing continued funding for dedicated training on brain tumour symptoms for healthcare professionals, including GPs and opticians, could also help support those healthcare professionals to recognise the non-specific symptoms that often are associated with brain tumours.

The introduction of the Early Cancer Diagnostic Centres in Scotland is really promising for many cancers, but whether these hubs will provide a direct benefit for those with brain tumour symptoms is currently unclear. In a pilot study of this approach run by Cancer Research UK in England, 239 diagnoses of cancer were made from 2961 referrals. Of the 239 diagnoses only one was for brain cancer (unspecified). The small sample size means we cannot draw any definitive conclusions on their benefit. **We would welcome consideration of how Early Cancer Diagnostic Centres could help improve brain tumour diagnoses and patients' experiences in Scotland in future.**

⁴ NHS Digital (2022) Routes to Diagnosis, 2018. Available at: <https://digital.nhs.uk/data-and-information/publications/statistical/routes-to-diagnosis/2018#>

⁵ Liu, J. F., et al. (2017). 'REDUCING TIME TO DIAGNOSIS OF PAEDIATRIC BRAIN TUMOURS IN THE UK – HEADSMART AWARENESS CAMPAIGN (WWW.HEADSMART.ORG.UK)', *Neuro-Oncology*, 19(Suppl 4), iv57. <https://doi.org/10.1093/neuonc/nox083.236>

- b. Should the Earlier Diagnosis Vision set itself a numerical target? For example, 75% of all cancers diagnosed at an earlier stage. Please provide any suggested target you have.**

While England's NHS Long Term Plan has a welcome goal for 75% of cancers to be diagnosed at stage 1 or 2 by 2030, it is unclear how and progress on early detection of brain tumours may be included in this ambition and in action to reach this target. This is because brain cancers are not staged in the same way as other cancers. Blood cancers are also not staged in this way. If Scotland introduces a similar target, **there needs to be acknowledgement that a different way of measuring earlier diagnosis progress for brain tumours and other cancers that are not staged will be necessary.**

Because brain tumours act differently and are not staged, we know that English targets and figures on how many people are diagnosed at stage 1 or 2, provided by NHS England, and are not representative for brain tumour patients. In setting targets for early diagnosis, the Scottish Government cannot leave brain tumour patients behind. **We need to see clear targets that address early detection for cancers that aren't staged in the same way as other cancers, including developing proxy measures to monitor progress.** The Brain Tumour Charity would welcome discussions with the Scottish Government to help develop a proxy measure for early diagnosis of brain tumours.

- c. Should the earlier cancer diagnosis vision focus on specific cancer types? The current programme focusses on lung, bowel and breast cancers that account for 45% of all cancers diagnosed in Scotland.**

The Early Diagnosis Vision should have a focus on brain cancer due to the unique difficulties surrounding early diagnosis, as outlined in previous questions. The Less Survivable Cancers, where early diagnosis is also harder, should also be prioritised.

- d. If you or a family member or friend have previous experience of a cancer diagnosis, where did the service work well and why was that? What could have improved the experience? Please refer back to your personal experience to identify how services worked well and where improvements could be made.**

N/A

- e. From your previous experience where would you like to access care if you had concerns about cancer that would be different to what is available currently? Please identify where you would like to access care differently to your experience.**

N/A

- f. What does good earlier cancer diagnosis look like for you? Think about what a good outcome would be, for example more people being diagnosed when they can be cured of cancer, living well with cancer for longer etc.**

N/A

Impact Assessments

16. Question 16

- a. In your experience, are there aspects of cancer diagnosis, treatment or care that affect people from marginalised groups differently? If there are negative effects, what could be done to prevent this happening? Please consider the 'protected characteristics' of age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, and sexual orientation.**

N/A

- b. Similarly, is how we manage cancer different for wealthy or poor people? What could be done to do this better? Please consider the impact of socio-economic inequality.**

N/A

- c. **Is the experience of cancer different for people living in rural or island communities? What could be done to prevent any negative impacts? Please consider the impact of rurality on access to and quality of cancer services.**

N/A

Conclusion

17. Question 17: What other comments would you like to make at this time? Please provide any additional comments regarding the long or short-term ambitions for cancer services.

The opportunity this strategy presents is huge and we are grateful for the chance to submit our views. A brain tumour diagnosis is devastating and any action to improve the cancer experience for these patients, as well as the other less survivable cancers, must be taken. By focusing on diagnosing earlier, faster and ensuring everyone has optimal pathways of care, including holistic support and palliative care, we can transform outcomes and experiences. Triage tools to support faster diagnosis must be further developed and validated as a matter of urgency and then implemented into primary care swiftly as the evidence emerges – and research has to be prioritised both in terms of funding and patient participation.

We look forward to continuing to work closely with the Scottish Government to develop, drive forward and implement the Strategy and resulting Action Plans.