LSCT submission to the Scottish Government's consultation on a new 10-year cancer strategy
June 2022

About the Less Survivable Cancers Taskforce: The six less survivable common cancers (lung, pancreatic, liver, brain, oesophageal and stomach) are responsible for a quarter of all cancer diagnoses each year in Scotland and, because of their poor outcomes, around 44% of cancer deaths. Only 16% of the 9,000 people diagnosed every year with one of the six less survivable cancers will survive for five years. These cancers have not seen the same improvements in survival rates that other cancers have in the last forty years.

The Less Survivable Cancers Taskforce (LSCT) brings together six charities representing patients from each of these cancers to improve experiences and outcomes for all people diagnosed with a less survivable cancer in the UK. Our founding member charities are:

- Action Against Heartburn (oesophageal cancer)
- The Brain Tumour Charity (brain cancer)
- The British Liver Trust (liver cancer)
- Guts UK (stomach cancer)
- Pancreatic Cancer UK (pancreatic cancer)
- Roy Castle Lung Cancer Foundation (lung cancer)

We are supported by an additional 10 charity registered supporters: Barrett's Oesophagus UK, Brains Trust, Brain Tumour Research, Heartburn Cancer UK, Hepatocellular Carcinoma UK, Oesophago-Gastric Cancer Northern Ireland, Ochre, Pancreatic Cancer Action, Pancreatic Cancer Action Scotland and Tenovus Cancer Care.

For more information and to meet our membership charities and supporting clinicians and patients, please contact lesssurvivablecancers@principleconsulting.org.uk or find us on our website, www.lesssurvivablecancers.org.uk.

1a. What are the most important aspects of the cancer journey you would like to see included in a long-term strategy?

The Less Survivable Cancers Taskforce welcomes the development of a new Cancer Strategy for Scotland, and we are pleased to have the opportunity to contribute to this consultation.

We see this Strategy as an opportunity to address all aspects of the cancer journey for people diagnosed with a less survivable cancer (cancers of the lungs, liver, stomach, pancreas, oesophagus or brain) - earlier diagnosis, faster diagnosis, optimal treatment pathways and supportive care throughout, including palliative care if needed.

All of these facets are important but the critical area that needs focus if we are to improve survival rates

is to diagnose people **earlier and faster.** Over 9,000 people are diagnosed with one of these cancers every year in Scotland and sadly only 16% of people diagnosed with a less survivable cancer will survive for 5 years [ref 1]. Therefore a step-change in early and fast diagnosis is absolutely critical to detecting these cancers at a stage when curative treatment is possible.

We recommend that the Strategy has a clear focus on making progress with diagnosing people with a less survivable cancer earlier and faster, including investing in research to find new and easier diagnostic tests; to explore effective targeted screening options; and to monitor people who are at high-risk. To progress with this, we suggest setting up an Early Diagnosis Progress / Strategy Group to focus on diagnosing each of the 6 less survivable cancers earlier. They should drive forward the implementation of interventions such as:

- The full roll-out of targeted lung cancer screening. We are delighted to see the UK National Screening Committee propose that a targeted screening programme for lung cancer in people age between 55-74 with a history of smoking should be rolled out across the UK. With over 5,000 people a year dying from lung cancer in Scotland, we believe that this should be agreed and rolled out as soon as possible as a key part of the Strategy, in tandem with the development of the necessary pathways and workforce.

- Continued support for the development piloting and implementation of Dxcover's diagnostic blood test, which aims to support primary care to triage and identify symptomatic patients most in need of an urgent brain scan as the evidence develops. As non-specific symptom presentation is very difficult for GPs, this test is a rapid point of care option, using a blood test chip put into a machine which then can prioritise the patient for imaging according to results.

- We understand that Cytosponge continues to be rolled out across primary care in Scotland. This is to be welcomed and as people return to attending NHS services we hope it will be a more accessible form of earlier diagnosis than endoscopy and will support the reduction of the current, alarming waiting times.

- Roll-out of a comprehensive programme for the early detection of liver disease. 75% of people with cirrhosis are diagnosed at a point when it is too late for treatment yet we know that one in three people with cirrhosis will go on to develop liver cancer. Cirrhosis is therefore the major risk factor for liver cancer. Early detection of asymptomatic cirrhosis in populations at risk is therefore the best way to prevent many liver cancers. Moreover, earlier detection of liver disease will allow opportunity for people to enter surveillance programmes that can detect liver cancer faster and earlier.

- For pancreatic cancer, increasing evidence shows that new onset of diabetes, pancreatitis and asymptomatic cystic lesions of the pancreas are all associated with an increased risk to develop pancreatic cancer. Further work is needed to define the populations with the highest risk based on a combination of factors, so we're not targeting whole populations.

- As approximately 10% of pancreatic cancers are hereditary, we recommend a roll out of a national surveillance programme of people with hereditary pancreatic cancer.

Intelligent Liver Function Tests (iLFTs) should be rolled out across all Health Boards in Scotland

as a Nationally adopted pathway so that we can improve early detection of liver disease and therefore liver cancer.

While there is some available data on high-risk populations for some less survivable cancers, more research must be done to identify and understand risk factors and high-risk populations and to develop tailored screening programmes for each cancer. These areas should be explored and researched through the 6 strategy groups.

Ref 1: Scottish Cancer Registry, PHS

1b. 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 are delighted 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 10-year Strategy.

Only 16% of people diagnosed with one of our 6 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 6 cancers have barely 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. Of our cancers, in Scotland, 78% of pancreatic patients will die within a year and half of them will pass within 3 months of diagnosis. For cancers of the brain, lung, oesophagus, liver and stomach, 60% of people diagnosed will die within one year.[ref 1]

We believe that pan-cancer commitments, ambitions and targets have led to less survivable cancers being overlooked and under-resourced across the UK. We urge the Scottish Government to use this Cancer Strategy to make specific commitments and targets for the less survivable cancers to drive forward the transformational changes we need in diagnosis, treatments and care required in these cancer areas. We believe the Government should use this strategy to set an ambition to double survival rates for people with a less survivable cancer over the course of the next decade.

Ref 1: Scottish Cancer Registry, PHS

1c. What do you think we should prioritise over the short-term?

We believe that priorities for the first 3 years should be:

- **Early Diagnosis Progress / Strategy Groups for each of the 6 less survivable cancers** should

be set up to focus on diagnosing the 6 less survivable cancers earlier. These groups should explore and invest in better tools, tests and analysis to identify at-risk people who are asymptomatic and need further investigation. As brain tumours (and other cancers such as blood cancers) cannot be staged, we need proxy measures to be developed. 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.

- **Faster diagnostic pathways** should be developed and implemented for each of the 6 less survivable cancers, for example standardised diagnostic bundles with simultaneous booking of all likely investigations and rapid turn-around times. Even when diagnosed at an early stage, less survivable cancers can nonetheless have poor outcomes due to delays in pathways, meaning that some people transition from operable to inoperable during the diagnosis process due to rapid progression of their cancer.

- **Timed, optimal pathways** should be developed and implemented for each of the 6 less survivable cancers. Work is underway on this and should be accelerated: An optimal pathway for lung cancer has been agreed by the clinical community but needs support with roll-out; and pathways are being developed for pancreatic and HCC cancers.

- As many people will be diagnosed with one of these 6 cancers at a stage where treatment is not possible, pathways must be in place for every patient to receive **the best supportive and palliative care,** including support for their families and carers. The psychological burden of being diagnosed with cancer, and knowing that it is life-limiting, is huge. Mental health support must be available for those who need it, including family and carers, with links to well-resourced palliative care teams. At the moment, our charity support services hear from people receiving inconsistent support in different areas.

- It is vital that the Government uses this strategy to address the workforce issues across the NHS in Scotland and makes a **long-term plan to train, recruit and retain the specialist cancer workforce needed** to meet the needs of all cancer patients. In particular, we would like all of our patients to receive the support of a CNS.

2a. Do you agree with the proposal for a 10-year strategy?

Yes.

2b. Please explain your answer and provide any additional suggestions.

We welcome a long-term commitment and feel that broader, overarching aims are conducive to the structural changes that we would like to see. We also agree that the three shorter-term action plans will ensure that these overarching aims are manifested in practical, results-driven progress for patients.

3a. Our 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"

Do you agree with this vision?

Yes.

4a. The Aims of the strategy set out more-specific goals that we will prioritise and that we can measure. Our 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

Do you agree with these goals?

Yes.

4b. Please explain your answer and provide any additional suggestions.

We support the goals highlighted in section 52, and additionally propose that an aim regarding supportive and palliative care is added to this list.

It is an unfortunate reality that many patients with less survivable cancers will not survive their illness. In these cases we feel it is vital that there is consistent, person-centered care which delivers support and palliative options to those who need it.

In particular, we support the focus on supporting people to live well and die well and plans for ensuring everyone with cancer has access to a Clinical Nurse Specialist, ensuring equitable access to tailored psychological support, appropriate access to therapeutic services, referrals for all to cancer information

and support services, and integrated personalised palliative care with access to palliative care key workers. These have the potential to improve the experiences of all patients, and particularly people with a less survivable cancer. Unfortunately we know that access to a CNS can vary. For example, according to the Scottish Adult Neuro Oncology Network (SANON) Audit, in 2020 under a third (31.8%) of patients with brain/CNS cancer have an identified key worker by the time of their first MDT meeting. The Brain Tumour Charity's Improving Brain Tumour Care (IBTC) survey also showed that, of those who did have access, only 38% in Scotland felt they were able to speak to their CNS or keyworker whenever they needed to.

The psychological burden of being diagnosed with cancer, and knowing that it is life-limiting, is huge. Mental health support must be available for all - the patients and their families.

5a. It is important to agree Principles that will underpin a future cancer strategy and guide our planning for and conducting future cancer services. These should reflect the values that we think are important in ensuring the best outcomes. Our proposed principles are:

- ***putting patients at the centre of our 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***

Do you agree with these principles?

Yes.

5b. Please explain your answer and provide any additional suggestions.

We agree with and support the proposed principles detailed in section 53. Additionally, we also feel that the Scottish Government should prioritise addressing health inequalities and disparities in outcomes and care.

Most less survivable cancers are associated with deprivation, with incidence and mortality higher within lower socioeconomic groups. For example, the disparity of lung cancer incidence between the most and least deprived areas is one of the widest of any cancer type [ref 1].

We believe that addressing these disparities should be a key principle in any cancer strategy, to ensure that inequality is not reinforced within our cancers due to their low survivability and disproportionate impact on lower socio-economic groups. Better published data is also required so that we can assess this

for all of our cancers in Scotland.

We believe it is vital that all patients are treated with compassion and that both principles of compassion and a focus on quality of life are prioritised when curative treatments are no longer an option. Being diagnosed with a less survivable cancer can be a lonely experience, with patients and carers sometimes adopting a nihilistic attitude when informed of the prognosis and mortality of our cancers. We must ensure that we are adequately supporting patients with the right information, easy access to help and care, and that the care provided is tailored and adapted to the patients and their needs.

Ref 1: Long-term Monitoring of Health Inequalities, Scottish Government, March 2022 report [https://www.gov.scot/binaries/content/documents/govscot/publications/statistics/2022/03/long-term-monitoring-health-inequalities-march-2022-report2/documents/long-term-monitoring-health-inequalities/long-term-monitoring-health-inequalities/govscot%3Adocument/long-term-monitoring-health-inequalities.pdf]

6a. We want to hear your views on how broad the strategy and actions plans should be, in addition to what the main areas of focus should be. We 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***

Do you agree with these themes?

Yes.

6b. Please explain your answer and provide any additional suggestions.

As well as the themes detailed above, we also feel there should be a specific effort to address variation in care, treatment, outcomes and data. This should be implemented through the development of optimal pathways for all less survivable cancers with fast access to treatment.

7a. Under Person-centred care we are considering:

- ***Individual experience (by responding to Scotland Cancer Patient Experience Survey 2022 (SCPES[24]); and by working with Third Sector and key partners on projects such as Care Opinion[25])***
- ***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)***

Do you agree with these areas of focus?

Yes.

7b. In your experience, what aims or actions would you like to see under any of these areas?

Under the proposed focus on person-centred care, we would like to see specific measures and metrics to measure and understand the experiences of people with less survivable cancers, which take into account LSC's rapid progression and high mortality.

7c. Please explain your answer and provide any additional suggestions.

While the focus on person-centred care is welcome, the Scotland Cancer Patient Experience Survey (SCPES) is not able to sufficiently capture the experiences of people with less survivable cancers.

The structure of SCPES has an in-built survivability bias as its timeline fails to capture patient experience for the majority of people with a less survivable cancer, where rapid progression and high mortality mean that people are often too unwell to respond, or have possibly passed. This means that their specific needs, experiences and concerns are not recorded and can be overlooked.

We need the timely collection of evidence of quality of care for people with a less survivable cancer and are therefore asking for a parallel metric or workstream to understand quality of life needs for people with a less survivable cancer.

8a. We 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. We 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.***

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?

Incidence of many of the less survivable cancers, in particular lung, liver cancer, stomach, oesophagus and pancreatic cancer, could be reduced with population-wide and targeted public health measures to reduce obesity, smoking and alcohol consumption.

For example, around 70% of lung cancer cases, a third of oesophageal cancer cases and 20% of liver cancer cases are linked to smoking; around a quarter of oesophageal and liver cancers (27% and 23% respectively), 10% of pancreatic, 6% of stomach and 2% of brain cancers are connected to obesity; and both oesophageal cancer and hepatocellular 2 carcinoma (HCC) are linked to alcohol consumption [ref 1]. Indeed, 90% of liver disease which can lead to liver cancer is preventable if caught early, and reversible through lifestyle changes including cutting out alcohol, weight loss (e.g. eating less HFSS foods) and increased exercise [ref 2].

One alcoholic drink per day (~12 g/day) is associated with a 1.1 times higher liver cancer risk so even drinking at low levels increases risk [ref 3]. The Scottish Government should introduce a joined-up, comprehensive, evidence-based alcohol strategy, to address the harm alcohol causes (including cancer) and improve health outcomes. There is also good evidence that alcohol consumption is closely linked to affordability. We recommend that the Minimum Unit Price for purchasing alcohol in Scotland is increased to 65p.

We would also like to see comprehensive strategic focus and investment on interventions such as smoking cessation services / tobacco addiction management services; more 'brief interventions' by healthcare professionals on smoking, obesity and alcohol; action on junk food advertising to children; and the introduction of minimum unit pricing for alcohol, in order to reduce the prevalence of these cancers.

Programmes that discourage smoking and encourage non-smoking to be the norm in communities are important. We must also challenge views about tobacco harm and educate people on the risk of adopting e-cigarettes.

Members of the public must be supported to understand the links between risk factors and cancer and to take steps to reduce their risk through well-researched and targeted campaigns, developed in partnership with people with experience of these cancers.

8b. Please explain your answer and provide any additional suggestions.

Any campaigns, such as those detailed in section 51, must also acknowledge and address that these cancers, although sometimes linked to preventable factors, are not exclusively the result of obesity, smoking or alcohol, to avoid fuelling a blame culture, stigma and shame. We must broaden awareness that anyone can get any cancer.

Awareness campaigns or policy aiming to address the causes of cancer must commit to understanding how social deprivation factors into the causes of cancer, its diagnosis and care.

Ref 1: CRUK website [https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/liver-cancer/risk-factors]

Ref 2: 1 PHE (2014) Liver disease: a preventable killer of young adults [https://publichealthmatters.blog.gov.uk/2014/09/29/liver-disease-a-preventable-killerof-young-adults/]

Ref 3: Chuang SC, Lee YC, Wu GJ, Straif K, Hashibe M. Alcohol consumption and liver cancer risk: a meta-analysis. Cancer Causes Control. 2015 Sep;26(9):1205-31. doi: 10.1007/s10552-015-0615-3. Epub 2015 Jul 2. PMID: 26134046.

9a. 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, we 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)***

Do you agree with these areas of focus?

Yes.

9b. In your experience, what aims or actions would you like to see under any of these areas?

Under the aim of timely access to care, we fully agree that working with primary care colleagues must be a priority to ensure they are monitoring people for less survivable and rarer cancers. We encourage return to face to face GP consultations where possible to assist with vague symptom presentation, and incidental conversations that people have with GPs about concerns.

GPs need to be informed and supported to ask the right questions when people present with vague

symptoms, such as where people have heartburn but no change in eating habits but symptoms, do they have discomfort when swallowing or pain between shoulder blades.

It is also vital that the diagnostic workforce, and necessary equipment, have capacity to allow tests and results to be conducted efficiently and quickly.

We would like to see the monitoring of people at-risk of some of the less survivable cancers. This could help diagnose people at very early stages or possibly prevent some of these cancers. For example:

- The full roll-out of targeted lung cancer screening will help diagnose more people with lung cancer at an earlier stage. We are delighted to see the UK National Screening Committee propose that a targeted screening programme for lung cancer in people age between 55-74 with a history of smoking should be rolled out across the UK. With over 5,000 people a year dying from lung cancer in Scotland, we believe that this should be agreed and rolled out as soon as possible as a key part of the Strategy, in tandem with the development of the necessary pathways and workforce.

- One in three people who develop cirrhosis will go on to develop liver cancer - it is therefore the biggest risk factor. Early detection of asymptomatic cirrhosis in populations at risk is therefore the best way to both prevent many liver cancers. Moreover, earlier detection of liver disease will allow opportunity for people to enter surveillance programmes that can detect liver cancer faster and earlier.

- For pancreatic cancer, increasing evidence shows that new onset of diabetes, pancreatitis and asymptomatic cystic lesions of the pancreas are all associated with an increased risk to develop pancreatic cancer. Further work is needed to define the populations with the highest risk based on a combination of factors, so we're not targeting whole populations.

- As approximately 10% of pancreatic cancers are hereditary, we recommend a roll out of a national surveillance programme of people with hereditary pancreatic cancer.

9c. Please explain your answer and provide any additional suggestions.

While there is some available data on high-risk populations for some less survivable cancers, more research much be done to identify and understand risk factors and high-risk populations and to develop tailored screening programmes for each cancer. For example, as few as 3% of brain cancers are classed as preventable (these few are often linked to obesity), and many of the cases of other less survivable cancers are not linked to preventable factors [ref 1].

For informed, effective strategies, the Government must commit to invest in research into LSCs, their causes, risk factors, at-risk populations, and the efficacy of prevention measures.

Ref 1: CRUK website [https://www.cancerresearchuk.org/health-professional/cancer-statistics/statistics-by-cancer-type/brain-other-cns-and-intracranial-tumours/risk-factors]

10a. Under High quality care, we want to think about actions outside of direct treatment that affect the care given to those affected by cancer. We are considering:

- ***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***

Do you agree with these areas of focus?

Yes.

10b. In your experience, what aims or actions would you like to see under any of these areas?

We agree that modeling workforce needs across the cancer pathway, and then recruiting and training to meet those needs as soon as possible, is absolutely critical for quality patient care. There will be many positive developments across the time of this Strategy, such as the introduction of targeted lung cancer screening, which will add CT and radiological needs - all these developments and projections need to be taken into account.

We welcome the Health and Social Care National Workforce Strategy but would like to see further details and clarity around where the funding will be spent. Significant investment and planning to support and grow the cancer workforce will be critical to improving access to and experiences of cancer treatment, in particular clinical nurse specialist access for all patients and addressing shortfalls in endoscopy, radiology and gastroenterology workforce capacity.

We would like to highlight some current workforce capacity issues:

- According to the Scottish Adult Neuro Oncology Network (SANON) Audit, in 2020 under a third (31.8%) of patients with brain/CNS cancer have an identified key worker by the time of their first MDT meeting. The Brain Tumour Charity's Improving Brain Tumour Care (IBTC) survey also showed that, of those who did have access, only 38% in Scotland felt they were able to speak to their CNS or keyworker whenever they needed to.

- The British Liver Trust has observed that the vast majority of liver cancer patients have never seen a CNS. Many patients phoning the British Liver Trust helpline report being unsure as to what is happening with their care and what the next steps are.

- Gastroenterology in the UK is facing significant capacity challenges. With the current

shortfall in workforce, predicted retirements and population growth, we need between 7 – 9% yearly expansion, but actual mean yearly expansion is between 4.5 and 5% [ref 1].

We recommend:

- Treatment and care audits should be established for each of the less survivable cancers and conducted regularly. This is necessary to provide insight into variations in care and treatment across the country to help support service improvements. It also needs to reflect the experiences of patients, for example, their access to CNS support or for lung cancer, the number of people who have accessed molecular testing to support their treatment decisions.

- Timed, optimal pathways looking at diagnosis, treatment, support and care should be developed and implemented for all 6 less survivable cancers. For example, a national lung cancer optimal pathway has been developed and agreed by the clinical community but has not been funded and implemented yet.

- Significant workforce investment is needed to ensure that every person with a less survivable cancer be assigned to a CNS with expertise in their cancer, and to ensure the full diagnostic and care pathway is sufficiently staffed to avoid delays and backlogs.

- Prehabilitation and rehabilitation should be available to all less survivable cancer patients where appropriate to maximise surgery and treatment success rates.

- People with pancreatic cancer should be prescribed Pancreatic Enzyme Replacement Therapy (PERT) as standard, and the Scottish Government should introduce a national PERT target through a Quality Performance Indicator (QPI) in the 2022 QPI review.Currently, PERT is only prescribed to 1 in 3 pancreatic cancer patients in Scotland, and is more likely to be prescribed to those who are treated within a specialist setting than to those who are treated within a general or community setting.

- Improved and equitable access to Selective Internal Radiation Therapy (SIRT). SIRT is a minimally invasive cancer therapy involving 'no surgery' and 'no full body radiotherapy'. ● Equity to all forms of treatment for Hepatocellular Carcinoma (HCC) whether curative or palliative across the country. Standardisation of care for Hepatocellular Carcinoma patients should be prioritised across the country. Likewise, we'd like to see equity of access to clinical trials across Scotland.

- Coordinated research investment into the 6 less survivable cancers, with a focus on new treatment options and clinical trials, providing more effective options for people who are diagnosed with a less survivable cancer.

Ref 1: British Society of Gastroenterology Workforce Report 2021 Microsoft Word - British Society of Gastroenterology Workforce Report 2021 final.docx (bsg.org.uk)

11a. 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, we are considering:

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

Do you agree with these areas of focus?

Yes.

11b. In your experience, what aims or actions would you like to see under any of these areas?

In addition to the areas above, we would like molecular testing to be embedded in lung cancer pathways and a move towards whole genome sequencing. Some treatments are available if you have certain mutation driven cancers but people need testing to know.

12a. Treatment may not be the solution and, alone, is not sufficient. We also 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, we 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***

Do you agree with these areas of focus?

Yes.

12b. In your experience, what aims or actions would you like to see under any of these areas?

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 holistic support given to every patient, meeting their psychological and wellbeing needs, and those of their families and carers. Being diagnosed with one of the 6 less survivable cancers is a shocking and often devastating diagnosis - every patient and their family must have access to the full range of psychological services, including those provided by NHS / social care / third sector organisations.

All less survivable cancer patients should be offered a tailored holistic needs assessment throughout their pathway starting at the point of diagnosis, covering emotional, psychological, financial and other holistic needs. We know that this does not occur for many patients, for example The Brain Tumour Charity's 2021 Improving Brain Tumour Care survey showed that only 37% of Scottish respondents said they had been offered a holistic needs assessment, and only 5% of respondents who did have a resulting care plan, felt that it was working well. As brain tumours can have significant effects on a person's personality, support for the patient and their families is particularly important.

As the prognosis for many people diagnosed with a less survivable cancer is so poor, recognising and managing psychological distress is particularly important. Given the progressive nature of these cancers, mental health support for patients should be offered promptly and without waiting lists wherever possible to ensure both patients and wherever possible carers can be supported effectively.

Over 9,000 people are diagnosed with less survivable cancers in Scotland every year. Given the large numbers of patients with these cancers, and their rapid progress, links to palliative care teams must be rapid, smooth and well-resourced. We have heard cases of patients who die before their scheduled Marie Curie nurse is able to see them. Delays in pathways for less survivable cancers can be devastating for patients and their families. We believe that there should be a review of these links to palliative care to ensure consistency and fast access across Scotland, particularly for less survivable cancers.

13a. Data (knowledge, information and statistics) are important to help manage cancer care as well as for measuring how well we 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. We 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***

Do you agree with these areas of focus?

Yes.

13b. In your experience, what aims or actions would you like to see under any of these areas?

To achieve the transformational improvements in survivability that we need to see for the less survivable cancers, we need significant levels of investment in research for new treatments (at every stage), new diagnostic and screening biomarkers, and a targeted commitment to better data to understand outcomes, progress and variations for all 6 less survivable cancers.

We recommend that the less survivable cancers are identified as a specific focus area by the Government for technology and innovation. This will help ensure that inequality is not reinforced within our cancers due to their low survivability and disproportionate impact on lower socio-economic groups.

There are already some promising areas of research in the less survivable cancers and these need to be supported, and the findings to be translated into practice as soon as possible. Unfortunately, we have seen how innovations for our cancers such as the Cytosponge test have taken excessively long times to be implemented.

13c. Is there any technology that you would like to see introduced to improve access to cancer care?

The new strategy should focus on building and investing in research partnerships for each of the 6 less survivable cancers. The publication of more up-to-date and disaggregated data on our cancer types would also help to drive forward research.

Areas of promise include:

- Olympus/Guts UK's research fellow Dr Sara Jamel's innovative project will explore the use of breath-testing for pre-cancerous cell changes in patients with Barrett's oesophagus. If successful, this breath test could save lives by diagnosing oesophageal cancer early, when it is far more treatable.

- Dxcover's diagnostic blood test aims to support primary care to triage and identify

symptomatic patients most in need of an urgent brain scan. As non-specific symptom presentation is very difficult for GPs, this test is a rapid point of care option, using a blood test chip put into a machine which then can support doctors to prioritise patients for imaging according to results.

- Gene mutation testing for lung cancer: Gene mutation testing can identify specific genetic changes in lung cancer tumour cells that might be treatable with targeted therapies, and can block growth of cancer cells without harming healthy cells. We would like to see more patients having access to research and the opportunity to participate in research including through biobanking.

We also need more people to have access trials. Data from The Brain Tumour Charity's Improving Brain Tumour Care Survey (October 2020) showed that many patients are not informed about research participation opportunities. Only 21% of Scottish respondents stated they had been informed about potential opportunities.

Tools like the BRIAN App (Brain Tumour Information and Analysis Network) [ref 1] 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. We need more direct access to fulfill the promise of BRIAN to link clinical and quality of life data to share real experiences of patients.

We would also like to see a rollout of e-health interventions. These could take the form of online appointments and support, and would be vital for patients with less survivable cancers who are often diagnosed very late and deteriorate very quickly. These interventions would also alleviate the burden of extensive travel for consultations, which is often an issue for people in rural Scotland.

Ref 1: The Brain Tumour Charity website [https://www.thebraintumourcharity.org/living-with-a-brain-tumour/brian/]

14. The final proposed section is Outcomes, where we will describe how we will monitor and evaluate the strategy and plan.

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?

Treatment and care audits should be established for each of the less survivable cancers and conducted regularly. This is necessary to provide insight into variations in care and treatment across the country to help support service improvements.

Experience and outcome measures must be prioritized. PROMs and PREMs should be scaled up, and

data and insights from these measures must be intrinsically linked with QPIs to holistically measure improvements within cancer services.

15a. 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.

We 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.

What would you like to see an Earlier Diagnosis Vision achieve?

We would like the Earlier Diagnosis Vision to specifically identify less survivable cancers as an area of focus, where earlier diagnosis is urgently needed. An ambitious and achievable target specific to the less survivable cancers would help to drive improvements, and a Strategy / Progress Group.for each of the 6 less survivable cancers would enable specialists to explore and implement innovations and interventions to meet the target.

It is important to note that no staging data is available for brain cancer and a proxy measure is needed so brain cancer can be included in the drive for earlier diagnosis.

There are many areas that could be boosted to diagnose less survivable cancers earlier, driven forward by the suggested Strategy / Progress Groups. For example:

- To diagnose liver cancer earlier, liver disease must be diagnosed much earlier. We therefore need wider use of FibroScan and ELF tests for early detection of liver fibrosis in primary care.
- We are calling for intelligent Liver Function Tests (iLFTs) to be urgently rolled out across all Health Boards in Scotland as a Nationally adopted pathway so that we can improve early detection of liver disease and therefore liver cancer.

    o iLFTs provide a simple way to minimise primary care workload and streamline referrals**.** They support early diagnosis of liver disease which is vital for the early diagnosis of liver cancer. In summary,

    o The GP takes a simple blood sample and sends it to the lab

    o A new software analyses the results and puts them in an algorithm – if necessary it sends the same sample for more advanced tests

    o It then generates an automatic report with all the results and the suggested diagnosis that tells the GP what to do next.

  - This system is now live in several regions of the NHS, developed in Dundee, it increases delivery of correct investigation to 100% of patients, it increases the diagnosis of liver disease nearly 3-fold and is cost saving to the NHS at over £3,000 per patient with abnormal liver blood tests.

- To diagnose lung cancer earlier, we support the full roll-out of targeted lung cancer screening. We are delighted to see the UK National Screening Committee propose that a targeted screening programme 4 for lung cancer in people age between 55-74 with a history of smoking should be rolled out across the UK. With 48,000 people a year dying from lung cancer in the UK, we believe that this should be agreed and rolled out as soon as possible in Scotland as a key part of this strategy, in tandem with the development of the necessary pathways and workforce.

- The Dxcover blood test (in development in Scotland), has shown promise in preliminary studies having recently been found to identify more than 90% of glioblastomas (the most common type of brain tumour) and more than 80% of all other brain tumours. This could support primary care to triage and identify symptomatic patients most in need of a brain scan.

- The Olympus/Guts UK's current research project using breath testing for pre-cancerous cell changes in patients with Barrett's oesophagus could save lives diagnosing oesophageal cancer early, when it is far more treatable.

- Imperial College London is researching an early detection exhaled breath test based on volatile organic compounds (VOC) that are unique to patients with pancreatic cancer.

- AI tools could assist GPs to diagnose earlier and faster - this needs further research to develop AI / algorithm tools to identify people in GP records with a combination of symptoms, conditions and risk factors that associated with a high risk of developing less survivable cancers, which could then lead to a referral or follow up survey / set of questions to further enrich these population data. An example is the QCancer tool to better pick up those with suspected symptoms of pancreatic cancer for referral. QCancer has been designed with the aim of developing machine learning tools to identify combinations of symptoms in health records which generate a risk score and a red flag for pancreatic cancer.

When successful, any innovation / new test needs to be swiftly incorporated into early diagnostic pathways.

Diagnosing people who have a less survivable cancer faster, as well as earlier, is vital to ensure people receive the best treatment and care as soon as possible. By improving the efficiency and sequencing of diagnostic and pathways, more people will be able to access potentially life-saving surgery and treatment. Increasing diagnostic capacity, e.g. number of CT and MR scanners, with the supporting workforce, is needed to support this.

We also believe that capacity and workforce should be provided to implement the Pancreatic Cancer Pathway Improvement Project after its pilot phase, and that this centralised approach should also be considered for other lower volume, less survivable cancers.

15b. Should the Earlier Diagnosis Vision set itself a numerical target?

We believe that targets drive improvements and are integral to progress. However, we need specific targets tailored to less survivable cancers, so that our cancers are not lost in broader pan-cancer aims. Pan-cancer commitments, ambitions and targets have, to date, led to less survivable cancers being overlooked and under-resourced. We urge the Government to use this Cancer Strategy to make specific commitments and targets for the less survivable cancers to drive forward the transformational changes we need in diagnosis, treatments and care required in these cancer areas.

We need to improve outcomes in each less survivable cancer and we believe the Government should use this strategy to set an ambition to double survival rates for people with a less survivable cancer over the course of the next decade.

Again, it is important to note that proxy staging data must be developed for brain cancer to support the drive to diagnose this cancer earlier.

15c Should the earlier cancer diagnosis vision focus on specific cancer types?

Yes, we believe there should be a specific focus on less survivable cancers, which account for a quarter of all cancer diagnoses each year in Scotland and, because of their poor outcomes, around 44% of cancer deaths.

16a. We want to hear your views on how this cancer strategy could affect various aspects of inequalities, and how potential negative impacts could be avoided.

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?

As mentioned in our answer to question 5a, less survivable cancers are associated with deprivation, with incidence and mortality higher within lower socioeconomic groups.

Tobacco consumption is hugely variable and closely linked to social inequalities. We need to ensure that all communities become tobacco-free.

Awareness campaigns or policy aiming to address the causes of cancer must commit to understanding how social deprivation factors into the causes of cancer, its diagnosis and care.

As part of the strategy's 'compassionate and consistent' vision, specific resource should be dedicated to reduce inequalities and address the disparities in cancer awareness and prevention in deprived communities.

16b. Similarly, is how we manage cancer different for wealthy or poor people? What could be done to do this better?

Most less survivable cancers are associated with deprivation, for example, the disparity of lung cancer incidence between the most and least deprived areas is one of the widest of any cancer type [ref 1].There is also a visible link between rates of liver cancer and social deprivation [ref 2], linked to a combination of factors such as exposure to risk factors, late presentation and less access to health care.

We believe that addressing these disparities should be a key principle in any cancer strategy, to ensure that inequality is not reinforced within our cancers due to their low survivability and disproportionate impact on lower socio-economic groups.

16c. Is the experience of cancer different for people living in rural or island communities? What could be done to prevent any negative impacts?

It is vitally important that this Strategy considers the impact of rurality on access to and quality of cancer services. We know that people who live in rural and island communities simply don't have the access to specialist care that people in cities do. Traveling to appointments and staying away from home is costly, and can be very difficult psychologically for patients and their families.

During the pandemic, many services were forced to become remote. We believe that the learnings from this time should be implemented in a way that supports a much more holistic approach to treatment and care, particularly when cure isn't an option. Options such as telemedicine have been embedded successfully in various parts of the country, and these locations should be seen as an example to learn from.

It is crucial that care is consistent, and that lives and livelihoods are not vulnerable to postcode lotteries. Care should have a multi-stakeholder approach which is localised as much as possible, and tests and services, such as blood tests or chemotherapy, should be offered close to home.

As a coalition of charities, we understand the integral role that the third sector can play. This role should be acknowledged and utilised, particularly in the delivery of care and the funding of travel and accommodation. Services and health care professionals should be made aware of these options, and be made to link and signpost patients where possible.

Ref 1: Long-term Monitoring of Health Inequalities, Scottish Government, March 2022 report [https://www.gov.scot/binaries/content/documents/govscot/publications/statistics/2022/03/long-term-monitoring-health-inequalities-march-2022-report2/documents/long-term-monitoring-health-inequalities/long-term-monitoring-health-inequalities/govscot%3Adocument/long-term-monitoring-health-inequalities.pdf]

Ref 2: ISD Scotland website [https://www.isdscotland.org/health-topics/cancer/cancer-statistics/liver/]

17. This is the conclusion of the consultation. We would like to offer an opportunity for any final thoughts for inclusion or consideration in our long-term strategy or short-term action plan.

This Strategy presents an opportunity to drive forward transformational improvements in outcomes and experiences for people with a less survivable cancer. Through focusing on diagnosing these cancers earlier, faster, and ensuring everyone has optimal pathways of care, including palliative alongside holistic support, we will transform outcomes and experiences for thousands of people.

It is important that the 3-year plans are dynamic and flexible, able to adapt to new circumstances and technologies, such as AI, screening or genetic mutation breakthroughs.

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