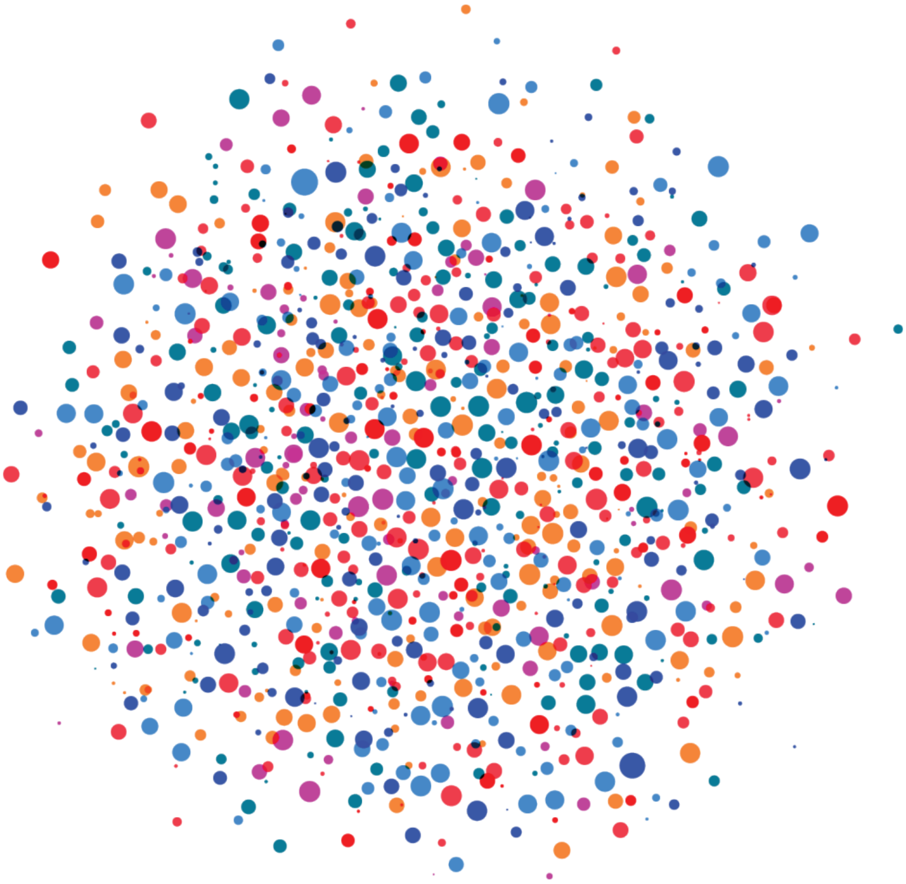
Scottish Government
Riaghaltas na h-Alba

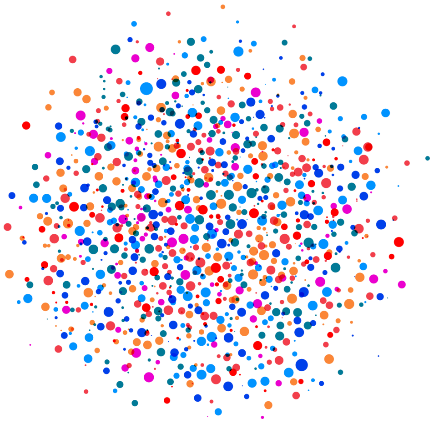
Consultation Analysis: New Cancer Strategy

November 2022



alma economics

An independent analysis commissioned by the Scottish Government



Consultation Analysis:
New Cancer Strategy

This is an independent analysis by Alma Economics of the responses to the public consultation on a new cancer strategy. This work was commissioned by the Scottish Government.

Table of Contents

Abbreviations 6

Executive Summary 7
  Purpose of the consultation 7
  Methodology and key findings 7

Introduction 11
  Cancer in Scotland 11
  The need for evidence and strategic decision-making 12
  Written consultation 12

Methodology 14

Question 1 16
  Question 1A 16
  Question 1B 18
  Question 1C 20

Question 2 22

Question 3 25

Question 4 28

Question 5 31

Question 6 34

Question 7 37

Question 8 40

Question 9 43

Question 10 46

Question 11 49

Question 12 52

Question 13 55

Question 14 59

Question 15 61

Question 15A 61
Question 15B 62
Question 15C 64
Question 15D 66
Question 15E 69
Question 15F 70

Question 16 73
Question 16A 73
Question 16B 75
Question 16C 76

Question 17 78

Appendix A: Tables 80

Appendix B: Glossary 83

List of figures

Figure 1. Share of Yes/No responses to Question 2 22
Figure 2. Share of Yes/No responses to Question 3 25
Figure 3. Share of Yes/No responses to Question 4 28
Figure 4. Share of Yes/No responses to Question 5 31
Figure 5. Share of Yes/No responses to Question 6 34
Figure 6. Share of Yes/No responses to Question 7 37
Figure 7. Share of Yes/No responses to Question 9 43
Figure 8. Share of Yes/No responses to Question 10 46
Figure 9. Share of Yes/No responses to Question 11 49
Figure 10. Share of Yes/No responses to Question 12 52
Figure 11. Share of Yes/No responses to Question 13 56

List of tables

Table 1. Breakdown of responses received from individuals and organisations 7
Table 2. Breakdown of responses received from individuals and organisations 12
Table 3. Breakdown of responses received per type of organisation 13
Table 4. Breakdown of Yes/No answers to Question 2 80
Table 5. Breakdown of Yes/No answers to Question 3 80
Table 6. Breakdown of Yes/No answers to Question 4 80
Table 7. Breakdown of Yes/No answers to Question 5 81
Table 8. Breakdown of Yes/No answers to Question 6 81
Table 9. Breakdown of Yes/No answers to Question 7 81
Table 10. Breakdown of Yes/No answers to Question 9 81
Table 11. Breakdown of Yes/No answers to Question 10 82
Table 12. Breakdown of Yes/No answers to Question 11 82
Table 13. Breakdown of Yes/No answers to Question 12 82
Table 14. Breakdown of Yes/No answers to Question 13 82

Abbreviations

AI	Artificial Intelligence
BAME	Black, Asian and minority ethnic
CMOP	Cancer Medicines Outcome Programme
CNS	Clinical Nurse Specialist
CWT	Cancer Waiting Times
ECDC	Early Cancer Diagnostic Centre
GP	General Practitioner
HNA	Holistic Needs Assessment
MDT	Multi-Disciplinary Team
NHS	National Health Service
PROMs	Patient Reported Outcome Measures
QoL	Quality of Life
QPI	Quality Performance Indicator
SACT	Systemic Anti-Cancer Therapy
SCPES	Scotland Cancer Patient Experience Survey
SCRIS	Scottish Cancer Registry and Intelligence Service

Executive Summary

Purpose of the consultation

The Scottish Government launched a written consultation on a new cancer strategy between 12 April 2022 and 7 June 2022, which sought views on areas to prioritise in relation to cancer prevention, management and care. Responses submitted to the written consultation were rigorously analysed in order to provide a transparent evidence-base (including evidence on lived experiences) to the government. This evidence-base will effectively inform the decision-making process about a new cancer strategy and socialise the findings gathered from this exercise.

Methodology and key findings

The consultation was open to the public and received 257 responses in total, either through the online platform Citizen Space or via e-mail. The vast majority of responses (96%) were submitted through Citizen Space, while the remaining 4% of responses were submitted via e-mail. Out of the 257 responses, 156 were submitted by individuals and 101 were submitted by organisations.

Table 1. Breakdown of responses received from individuals and organisations

Total respondents	Citizen Space	E-mail
Individual	151	5
Organisation	94	7
Total respondents	**245**	**12**

The Scottish Government’s online consultation was hosted on the Citizen Space portal and consisted of 11 closed-format and 33 open-format questions. Descriptive analysis was conducted on the responses to the 11 closed-format questions using Python. To synthesise important themes and perspectives raised across respondents for each of the open-format questions, a thematic analysis was conducted based on the manual review of all responses.

Overarching themes

Following the conclusion of thematic analysis, a number of recurring themes were identified across the responses submitted to all 33 open-format questions. These summarise the views most frequently shared by respondents and are presented below in order of frequency.

Prevention

Respondents came back to the notion of prevention numerous times, mainly focusing on three broad goals:

A. Promoting healthier lifestyles. There was almost unanimous agreement coming through responses that unhealthy habits can be a root cause for developing cancer, with references mainly made to smoking and high alcohol consumption. Suggestions were made about educating the public from a young age about the negative impacts of smoking and alcohol consumption on one's health as well as the merits of developing healthy lifestyle habits such as exercising.

B. Raising cancer awareness. Respondents stressed the importance of raising awareness among the population of common cancer symptoms and symptoms that can be mistakenly taken as signs of a different disease, as well as educating the public (and particular high-risk groups) to self-check regularly. Suggestions made included opening up the discussion about cancer in schools and the media, and organising public health campaigns in local communities.

C. Facilitating earlier diagnosis. Diagnosing cancer at the earliest stage possible was seen as critical by respondents. Responses identified a number of barriers that would need to be overcome to achieve that, including: i) extending the age range of regular testing to include young people as well as those older, ii) establishing regular testing for people with family history of cancer, high-risk groups and for those who have developed cancer before, iii) upskilling General Practitioners (GPs) to reach a timelier and more accurate cancer diagnosis (i.e. reducing the number of cancers initially being misdiagnosed).

Ensuring equal access

Equal access to testing and screening as well as to cancer care came up repeatedly in responses to the consultation mainly with reference to two issues:

A. Tackling unequal access driven by one's place of residence, sometimes also referred to by respondents as 'postcode lottery'. Responses mentioned rural areas and island communities as being disadvantaged by having less testing and treatment options made available locally, as a result of which individuals have to travel long distances to get a screening or to receive their treatment. Travelling long distances was also seen as detrimental to cancer patients' mental health as well as a deterrent for people to get regularly tested. Related to these issues were suggestions for community-based treatments, enhancing the role of community pharmacies, etc.

B. Tackling the role of socio-economic inequalities in people's access to testing and treatment. Respondents repeatedly acknowledged that the financial pressures for a cancer patient coming from a disadvantaged background are higher compared to other socio-economic cohorts. Suggestions featured in the responses included covering for transportation and any accommodation costs related to accessing one's treatment, including the reimbursement of family members and carers where appropriate. It was also stressed that financial support should be provided when patients have to take time off their work, during or after treatment.

Workforce support

Responses several times acknowledged the efforts and commitment of the workforce, but nonetheless mentioned that the workforce needs greater support. Suggestions included recruiting more staff and professionals with expertise currently missing from the health system, providing the workforce with more training opportunities to improve their skills, as well as making provisions for the emotional support of staff in cancer care (including access to counselling). With reference to the latter, some respondents reflected that the better emotional support the workforce receives the better care they can provide to patients.

Research and innovation

Respondents reflected repeatedly on the need to conduct more research in the area, so that innovative treatments and evidence-based approaches to care can be made available to patients. With reference to the latter, it was considered very important to be encouraging and making use of patients' feedback on the care they receive. Further suggestions included incorporating state of the art technologies, ensuring that patients with different types of cancer contribute to clinical trials and expanding data collection to identify patients' needs as well as develop a better understanding of less common cancer types. The collaboration between all relevant stakeholders (the NHS, patients, community services, academia, industry, patient representative bodies, etc.), including seamless communication channels, was seen as a key step to achieving the aforementioned.

Secondary, rare and less survivable cancers

It was identified across responses that some cancer types, particularly metastases and cancers that are rare or less survivable, need to gain greater recognition in the new cancer strategy. Respondents proposed that there is greater awareness raising regarding these types of cancer, including educating the public about the symptoms and where to access support. With reference to less survivable cancers, responses suggested that palliative care needs to be further developed for patients and their families/carers as well as bereavement support for the latter.

Person-centred approach

Placing the patients and their experiences at the centre of the new cancer strategy was seen as critical by respondents. It was mentioned that each patient's voice and their individual needs have to be listened to at all stages of their journey, from diagnosis to learning to live with cancer after treatment. It was suggested a number of times that care plans should be as personalised as possible so that patients feel that they are being valued and the care they receive is holistic, whereas keeping the patients informed about the treatment they receive at all stages of their care plan was seen as important at all times.

Involving a patient’s family in their treatment plan was also seen as an important step to personalising the support provided to them.

The Covid-19 pandemic

The Covid-19 pandemic came up several times in responses, particularly with reference to the challenges it posed for the health sector and the lessons that can be learnt from these. Respondents referred to the backlog of late diagnoses caused by the interruption of services and the expected increase in the demand for cancer care in the years to come as a result of this. Yet, respondents also considered that solutions introduced during the Covid-19 pandemic, such as alternatives to face-to-face GP appointments and screening, could be further developed to better manage workload in the health system and facilitate access to services in remote areas.

Planning for the new cancer strategy

Comments were identified across consultation responses on the feasibility of the set targets and proposed themes and areas of interest. Respondents suggested that targets should be made measurable to ensure they are met and advised to set shorter-term milestones so that progress can be meticulously tracked down. Furthermore, responses acknowledged that the new cancer strategy would have to address more clearly the barriers that need to be overcome in the process (e.g. lack of capacity within the NHS) and how this will be achieved.

Introduction

Cancer in Scotland

The number of new cancers in Scotland decreased by 8% between 2019 and 2020, though this is likely due to under-diagnosis caused by the Covid-19 pandemic with patients being less likely to seek help and delays occurring in screening.[1] Cancer incidence projections for Scotland prior to the onset of the pandemic suggested, among others, a 33% increase in the number of new cancer cases between 2008-2012 and 2023-2027, estimating the total number of cases to be over 40,000 in 2023-2027 (from over 30,500 cases in 2008-2012) with lung cancer expected to remain the most common cancer in 2023-2027.[2]

The growing population of older people in Scotland (with a 29.7% increase in over-65s projected by mid-2045 compared to 2020[3]) increases cancer's significance as a public health issue. In addition, the rising number of people surviving cancer in Scotland[4] creates new challenges for the public health system due to health needs becoming more complex, therefore driving up demand for specialist and primary care services.

Furthermore, the incidence of cancer in Scotland differs significantly by socio-economic status, creating challenges for policymakers to reduce health inequalities relating to cancer incidence and care. For example, lung cancer is three times more prevalent in the most socio-economically deprived areas relative to the least deprived areas, and the probability of being diagnosed with a wide range of advanced cancers increases with socio-economic deprivation.[5]

These existing difficulties were compounded by the emergence of the Covid-19 pandemic, which significantly disrupted cancer pathways due to health protection measures, workforce isolation and other pressures experienced by the NHS. These disruptions are likely to persist with the Covid-19 becoming endemic, highlighting a new imperative to improve cancer services' resilience to rises in Covid-19 cases as well as any future pandemics.

---

[1] Public Health Scotland (2022) Cancer survival statistics: People diagnosed with cancer during 2015 to 2019. Available from: https://publichealthscotland.scot/publications/cancer-survival-statistics/cancer-survival-statistics-people-diagnosed-with-cancer-during-2015-to-2019/

[2] Public Health Scotland (2015) Cancer incidence projections for Scotland: Cancer incidence projections for the period 2013-2027. Available from: https://beta.isdscotland.org/find-publications-and-data/conditions-and-diseases/cancer/cancer-incidence-projections-for-scotland/

[3] National Records of Scotland (2022) Projected Population of Scotland (Interim) 2020-based. Available from: https://www.nrscotland.gov.uk/files/statistics/population-projections/2020-based/pop-proj-2020-scot-nat-pub.pdf

[4] Public Health Scotland (2022) Cancer Survival in Scotland (to 2019): A National Statistics release for Scotland. Available from: https://publichealthscotland.scot/media/14024/2022-07-05-cancer-survival-report.pdf

[5] Public Health Scotland (n.d.) Latest Cancer data and intelligence. Available from: https://beta.isdscotland.org/find-publications-and-data/conditions-and-diseases/cancer/

The need for evidence and strategic decision-making

Taken together, the trends and challenges described above raise the need for evidence and strategic decision-making. This has led to the Scottish Government developing a new cancer strategy for Scotland that has the intention of being responsive to evolving needs and is able to achieve maximum effectiveness (including in terms of survival rates, prevention, and minimising negative impacts on the wellbeing of patients and their friends and family) given resource constraints.

This can be achieved by defining priority areas of actions, including in terms of the groups of cancers that should be focused on, and the various aspects of the cancer journey (e.g. prevention, diagnosis, treatment) that need most investment. In turn, this requires strategic decision-making considering the medium- and long-term as well as the short-term.

Written consultation

In this context, the Scottish Government launched a written consultation on a new cancer strategy, which sought views on areas to prioritise in relation to cancer prevention, management and care. This constitutes best-practice in policy-making as it increases the evidence-base for decision-making (including adding evidence on lived experiences) and enhances the democratic process behind it by building an understanding of public priorities and preferences.

Responses submitted to the written consultation have been rigorously analysed in order to provide transparent evidence that will effectively inform the decision-making process and socialise the evidence-base gathered from this exercise.

Overview of respondents

The consultation was open to the public and received 257 responses in total, either through the online platform Citizen Space or via e-mail. The vast majority of responses (96%) were submitted through Citizen Space, while the remaining 4% of responses were submitted via e-mail. Out of the 257 responses, 156 were submitted by individuals and 101 were submitted by organisations.

Table 2. Breakdown of responses received from individuals and organisations

Total respondents	Citizen Space	E-mail
Individual	151	5
Organisation	94	7
Total respondents	**245**	**12**

Though the research team could not verify whether all responses identifying as organisations were submitted in an official capacity, a breakdown of the types of organisations that responded to the consultation is provided below.[6] It was also evident from reading the responses that some of those who participated in an individual capacity had professional experience in cancer care through working in relevant charities, industry associations or the NHS.

Table 3. Breakdown of responses received per type of organisation

Organisation type	Count	Percentage
Charity	36	36%
Industry association	24	24%
NHS group	24	24%
Pharmaceutical company	11	11%
Other	6	6%
Total responses	**101**	

---

[6] Percentages in the tables have been rounded up to the first decimal and thus may not add up to 100% at all times.

Methodology

The Scottish Government's online consultation was hosted on the Citizen Space portal and consisted of 11 closed-format and 33 open-format questions. Responses could be submitted via the online platform or directly to the Scottish Government by e-mail (to a dedicated consultation inbox) or post. Responses from Citizen Space and those sent by e-mail and post were merged into a single, final dataset combining all responses to the consultation.

As is usual for a large-scale government consultation, there were a small number of responses that shared identical or near-identical text, though it is difficult to robustly identify whether these responses came from coordinated campaigns or individuals and/or groups who informally consulted each other before submitting their responses. Because no two respondents submitted close or exact duplicate text across all questions in their responses, this suggests that the results of the consultation reflected the views of a range of organisations and individuals rather than being dominated by specific campaigns. Due to the small sample sizes involved and to ensure that all responses were considered, responses which were close or exact duplicates were only removed from the thematic analysis (and not the quantitative analysis) presented in the report.

Descriptive analysis was conducted on the responses to the 11 closed-format questions using Python. The main body of this report presents a breakdown of responses to each consultation question. Each question includes a chart that summarises responses as a percentage of all consultation respondents who answered the question. Full tables of results are presented in Appendix A.

For the 33 open-format questions, there was no limit to the amount of text in which respondents could write in their answers. To synthesise important themes/perspectives raised across respondents for each question, we followed a thematic analysis approach based on Braun and Clarke (2006) that involved four phases:[7]

1. Manually reviewing each free-text response to highlight patterns/recurring themes as well as singular cases (ideas/perspectives not raised in other responses).
2. Mapping the qualitative themes to specific components of the consultation and developing a narrative description for each theme.
3. Triangulating themes within/across respondents and assessing their substantive significance based on convergence/divergence of perspectives.
4. Identifying any insightful outlier responses that do not fit in with the general emerging themes and analysing patterns of non-responses (if there are any).

The total number of respondents answering each open-format question is listed at the

---

[7] Virginia Braun & Victoria Clarke (2006) Using thematic analysis in psychology, Qualitative Research in Psychology, 3:2, 77-101, DOI: 10.1191/1478088706qp063oa

beginning of each section. This total includes respondents who wrote in “No comment”, “Nothing to add”, “N/A”, etc., though in general these responses made up less than 10% of total responses to open-format questions.

There were 12 consultation responses submitted via e-mail with PDF attachments, and respondents did not indicate which questions of the consultation they were responding to in the PDF attachments. We reviewed these responses in full, and themes were assigned to one or more individual consultation questions where possible. In general, the key points and ideas raised in e-mailed consultation responses did not differ from those raised in responses submitted via Citizen Space.

The main body of this report follows the same question order as the consultation document, and themes for each open-format question are presented in order of frequency (number of responses that discussed the theme). Specific themes are highlighted if the proportion of individuals or organisations mentioning these themes differs from the overall proportion of individuals which answered the question. In the qualitative analysis, the research team has sought to be respectful of the full spectrum of emotions, views and perceptions expressed within the consultation. Written responses were self-selecting, and it is understood that these do not necessarily represent the wider public opinion in Scotland. Individual quotes have been used, where appropriate, to illustrate the narrative around specific themes, and quotes were only selected from respondents who provided permission for their views to be published and with any potential identifiers (such as the name of a specific organisation) removed. Where the quotes selected included typos, these were corrected by the research team to allow readers to read the views shared uninterrupted.

Question 1

Question 1A

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.

There were 243 responses to this question (149 were from individuals and 94 from organisations).

Pre-cancer journey

The most common theme identified related to the patients' journey prior to a confirmed cancer diagnosis. There was a strong focus on prevention whereby respondents called for increased education around healthier lifestyles (such as tackling smoking, alcohol use and obesity) as well as raising awareness for symptoms and signposting relevant cancer services where necessary.

Early diagnosis was also frequently discussed, and respondents felt that regular screening for at-risk populations, including for asymptomatic and secondary cancers, would be beneficial in achieving this. They also stated that accessing screening should be easier and suggested that research into innovative diagnostic technologies should be done.

> *"Prevention and early diagnosis offer the best outcomes for patients. Investment in these two areas will achieve the greatest impact for a given investment. […]" (Individual response)*

Respondents also expressed that increasing the number of General Practitioners (GPs) and upskilling them would lead to swifter referrals and decrease the occurrence of late diagnoses. They suggested that community-based support within the pre-cancer journey, such as community pharmacies, would improve equity of access and should be considered.

> *"The initial diagnosis. Myself and others who I have spoken with don't feel that GPs are taking us seriously. If the GPs don't fob people off and deal with early intervention then it would negate the need for long term treatment due to late diagnosis." (Individual response)*

Effective cancer care

The next most frequently discussed theme regarded effective cancer care once diagnosis has been confirmed. Respondents often called for more patient-centred care with personalisation of treatment plans and consideration of patients' wants and experiences. It was also mentioned that information about treatment options and risk of secondary cancer should be communicated more clearly to help patients feel more in control of their care.

> *"[…] So many people struggle to access treatment and support for various reasons such as means to do so, other responsibilities i.e. caring, work etc., knowledge of what's available, confidence to ask questions, understanding of diagnosis and options." (Individual response)*

Respondents suggested that better understanding of inequalities in accessing care would lead to more equitable access to treatments and support. They felt that cancer patients should be provided with timely emotional, financial and palliative support with the option to access this within their local communities. Respondents also suggested increasing the number and skill levels of staff as well as encouraging research into innovative, evidence-based treatments especially for less survivable and secondary cancers.

> *"I think that after being diagnosed you are hit with so much information at the time you can't process it all. I had a mastectomy at 45 and felt that my mental health was completely ignored and it has taken me years to come to terms with it on my own" (Individual response)*

Post-cancer journey

Another theme identified within the responses related to patients' experiences and needs after their treatment has been concluded. There was an emphasis on rehabilitation and learning to live with cancer. Respondents frequently called for effective rehabilitation plans to support patients, including those with learning difficulties. They suggested that patient work arrangements post-treatment should be considered as well as any reconstructive surgery needs.

> *"A follow up plan that not only facilitates but promotes rehabilitation, and has easy and quick access to Speech and Language Therapy." (Individual response)*

Many respondents wanted long-term support post-treatment for cancer patients suggesting regular follow-ups, funding to cover costs for treatment of returning diseases, financial support as well as support for bereaved families. Respondents felt that any improvements in long-term support should be based on listening to patient experiences.

> *"[…] Post cancer care, when treatment is finished, you are often waved off and told to get in touch if you have any concerns, better information on support services available." (Individual response)*

Lessons learnt from the Covid-19 pandemic

The next most common theme was the need to reflect on the impacts of the Covid-19 pandemic. Respondents often discussed late diagnoses resulting from lower-risk groups being neglected during the pandemic and ineffective diagnoses over the phone. There were many calls to make use of genome sequencing techniques, as these were utilised during the Covid-19 pandemic, to enable earlier cancer diagnosis.

> *"Screening and diagnosis. Particularly of the under 50s - an age group severely neglected during the pandemic." (Individual response)*

> *"Since the pandemic began, GPs who don't have access to video consultations have attempted to diagnose over the phone and regular check-ups are still on hold; this has drastically affected the rate at which cancers are caught early. […]" (Individual response)*

Respondents also spoke about difficulties in accessing cancer care such as delays in obtaining GP and hospital appointments due to increased demand because of patients presenting later as a result of the pandemic. The need for a more effective alternative where in-person check-ups are not feasible was also commonly discussed. Respondents also welcomed out-of-hospital care units to improve accessibility.

Secondary cancer

Lastly, the theme of secondary cancer was discussed often by respondents, almost unanimously referring to secondary breast cancer within this theme. Respondents felt the new cancer strategy should raise awareness around the symptoms of secondary cancer as well as testing and treatment options. They suggested more frequent screening and enhanced diagnostic testing for those who have had cancer before.

> *"Regular routine screening is so important for early diagnosis of primary & secondary breast cancer. I found my lump myself which turned out* to be cancerous, but many ladies I met only found theirs through routine scans. I am keen that I continue to get annual checks, ensuring should the cancer come back it will be identified early." (Individual response)

Respondents often expressed concerns over accessing clinical trials for patients with secondary cancer. They also felt that access to care and support for patients living with a metastatic disease should be improved.

Question 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.

There were 215 responses to this question (138 were from individuals and 77 from organisations).

Specific cancer types

The majority of respondents provided specific examples of cancers that should be prioritised within their answers. Of those that included an example, lung cancer was the most commonly cited, followed by breast, blood, pancreatic and bowel cancers respectively.

The most frequently given reasons for the need to focus on breast and bowel cancers were to do with high prevalence rates and therefore their potential impact on a greater number of people. For lung and blood cancers respondents stated that high severity and low survivability were the reasons for prioritisation. Pancreatic cancer was often cited to be lesser known and harder to detect thus requiring a specific focus within the new cancer strategy.

Less survivable cancers

A very common theme identified within the responses was the need to focus on less survivable cancers. Respondents felt that cancers with high mortality rates required increased support in order for them to ‘catch up’ to the survival rates of other cancers.

> *“We would welcome a focus on the less survivable cancers. In addressing the survival deficit for these cancers there is much to gain in terms of improving cancer outcomes and addressing inequity. […]” (Organisation response)*

> *“[…] There is obviously a tension between tackling high volume cancer and low survivability but given the progress that has been made with the high volume, it would be legitimate to invest in the big, less-survivable cancers, and to target the sorts of improvements we have seen in other tumour sites. […]” (Organisation response)*

Secondary cancers

The next most common theme identified regarded respondents wanting secondary cancers to be prioritised. Respondents felt that there needed to be a greater focus on improving the experience and outcomes for those diagnosed with secondary cancers.

> *“Secondary cancers (more robust and regular testing of people with primaries will help to reduce the huge cost of someone’s medical care when they develop a secondary which is often diagnosed at a late stage). And will of course help to save lives.” (Individual response)*

> *“The strategy should include a focus on an improvement in the experiences, treatment, care and outcomes for secondary breast cancer patients.” (Individual response)*

Different demographic groups

Another theme found within the responses was respondents wanting different demographic groups to be focused on, rather than particular types of cancer.

Within this theme children and young adults were frequently cited as the target age group to prioritise. Respondents also commented that those from low socio-economic backgrounds were subject to inequalities in accessing cancer care and they felt this needed to be addressed. There was also a call for cancers specifically affecting females to be prioritised.

> *“Teenagers’ death from cancer rate is so high so anything to research and bring to market new medications. […]” (Individual response)*

> *"Focus on cancers that would impact most on current social inequalities to reduce the gap between the least and most deprived." (Organisation response)*

Question 1C

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

There were 233 responses to this question (145 were from individuals and 88 from organisations).

Screening and diagnosis

The most common theme identified within this set of responses related to the screening and diagnosis of cancer. Respondents felt that these stages of the cancer journey needed to be timelier, more accurate, and have an increased capacity.

> *"[…] Diagnosing more cancers at an earlier stage (especially blood cancers) by investing in Early Cancer Diagnostic Centres, the oncology workforce, and diagnostic capacity. […]" (Organisation response)*

> *"Improved access to screening - early signs of pain & discomfort should be more vigorously investigated as should high risk groups due to age, lifestyle and/or hereditary risk factors." (Individual response)*

Respondents also suggested that screening should be encouraged for a younger age range. Concerns were also raised over the increases in late-stage diagnoses resulting from delays due to the Covid-19 pandemic and respondents wanted this to be considered within the new cancer strategy.

Issues and needs of the workforce

The second most common theme found regarded the workforce and where respondents felt improvements could be made. Recruiting more staff as well as increasing skill level through more training were frequently cited as areas to focus on within the new cancer strategy. Respondents also felt that there should be a more even distribution of specialist staff throughout the country.

> *"Staff currently feel stressed and overworked. Addressing this will allow improvements across the board. There needs to be expansion of the work force to reflect the increase in demand for SACT and radiotherapy. Allied health professionals also need to be rapidly increased. Additional training places need to be created at every level from undergraduate to specialty training and consideration should be given to bursaries etc to attract people into these professions. […]" (Individual response)*

Respondents called for more radiographers and radiologists in particular and suggested that community pharmacies have the potential to play a more integral role in recognising cancer symptoms and referring patients than they currently do.

Speeding up the cancer pathway

Another significant theme identified regarded the need to streamline cancer pathways and reduce the time taken between all elements from initial suspicion of cancer through to rehabilitation. Respondents felt a reduction in waiting times, specifically those for GP appointments, was required.

> *"Giving speedy access to treatment and reducing waiting times. Having been diagnosed with womb cancer last year I waited 4 months for my hysterectomy and then a further period before starting chemo." (Individual response)*

The need to clear backlogs resulting from the Covid-19 pandemic was also commonly cited as a priority for respondents.

> *"The obvious. Waiting times. The backlog which has built up with staff shortages, financial cutbacks and of course COVID. That is vital. An enormous effort should be put in place to clear the backlog of patients and tests and surgeries. If that can be achieved then the whole system would be able to be run smoothly and efficiently. […]" (Individual response)*

Prevention

The fourth most common theme that arose from the responses was the importance of prevention. This included the need for increased education and awareness surrounding symptoms and self-checking, with respondents specifically asking for this to be targeted towards school-aged children, hard to reach groups, and less engaged groups.

> *"Greater emphasis on advertising/awareness of symptoms for all cancers especially the common ones that people may ignore. This should be aimed at all age groups. Followed by training for GPs on symptoms." (Individual response)*

Respondents also felt that the new cancer strategy should aim to reduce health inequalities more generally and promote healthier lifestyles, with examples commonly given being better diet, more exercise and reduced alcohol consumption.

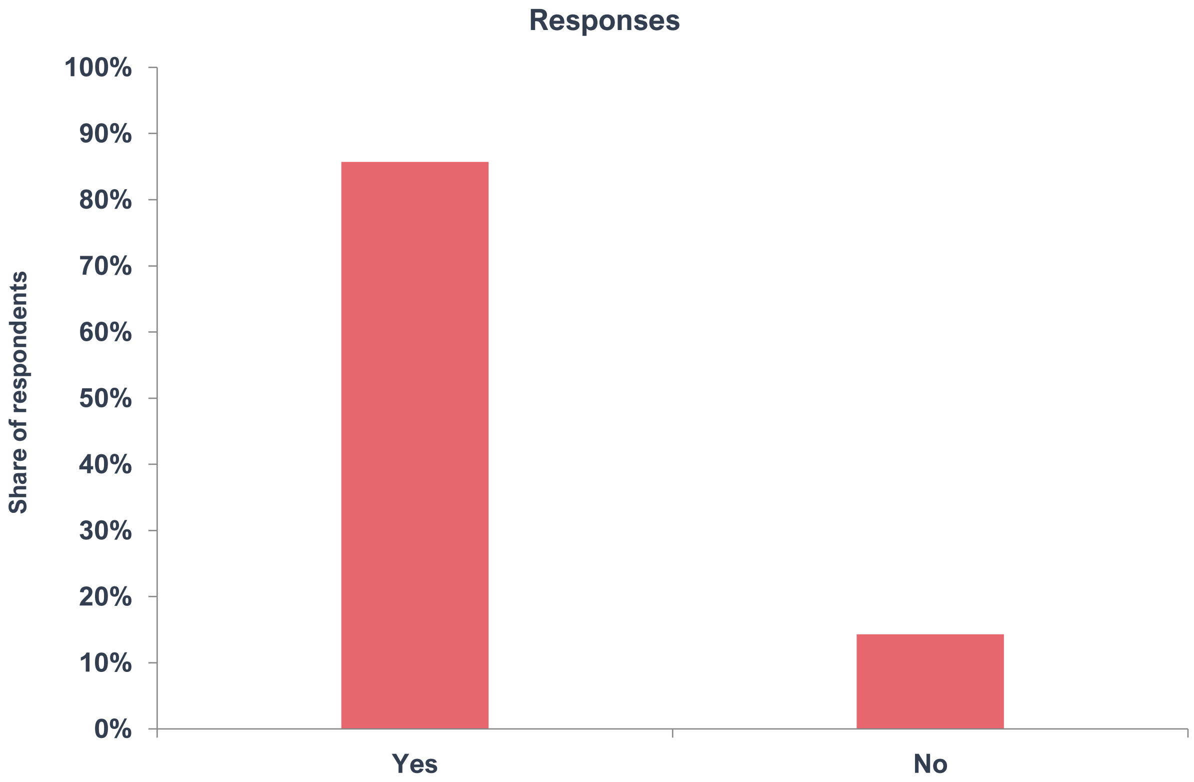
> *"[…] A revised focus on preventative services is urgently needed. A key focus should be on tackling the inequalities, which lead to health inequality and disease progression. […]" (Organisation response)*

> *"Prevention strategies need to be included in short- and long-term planning. Significant endeavours are currently being undertaken within the prehabilitation period but support for increasing physical activity and healthy diets need to start as early as possible. […]" (Organisation response)*

Question 2

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.

Figure 1. Share of Yes/No responses to Question 2



There was a high level of support for this proposal among respondents. 86% of respondents agreed with the proposal, while 14% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were 198 responses to the open-format question (118 were from individuals and 80 from organisations).

General agreement with the proposal

The most common theme related to instances where respondents would generally agree with the proposed strategy as well as the rationale behind it without providing additional suggestions for how it should be implemented. Many respondents agreed that a longer-term strategy would mean that more ambitious goals could be set which would lead to more meaningful change. They also agreed that the 10-year high-level strategy provided a good focus and was realistic in its aims.

> *“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." (Organisation response)*

Some respondents stated that they would welcome any form of strategy attempting to improve cancer experiences and outcomes in Scotland and others praised the fact that a 10-year strategy would outlive 'political cycles'.

Short-term goals and progress monitoring

Another common theme within this set of responses regarded suggestions around short-term goals and progress monitoring. Respondents felt that progress reviews at regular intervals throughout the proposed 10-year plan would help to maintain momentum and allow for flexibility where changes could be implemented, for example where new treatments and diagnostic techniques are developed.

> *"[…] Three-year action plans allow reflection on the outcomes achieved, how they relate to the vision and the learnings gained through the implementation of tactics. Using these insights empowers flexibility and allows the plan to evolve and successfully achieve the vision." (Organisation response)*

Many respondents suggested that a Covid-19 'recovery period' should be the first short-term goal. It was also stated frequently that reporting publicly on progress would keep the public up to date and ensure accountability.

Areas of priority for the strategy

The next most frequently discussed theme was where respondents would suggest areas to prioritise within the proposed 10-year high-level strategy. Most responses within this theme were centred around the need for more effective and timelier screening and diagnosis, increased workforce capacity and investment into infrastructure.

> *"We agree with a 10-year high-level strategy as it is important to embed a longer-term direction and vision. Addressing workforce capacity particularly requires longer-term forecasting and planning." (Organisation response)*

Other respondents called for specific types of cancer, a common example being blood, to be prioritised within the new cancer strategy as well as more consideration around preventative measures and tackling root causes such as health inequalities.

> *"We suggest the high-level strategy should aim to achieve equity in awareness of condition, awareness of symptoms, speed of diagnosis and access to services and treatments for Blood Cancers in comparison to more commonly recognised cancers. […]" (Organisation response)*

Disagreement with the proposal

Lastly, the next theme related to respondents disagreeing with the proposed 10-year high-level strategy. The most common reason for respondents disagreeing was that the 10-year period was seen as too long. Respondents suggested that improvements in cancer care need to be implemented sooner rather than later, arguing that lives could be lost if there are unnecessary delays.

> *"10 years is too long for someone with cancer. A shorter period with a review on how successful it's been before designing the next part would be better." (Individual response)*

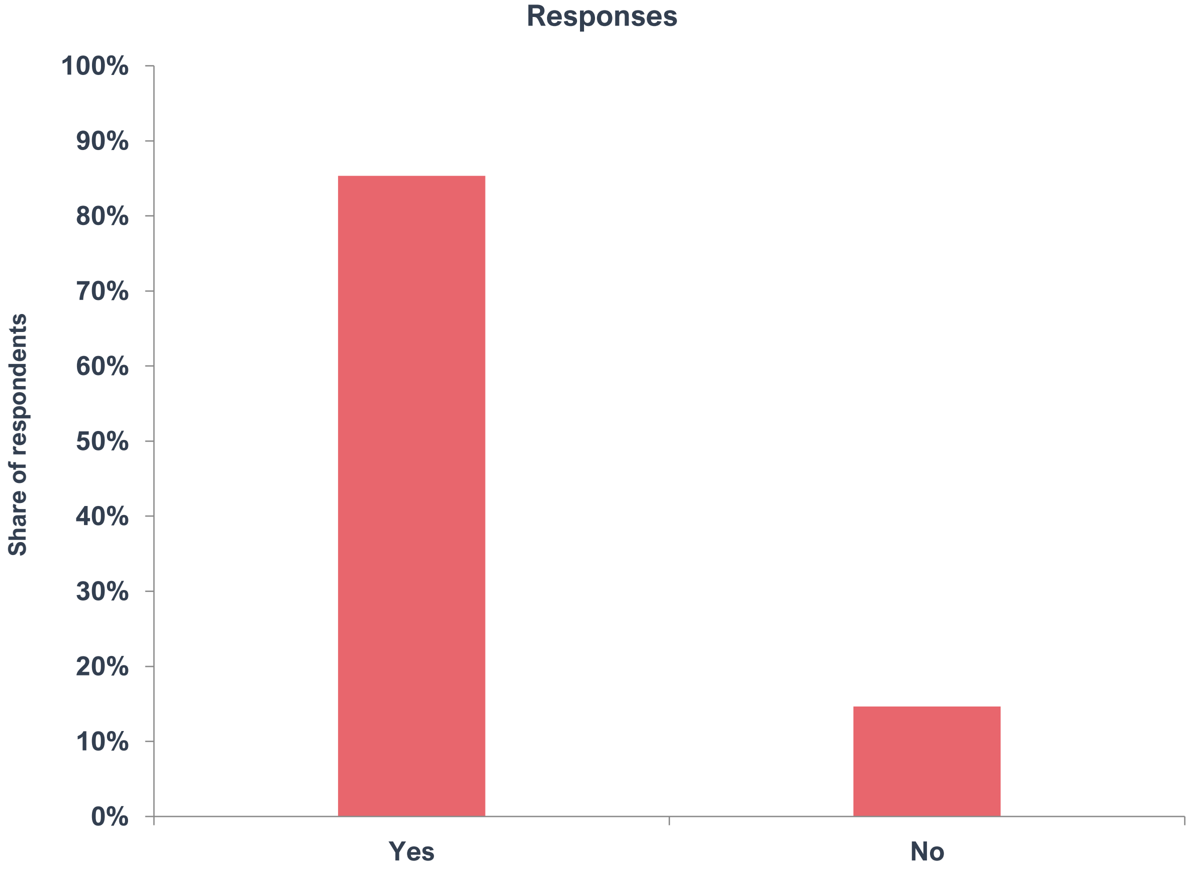
> *"5 year plan would be more appropriate with attainable goals in each year in line with the annual delivery plans being developed." (Organisation response)*

Respondents expressed concerns that long-term plans might not have the same level of flexibility as shorter-term plans. Others felt that the proposed strategy was unfocussed and lacked a sense of urgency and so would ultimately be ineffective.

Question 3

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?

Figure 2. Share of Yes/No responses to Question 3



There was a high level of support for the proposed vision amongst among respondents. 85% of respondents agreed with the vision, while 15% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were 186 responses to the open-format question (106 were from individuals and 80 from organisations).

Support and outcomes

A great number of respondents offered suggestions regarding the improvement of support offered to cancer patients and its subsequent outcomes. In general, respondents felt that the Vision should focus on a patient-centred approach and promote psychological support, wellbeing and wider societal benefits. Financial support of patients and investment in cancer strategies were also raised as a crucial target by respondents.

> *"The vision is fine, compassion and consistency are important. But put more simply we want to provide high quality patient-centred care and services available at the right time, in the right place all of the time. Given the aims set out below, we are presuming that preventative services are within the general definition of "cancer services" noted in this vision and that reducing the incidence of cancer through such services a desirable outcome." (Organisation response)*

Respondents also highlighted the necessity for strengthening the workforce and suggested that further training should be offered, including in how staff approach and support patients. For example, respondents suggested that staff need to work closely with patients and inform them appropriately.

> *"This is what people want and expect but the NHS will need to invest heavily in staffing to improve morale, we cannot continue a service on good will." (Individual response)*

Finally, respondents believed that the vision should be directed towards improving cancer survival rates.

> *"Cancer survival rates is the highest it's ever been. Despite this progress NHS Scotland can improve access to curative treatment and support long-term survival of cancer patients in Scotland." (Organisation response)*

Planning and methods

The second most popular theme concerned general planning and methods. It consisted of two sub-themes that were both mentioned quite extensively. The first sub-theme was about planning and suggestions on the overall strategy of the Vision, as well as concerns about its delivery. Respondents mentioned that the strategy should be more detailed. This sub-theme also included considerations on the treatment of specific cancer types.

> *"Vision is one thing, but the practical aspects will need discussion and attention. There is no point of having a vision if the bottle necks are not sufficiently identified and solutions are not created." (Individual response)*

The second sub-theme was about the necessity to do further innovative research and improve existing methods. Some responses provided statistical evidence relevant to cancer, while some respondents also suggested that a comparison with international relevant evidence would be beneficial. Another point raised was that the vision should find effective ways to measure its expected outcomes.

> *"We agree with the vision but this needs all boards to be on a level playing field in terms of access to services, research and innovation" (Organisation response)*

Equality, equity and fairness

The next most common theme within the responses combined the themes of equality, equity and fairness. Respondents suggested that the Vision should ensure that services can be delivered to all patients and diminish inequalities.

> *"The vision encapsulates and sets out well the aim of having a forward looking compassionate caring cancer service focused on outcomes and survival. We wonder whether it might be helpful to include the attribute equitable, in addition to compassionate and consistent - as equity features strongly in the aims and is important element." (Organisation response)*

The geographic distribution of services was repeatedly linked to equality. Some common views were that the postcode lottery approach should be abolished, and policies should be applied equally across all regions. Other people highlighted the importance of more local treatments and health boards.

> *"Consistency across the country is key, at the moment it varies so much from one health board to another." (Individual response)*

Prevention and aftercare

Another common theme was about prevention and aftercare. A significant number of respondents suggested that the Vision should incorporate prevention and timely diagnosis, as well as other aspects related to time, such as the reduction of waiting times.

> *"Focus needs to be on early diagnosis to save more lives." (Individual response)*

Some respondents held the view that the vision should consider the impact being diagnosed with cancer has on patients' lives during and after treatment. Furthermore, respondents were interested in different ways that incurable patients could potentially be treated.

> *"[...]The other point that needs to be taken in to account is living after being treated, once all the chemo, surgery and radiotherapy is complete, the support seems to decrease and this probably due to how busy all the cancer clinics are." (Individual responses)*

General comments

Some respondents simply agreed with the proposed vision without making further suggestions, while a small number of responses disagreed without providing alternative ideas for improvement.

> *"Currently being treated and well, not impressed!" (Individual responses)*

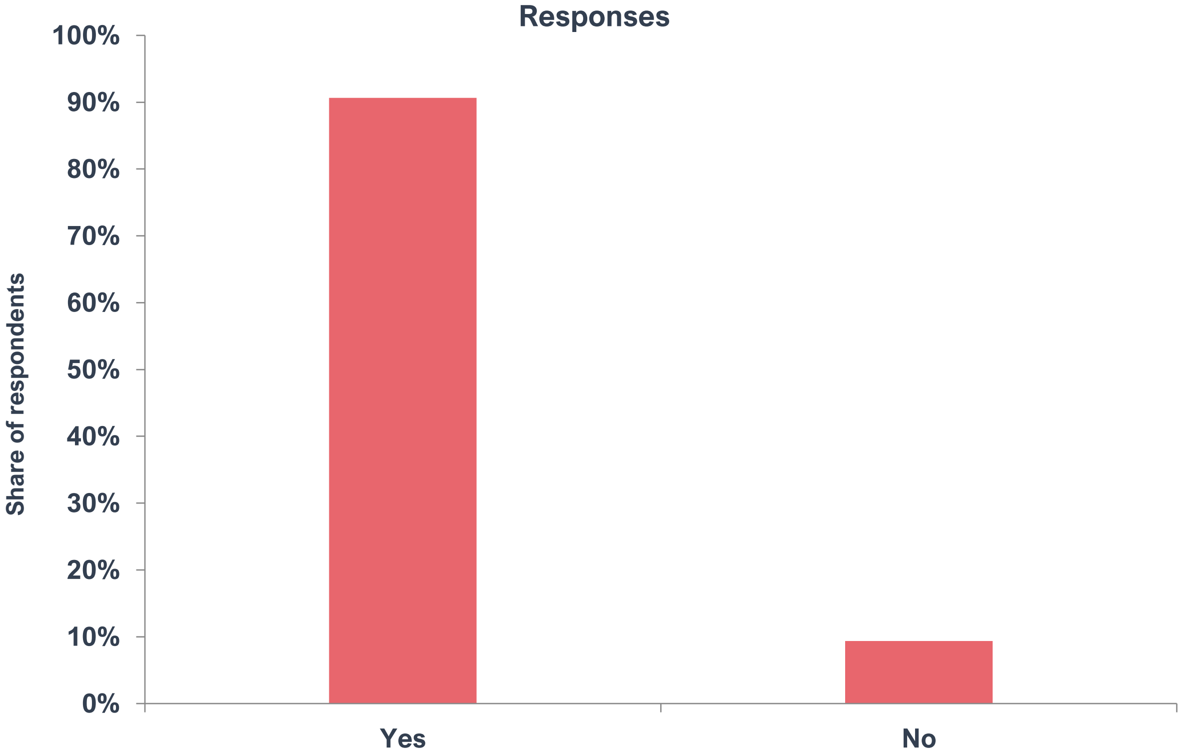
Question 4

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?

Figure 3. Share of Yes/No responses to Question 4



There was a high level of support for the proposed aims among respondents: 91% of respondents agreed with the aims, while 9% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were 186 responses to the open-format question (105 were from individuals and 81 from organisations).

Planning, service provision and innovation

The majority of respondents provided answers related to planning, service provision and innovation. Regarding planning, respondents provided suggestions for the implementation of the strategy. Among others, they underlined that the strategy should clarify the targets, introduce new policies or improve the current policy context, encourage leadership and accountability, increase workforce supply and raise awareness among the public (for example regarding cancer symptoms). However, some respondents highlighted the limitations of the strategy, such as it does not include incurable cancers, or they expressed doubts regarding the extent to which the set aims are achievable.

> *"Whilst we agree we acknowledge they are high level and are curious how they can be prioritised over each other. Action plans should facilitate." (Organisation response)*

Respondents discussing service provision emphasised issues such as the necessity for efficient coordination among service providers, provision of care for incurable cancers, the accessibility of services, the need for high-quality treatment and the role of informal care.

> *"Every instance of terminal cancer causes a legacy within the family which can further impact the health service through the support of mental health etc" (Individual response)*

Respondents were also concerned with research and innovation. Suggestions were made that the strategy should focus on measuring its intended goals, improving treatment methods and data collection, supporting research and innovation, and developing expertise and new models.

> *"We also feel it would be important to prioritise funding for research and innovation; and bringing greater awareness to the signs and symptoms of individual cancers, such as bladder cancer." (Organisation response)*

Efficiency, impact and inequalities

The second most common theme focused on efficiency, impact and inequalities. Regarding efficiency, respondents felt that the new cancer strategy needs to aim at achieving higher survival rates, less deaths, a better quality of life and wellbeing, reduced risks related to cancer, and lower recurrence rates. Furthermore, they suggested that the strategy considers the long-term impacts and side effects of cancer diagnosis and treatment.

> *"But there also needs to be dealing with the long term physical and mental impacts of a cancer diagnosis" (Individual response)*

It was stated that inequalities were largely associated with the variance of access to care depending on patients' region of residence. Therefore, respondents suggested that the strategy prioritised tackling regional inequalities, such as by ensuring equitable access to patients in both urban and rural/island areas. Furthermore, people mentioned that they would like to see improvements in health inequalities across socio-economic groups. Finally, some suggested that national and local treatments be considered separately.

> *"The inequalities that rural patients face must be a priority" (Individual response)*

Time considerations

The next most common theme was focused on time. Most responses reflected on the first three aims listed, namely (i) slowing down the increasing incidence of cancer, (ii) earlier stage at diagnosis, and (iii) shorter time to treatment. Respondents were happy with the aim of shortening the time to treatment and they supported the view that early diagnosis should be a priority. They also underlined that waiting lists should decrease, as they can cause stress to patients.

> *"A specific aim is needed around monitoring and early detection of incurable secondary cancers" (Individual response)*

> *"We agree with this prioritised list. We would recommend Goal C) is changed to read "shorter time to the correct treatment" given the importance of patients receiving the most appropriate treatment for their unique cancer diagnosis." (Organisation response)*

Engagement and support

The next most commonly discussed theme was about engagement and support. Under this theme, several sub-themes were covered. Specifically, respondents suggested that the strategy should encourage communication between patients and experts, collaboration between key bodies (e.g. NHS, stakeholders, academia, industry, or patient representative bodies), and incorporation of a more active role for cancer patients in determining and managing their care.

> *"Again, we believe that in order to provide more consistent care to all cancer patients, more needs to be done to create better communication and joint working between specialist services and board level cancer care." (Organisation response)*

Respondents also discussed the need for greater support to patients, their families and the health system more broadly, ranging from mental health to financial support. Among others, they suggested that the strategy should include funding priorities, post-treatment support, and funding for research and innovation.

> *"These are the right aims but will need to be qualified/tempered by the challenges which stand in the way of making these improvements. There will be a requirement for investment and for workforce recruitment & retention." (Organisation response)*

A smaller number of respondents mentioned how the time of a diagnosis can be defined by one's age and raised concerns over the higher rates of cancer diagnosis as well as disease across different age cohorts.

> *"I believe more people would be diagnosed at earlier stages if mammograms were available for younger patients" (Individual response)*

No further suggestions

Few respondents simply agreed with the aims without suggesting significant changes.

> *"Agree with all aims" (Individual response)*

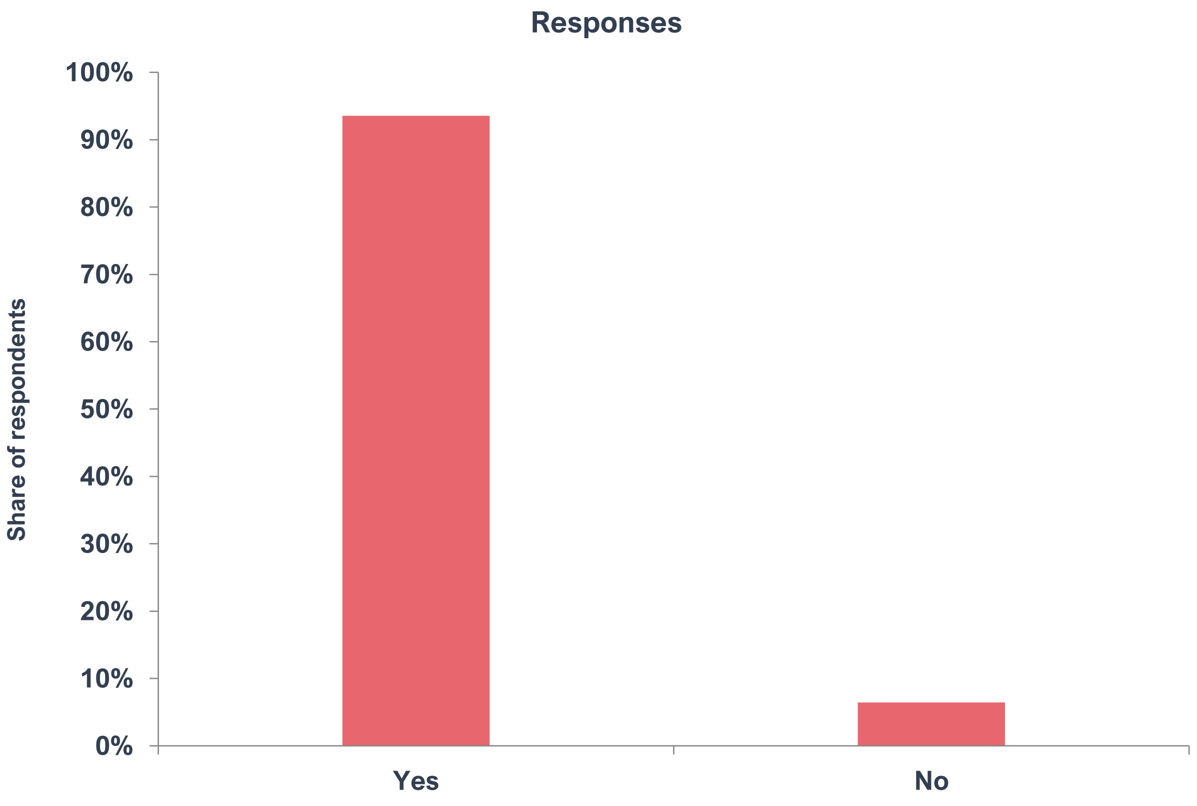
Question 5

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?

Figure 4. Share of Yes/No responses to Question 5



There was a high level of support for the proposed principles among respondents: 94% of respondents agreed with the principles, while 6% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were 175 responses to the open-format question (97 were from individuals and 78 from organisations).

Inclusivity and collaboration

The most common theme was about inclusivity and collaboration. This was a broad category, with the sub-theme of inclusivity encompassing community involvement and the sub-theme of collaboration mainly referring to the provision of services.

Regarding inclusivity, respondents suggested that the principles promoted equitable care that can be accessed by all people regardless of their socio-economic background, thus eliminating inequalities. They also supported the active involvement of communities and the inclusion of deprived areas.

> *"Again high level but action plan should provide detail and be meaningful. "be inclusive" is too vague - suggest "ensure equity of access and provision of service"." (Organisation response)*

A significant number of responses featured collaboration and service provision. Individuals supported that the government should engage with service users, stakeholders, charities and third sector organisations.

> *"[...] More collaboration across all four nations would benefit everyone but mostly patients." (Organisation response)*

Other responses under this theme referred to the distinction between regional and local care, regional disparities and the accessibility of services.

> *"Collaboration is important but equal access to diagnostic centres for patients living in more rural areas is equally important. These patients frequently will not travel a long distance even if transport is provided. Mini centres have to be created for helping diagnosis patients living in more rural areas." (Individual response)*

Patient-centred approach and high-quality, compassionate care

The second most common theme featured the principles of a patient-centred approach and the delivery of compassionate and high-quality care. Some key points of a patient-centred approach raised by respondents included communication with patients, particular attention to students, increased awareness, human rights and patients' empowerment.

> *"A suggestion would be to put the people of Scotland at the centre, as a member of the public only becomes a cancer patient once they have the diagnosis. Therefore, you can only put them at the centre, if you screen and diagnose the general population early enough." (Individual response)*

Regarding compassionate and high-quality care, many respondents were happy to address this principle and encouraged more investment in this area. However, some respondents expressed their concerns about how quality can be measured.

General planning and consistency

Another prominent theme was focused more broadly on planning for the principles set by the strategy, with responses stressing the importance of having a consistent approach. Respondents discussing planning, though being in agreement with the principles outlined, commented that these seemed to be unclear or unrealistic. A number of respondents also mentioned that the 'Once for Scotland' approach was not clear enough. Responses also raised issues around the accountability and delivery of principles, promotion of healthy behaviours, as well as different challenges on the implementation of the plan.

> *"Again, such a list of principles is also a no brainer but we are a million miles away from them today, and so a more pragmatic achievable set of principles needs also to be honest and take into consideration the lack of capacity to deliver this for many years. No point setting yourself up to fail – we need honesty in politics and healthcare." (Organisation response)*

Some respondents addressed the intention of the Scottish Government to strive for consistency, with most of these responses mentioning the 'Once for Scotland' approach. Some mentioned that consistency was not enough, and the strategy principles needed to guarantee efficiency as well.

> *"All of these points should be standard. Consistency is important. Let's lose the postcode lottery." (Individual response)*

Research and sustainability

The next most common theme incorporated ideas around research and sustainability. Responses focused on research included suggestions such as making use of evidence-based approaches, incorporating improved technologies (e.g. artificial intelligence) and conducting data collection. Respondents also acknowledged the importance of educating patients and the workforce as well as offering training opportunities to the latter and ensuring that patients contribute to clinical trials.

> *"Ensure all patients have equitable access to all evidence-based treatment options for their cancers and opportunity to contribute to that evidence base by participation in clinical trials wherever appropriate." (Individual response)*

Responses on sustainability mainly concerned funding, workforce supply and support, and service infrastructure.

> *"I feel we are already meeting theses needs for the majority of patients, as I said previously, having appropriate staffing can help streamline a patient's journey through the cancer journey" (Individual response)*

No further suggestions

Several responses simply noted agreement or disagreement without making further recommendations.

> *"I would have thought that these strategies are being used already." (Individual response)*

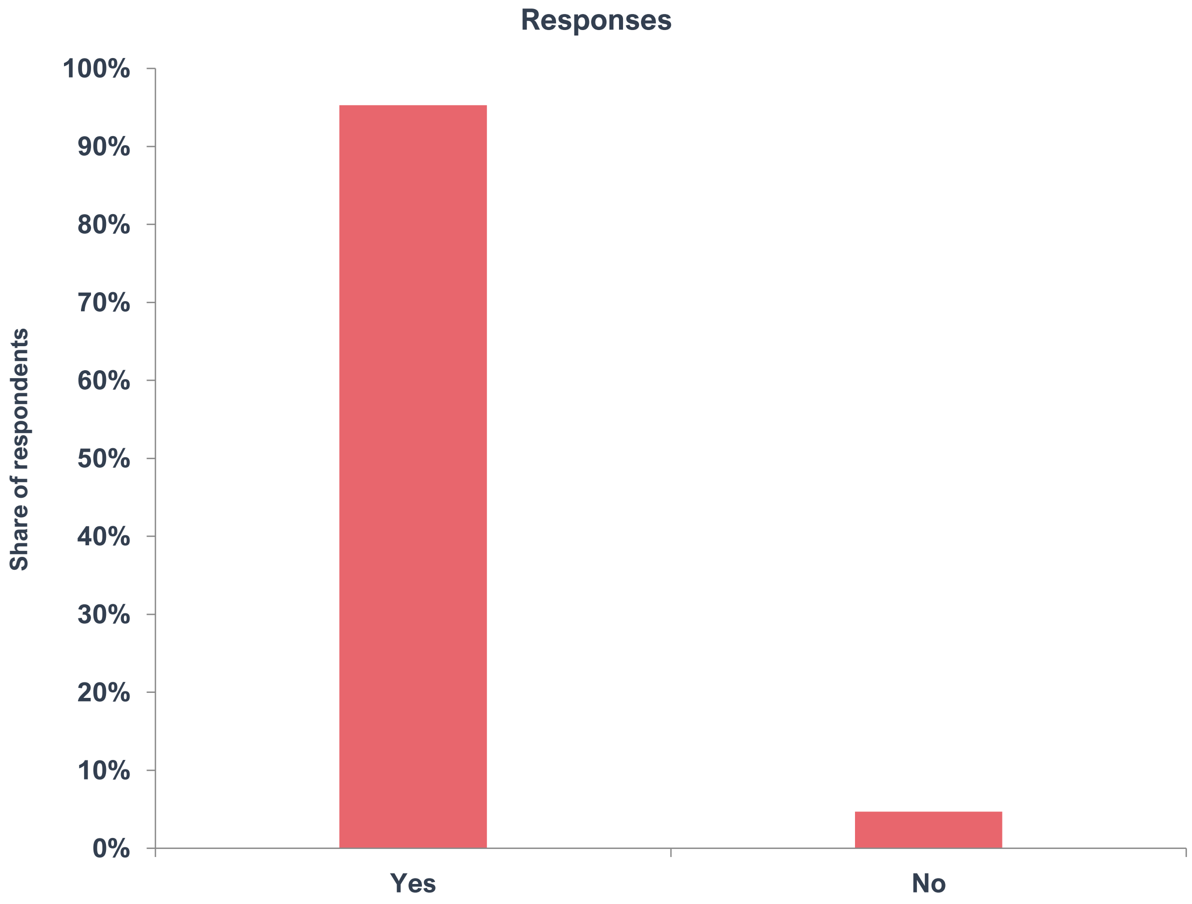
Question 6

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?

Figure 5. Share of Yes/No responses to Question 6



There was a high level of support for the proposed themes among respondents: 95% of respondents agreed with the themes, while 5% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were 163 responses to the open-format question (86 were from individuals and 77 from organisations).

Comments mainly highlighted suggestions for improvement or requested clarification regarding the list of themes provided by the Scottish Government.

Prevention, accessibility and quality of care

The most common theme identified within responses encompassed prevention, accessibility and equity. Respondents suggested that early diagnosis be included in the list of themes. Responses also raised issues around equal access to treatment as well as care and innovation (e.g. medicines, advanced therapies or clinical trials). Another prevalent point was about the reduction of health or regional inequalities.

> *"getting treatment as early and as quickly as possible is essential." (Individual response)*

> *"ease of access to care and support." (Individual response)*

Responses discussing the quality of care provided stressed the necessity to attract specialists as well as guarantee the safe and efficient treatment of high-risk cases, such as cancers with dangerous outcomes or secondary cancers. Palliative care was also mentioned.

> *"For me, improving quality of care and well-being is important. However, I personally get a sense that staff don't know who they are talking to most of time." (Individual response)*

Service and workforce management

The second most popular theme focused on how services and the workforce are being managed. Service management mostly regarded service delivery, support, infrastructure and partnerships with third parties such as the industry. Other responses underlined the approach towards leadership or adapting the strategies to respond to the needs identified during the Covid-19 pandemic.

> *"These are huge goals and will require a massive commitment from all cancer services. The clinical teams are often firefighting and the support services are always on funding limited timescales." (Individual response)*

Respondents also mentioned the need to better equip the workforce, including increasing the supplies available and the training opportunities offered.

> *"Again if availability of services is to increase so does investment in staffing and equipment" (Individual response)*

Person-centred care, wellbeing and communication

Another prevalent theme combined the person-centred care as introduced in the strategy with wellbeing and communication. Respondents paid particular attention to patients' quality of life, the involvement of patients' families in the care plan and allowing for some flexibility between care plans and each person's needs. Some responses also raised the role of community pharmacies in achieving person-centred care, while others made references to raising awareness and education.

> *"patient centred care at forefront of everything" (Individual response)*

With reference to person-centres care, some responses also addressed the communication between staff and patients. Respondents felt that individual experiences of patients should be taken into account, and that patients should be providing feedback on the care they receive.

Research and technology

Another theme frequently discussed was research and technology. Responses under this theme suggesting improving data collection, increasing the use of evidence-based approaches and enhancing digitisation. Some respondents also enquired as to how outcomes can be measured.

> *"We welcome data, technology, and measurement as an area of focus. At present, the lack of blood cancer data in Scotland hampers our ability to understand where action is most needed. Improved data collection will enable better analysis which can inform policies to improve blood cancer outcomes." (Organisation response)*

Broader agreement with the themes

Some respondents agreed with the list of themes without adding further suggestions. Some others agreed but raised concerns regarding the extent to which the themes were realistic or not, the clarity of their message and their aims and implications. Few responses addressed more practical issues (e.g. possible duplication of themes).

> *"I am not sure if some of the themes are too big which allows some areas to have improvement and others to slip through the net." (Individual response)*

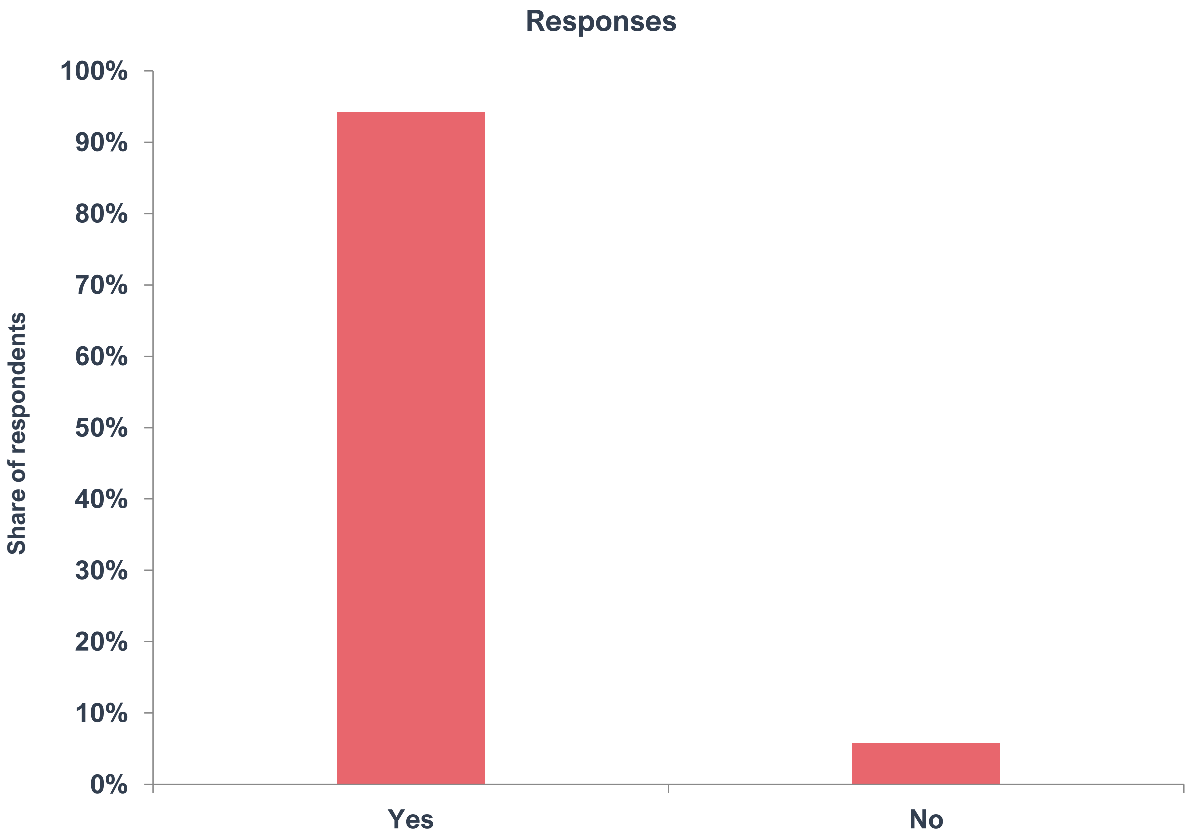
Question 7

Under Person-centred care we are considering:

- **Individual experience (by responding to Scotland Cancer Patient Experience Survey (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)**

Do you agree with these areas of focus?

Figure 6. Share of Yes/No responses to Question 7



There was a high level of support for the proposed areas of focus among respondents: 94% of respondents agreed with the areas of focus, while 6% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were two open-format questions on the areas of focus for person-centred care:

- 174 responses to the first question ("In your experience, what aims or actions would you like to see under any of these areas? Please focus your response on the person-centred care."): 100 from individuals and 74 from organisations.

- 110 responses to the second question (“Please explain your answer and provide any additional suggestions.”): 58 from individuals and 52 from organisations.

Service, staff and third sector management

The most common theme identified within responses concerned the management of services, staff and the third sector, including charities. Regarding service management and associated policies, respondents highlighted the necessity for a centralised administration as well as a holistic approach in the delivery of services, including suggestions for co-production and co-design. Other issues raised were the integration of different services, investment in advanced methods, accessibility of services, the reduction of waiting times and the involvement of community pharmacies.

> *“It needs to be coordinated from one building so it is a one stop for patients. Having days and weeks between seeing different professionals makes the mental trauma worse.” (Individual response)*

Respondents also raised the importance of supporting workers in health and social care, with suggestions made including offering additional education and training to improve compassionate or person-centred care, as well as psychological support, including access to counselling. Other issues discussed were the establishment of a Clinical Nurse Specialist (CNS), the investment in workforce specialising on blood cancer and the formation of a network of care providers to support patients.

> *“A go to person for follow up care/concerns. It's never clear if I should be going to breast cancer clinic or GP with concerns. I've contacted one and been told to contact the other.” (Individual response)*

Responses addressing the involvement of the third sector recommended that the third sector and charities should coordinate with patients and health care settings to support the implementation of a person-centred care.

> *“Greater support for local Cancer Support Charities.” (Individual response)*

Information, communication and education

The second most popular theme encompassed information, communication and education. Responses under this theme mostly referred to the person-centred approach. Respondents felt that patient experiences should be heard. Along these lines, respondents raised the role of the Single Point of Contact, the importance of engaging with communities and stakeholders as well as listening to patients’ feedback. In addition, age cohorts seemed to be important for a few respondents, who suggested that particular attention should be paid to the needs of either older or younger people respectively.

> *“Wider support for people with cancer is the most important aspect. It should be very practical based help e.g, access to someone who can do their shopping, cooking and cleaning. If you are older or on your own I simply have no idea how they cope.” (Individual response)*

Support

The theme of support was raised with reference to numerous aspects, such as mental health and psychological support for the patients or their families, financial support offered to carers or service providers and charities, better resources being made available and more broadly the necessity to facilitate support. Some respondents were interested in specific types of support, such as sexual health support for sexual health prostate cancer or support for pathology and radiology services.

> *"[…] Cancer and its treatment affect every person differently and take their toll, not just on people's physical health but their emotional wellbeing, finances, family, social and work life. […]" (Organisation response)*

> *"What about supporting families? Mental support in top of medication, education and prevention???" (Individual response)*

Diagnosis, care and aftercare

The fourth theme combined diagnosis with care and aftercare. Diagnosis was related to the importance of prevention and prehabilitation. Care and aftercare regarded issues such as rehabilitation, compassionate care and post-treatment care.

> *"need long term commitment to funding for aims mentioned in strategy-including prehabilitation/rehabilitation, single point of contact, improving cancer journey rather than constant short term funding [...]" (Individual response)*

Broader concerns

Some respondents raised broader concerns, including references to the implications of the Covid-19 pandemic on the envisioned person-centred care.

> *"Sadly due to Covid a lot of the resources previously available to people weren't available but good to see them opening up again [...]" (Individual response)*

Question 8

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?

Please focus your response on the prevention of cancer and inequalities in cancer incidence.

Please explain your answer and provide any additional suggestions.

There were two open-format sub-questions under this section:

- 216 responses to the first question ("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?"): 138 from individuals and 78 from organisations.
- 119 responses to the second question ("Please explain your answer and provide any additional suggestions."): 61 from individuals and 58 from organisations.

Education and awareness

The most common theme identified regarded the need for education and awareness as preventative measures. Respondents most commonly felt that promotion of a healthy lifestyle and awareness of cancer symptoms and how to self-check would be important for preventing cancer.

> *"Education from childhood onwards. Create a culture that focuses on health and well-being." (Individual response)*

> *"There must be a focus on raising awareness of the symptoms of secondary cancers (largely left to the third sector to do), so that people know the early warning signs to look out for. I had no idea of secondary breast cancer symptoms until I was admitted to A&E with suspected appendicitis and then told I had incurable stage 4 secondary breast cancer." (Individual response)*

Respondents also stated that education should target children and begin within schools, common examples including teaching sun safety and how to cook healthy meals. Other respondents felt that a community-based approach for awareness campaigns would be beneficial and some suggested involving people from ethnic minority backgrounds and religious leaders. Respondents also suggested that all messaging regarding cancer prevention should be clear and impactful.

Improving diet

The second most common theme related to the impact that diet can have on preventing cancer. Many respondents felt that access to healthy food was not adequate suggesting that fresh fruit and vegetables should not cost more than high sugar and high fat alternatives. They mentioned that this was especially true within areas of deprivation.

> *"When it comes to healthy eating, the proposals on advice, calorie labelling and restricting promotions and advertisings are welcome but actually do not address the core problem, which is that healthy food costs more. […]" (Organisation response)*

Specific initiatives relating to diet that were frequently commented on included the need for school- and community-based cooking classes, but many respondents expressed concerns that the proposed mandatory calorie labelling would be detrimental for those with eating disorders.

> *"[…] Calorie labelling can be useful but I feel like it can feed into eating disorders, with calorie counting. I'd like to see labelling making the main focus on nutrition and protein e.g. how many of your 5 a day, how much protein does it contain, percentage of vitamins. […]" (Individual response)*

Tackling socio-economic inequalities

Another significant theme found within the responses includes the need to tackle inequalities with a particular focus on socio-economic deprivation. Many respondents expressed the view that socio-economic deprivation is often the root cause of other risk factors for cancer. They provided examples such as lack of access to healthy food, green spaces and exercise facilities, and poor-quality housing.

> *"Many of the risk factors associated with the incidence of cancer are directly related to poverty and deprivation - the above are useful but of limited benefit on their own. More should be outlined about how to address some of the root causes and issues people face, particularly those on low incomes with poor housing and poor health outcomes." (Individual response)*

Respondents also called for financial support to be made available to those from deprived socio-economic backgrounds when going through their cancer journey.

> *"Financial support for people living with and affected by cancer. This is a key concern of patients with a cancer diagnosis, how will I pay my mortgage etc. […]" (Organisation response)*

Preventing smoking

Lastly, the theme of preventing smoking was common within the responses to this question. Respondents particularly felt that smoking cessation services were an asset within cancer prevention, and they called for more funding into these services to keep them open, increase their number throughout the country, and improve awareness, access and engagement.

> *"[…] Smoking cessation services need to be widespread and promoted and easily accessible to all. This should not require a GP appointment or referral. […]" (Organisation response)*

Many respondents also noted that the cancer strategy should specifically include vaping as well. Respondents suggested that it would be most beneficial to target preventative measures for vaping at teenagers and young adults.

> *"[…] Much more needs to be done to educate children and young adults about the dangers of smoking and vaping. There needs to be a bigger emphasis on smoking cessation measures. And the availability of cigarettes needs to be curtailed further." (Individual response)*

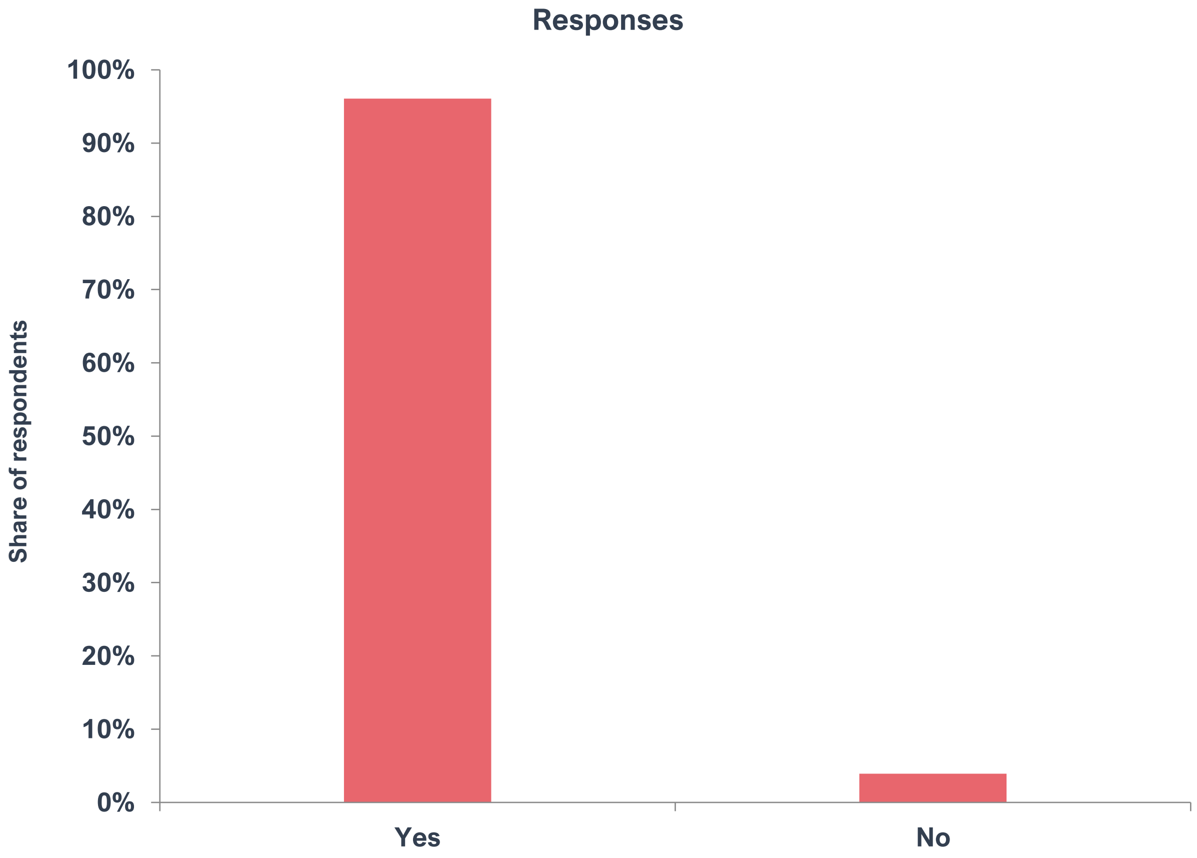
Question 9

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?

Figure 7. Share of Yes/No responses to Question 9



There was a high level of support for the proposed areas of focus among respondents: 96% of respondents agreed with the areas of focus, while 4% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were two open-format questions on the areas of focus for timely access to care:

- 176 responses to the first question (“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.”): 96 from individuals and 80 from organisations.

- 94 responses to the second question (“Please explain your answer and provide any additional suggestions.”): 40 from individuals and 54 from organisations.

Timely detection, screening and testing

The most common theme focused on the importance of timing in detection, screening and testing. Respondents highlighted the importance of early detection, and they provided suggestions on screening, such us prioritising screening on patients with history or higher chance of incidence. Furthermore, they suggested screening to take place annually. Responses also recognised the role of Early Cancer Diagnostic Centres (ECDCs) on timely diagnosis, and they provided suggestions for improving it, e.g. upgrading their role, expanding their principles, being more evidence-based and moving from a pilot to routine care. Respondents also mentioned that screening should be facilitated and be up to date, and that high-tech treatments should be considered (e.g. AI for skin imaging).

> *“Early detection of a condition (e.g. cancer) through a healthy living test (e.g. blood sample taken at regular check-ups in the community). When detected the care coordinated locally, regionally or nationally as required.” (Organisation response)*

> *“The role of ECDCs expand and transition from pilot to routine care” (Organisation response)*

Respondents also discussed the waiting times between having a test and knowing the diagnosis, timely access to care and services, as well as the acceleration of the patient pathway.

> *“Reduction in timescales between screening and more awareness of GPS of cancers that are uncommon within common groups eg: lobular breast cancer” (Individual response)*

Service management

The second more frequent theme was about service management, raising issues around service delivery and distribution. Among others, respondents suggested considering the financial or wider costs of services, accessibility, sustainability, higher availability, innovation, primary or secondary care education, better integration and co-ordination between services.

> *“[...] It will also be important to focus on capacity within the service to deliver the required treatments after diagnosis. Delays downstream after diagnosis may counteract all or part of the benefit gained from earlier diagnosis. It would be good to include some ambitions for a more integrated cancer service across and within primary, secondary and tertiary care.” (Organisation response)*

Furthermore, some respondents highlighted concerns on age cohorts. For instance, they suggested wider age limits for screening.

> *“Lower age of breast screening to 40[.] As standard where under 50 or breast tissue is dense, ultrasound or MRI scans” (Individual response)*

Information and financial support

The next theme was about information and financial support. Respondents underlined the necessity of adequate funding for services, investing in innovation, and raised issues around resource allocation.

> *"It needs to be properly funded so that there are sufficient staff and resources." (Individual response)*

Responses focused on information suggested actions to increase patients' awareness of cancer symptoms, such as campaigns, consultations or the promotion of digitisation.

> *"GPs need to restart face to face consultations as telephone consultation do not allow them to really get to know their patients" (Individual response)*

Workforce management

Responses under this theme considered issues such as the accountability, efficiency and awareness of GPs, the training and education of health professionals, as well as the development of a workforce strategy.

> *"There needs to be the workforce in place to respond!" (Individual response)*

Broader comments

A few responses featured broader comments on the implementation of a timely access to care.

> *"It's all overdue" (Individual response)*

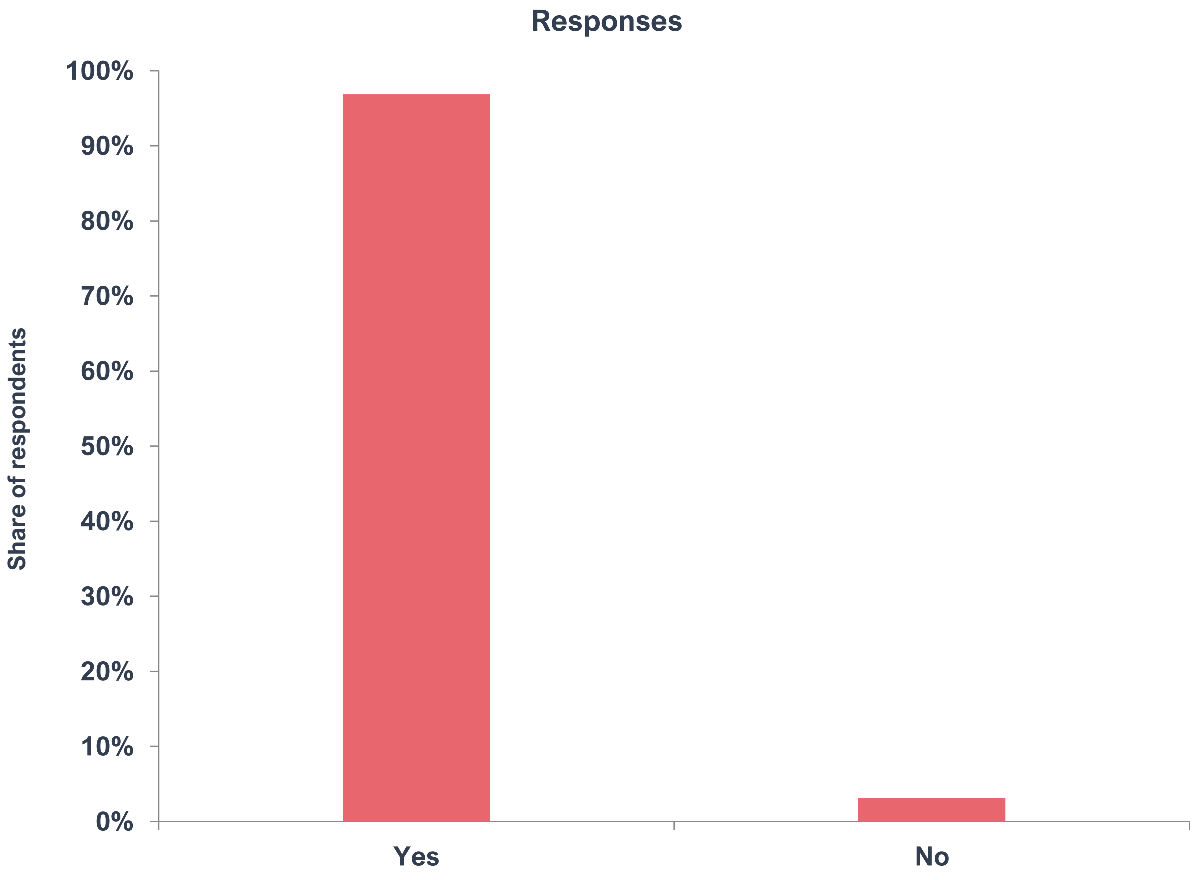
Question 10

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?

Figure 8. Share of Yes/No responses to Question 10



There was a high level of support for the proposed areas of focus among respondents: 97% of respondents agreed with the areas of focus, while 3% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were two open-format questions on the areas of focus for high quality care:

- 166 responses to the first question ("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."): 86 from individuals and 80 from organisations.
- 94 responses to the second question ("Please explain your answer and provide any additional suggestions."): 35 from individuals and 59 from organisations.

Service management

The most common theme regarded management of services. Respondents highlighted issues such as collaboration across different parties, shorter waiting times in health settings, accessibility of services and care, better infrastructure, diversity among services, consistency of care, forward planning, centralisation of services, enhanced leadership and capability, the inclusion of palliative care, and the integration of the third sector.

> *"Yes but we also need care in the community which is non existent just now. Hospitals are working hard and seeing people. GPs are impossible to even get a telephone call with. All receptionist wish to do is refer you to other services and not allow you to speak to a doctor." (Individual response)*

> *"increase the cancer workforce starting now, particularly in the biggest priority areas eg radiotherapy." (Individual response)*

Workforce management

The second more frequently highlighted theme was about the management of the workforce. Respondents mentioned the necessity for an upskilled and flexible workforce that receives decent pay, more recruitments, workforce assessments, daily access for patients and their carers to a CNS, and the development of a workforce action plan.

> *"[…] This Strategy should set out the steps to build the cancer workforce of the future by addressing current shortages, retaining expertise, and investing in innovative workforce planning models so that everyone with cancer has the dedicated support of a team of professionals to help meet their needs and navigate around the system." (Organisation response)*

> *"Quality of care is reliant on the right healthcare professional with the right skills being available at the right time. […]" (Organisation response)*

Engagement, support and inequalities

The next most discussed theme encompassed engagement, support and inequalities. Many respondents discussed the need for patients to have access to information that can help them make informed decisions. Education of the public using health-promoting messaging was called for as well as encouragement of community engagement. Some respondents specifically spoke about the role of cancer networks citing functions such as ensuring consistent and holistic management of cancer services as well as measuring quality in terms of outcomes instead of time-related measures and holding services accountable.

> *"Making screening and education about cancer vaccines available to all. [...]" (Individual response)*

Responses touching upon support mainly focused on offering psychological support to patients, adequately resourcing services, and enhancing innovation. Respondents addressing the topic of inequalities mainly did so with reference to the quality of care currently being determined by geographic location as well as other reasons that can hinder patients' access to treatment such as older age.

> *"Concentrate on the most deprived say 20 % of people." (Individual response)*

Treatment, diagnosis and innovation

The last theme was about treatment, diagnosis and innovation. Respondents provided suggestions on different or alternative treatments and models for care. Furthermore, responses favoured early interventions for high-risk populations.

> *"Massage for supporting patients who have a diagnosis of cancer. Massage can help manage symptoms of pain, fatigue, nausea and brain fog" (Organisation response)*

Responses focussing on innovation mainly did so by addressing topics relevant to research and technology. For example, some respondents suggested that data be updated and published regularly, and that research findings are integrated to support high-quality care.

No further suggestions

A few responders agreed without adding significant suggestions.

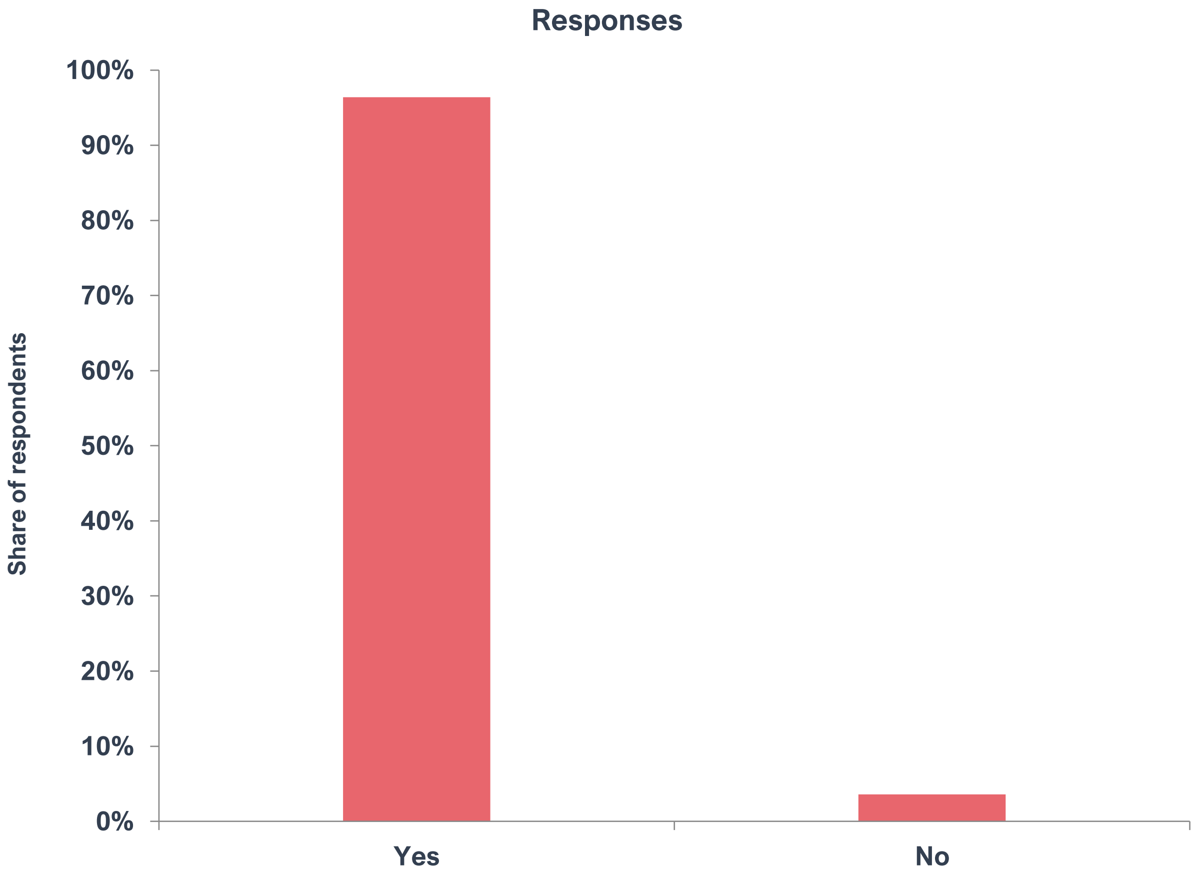
> *"Try and keep good strategies going" (Individual response)*

Question 11

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?

Figure 9. Share of Yes/No responses to Question 11



There was a high level of support for the proposed areas of focus among respondents: 96% of respondents agreed with the areas of focus, while 4% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were two open-format questions on the areas of focus for safe, effective treatments:

- 150 responses to the first question ("In your experience, what aims or actions would you like to see under any of these areas? Please focus your response on treatment."): 79 from individuals and 71 from organisations.
- 89 responses to the second question ("Please explain your answer and provide any additional suggestions."): 38 from individuals and 51 from organisations.

Specific treatments to prioritise

The most common theme identified within this set of responses was where respondents would specify a treatment out of the examples given to prioritise within the new cancer strategy. Systemic anti-cancer treatment was most commonly spoken about followed by acute oncology and realistic medicine, surgery (including calls for further developments in robotic surgeries) and radiotherapy. Out of the examples provided respondents discussed consent the least within their responses.

Respondents often commented on ways to improve these treatments such as expanding capacity and increasing accessibility and they suggested preparing resources to cope with an increased demand for treatments such as investing in infrastructure and training the workforce.

Patient-centred treatments

The next most frequently cited theme was the need for all treatments to be patient-centred. This included the need for treatment plans to be personalised and individual with patients involved in making decisions and able to provide informed consent.

> *"Person centred care is what it is all about. You are treated as an individual and not merely another patient with cancer." (Individual response)*

> *"I felt like I was not very involved in decisions about my treatment and no one had the time to talk in depth." (Individual response)*

To do so, respondents suggested that information about treatments and potential side effects should be accessible, and patients should be given options for different treatments. Respondents also wanted better mental health support for patients during treatment and post-treatment.

> *"I think looking at the treatment options are important to give patients the best possible care." (Individual response)*

Innovative treatments

Another common theme identified regarded the importance of continuous development of new and unconventional treatments. Respondents frequently spoke about the increased use of natural and combination therapies as being beneficial for cancer patients.

> *"There are emerging treatments that become available too late for a lot of people sadly – these should be discussed openly and whether they are available through any active research proposals/trials during early treatment discussions." (Individual response)*

Respondents also felt that any advancements in treatments would need to be supported by research evidence and suggested that an increased number of clinical trials would assist with this.

> *"Changes in cancer treatments are evidence based, driven by high quality clinical trials. It is essential that we invest in and promote research across the NHS. […]" (Organisation response)*

Accessibility of treatments

Lastly, the accessibility of treatments was the next most common theme. Respondents were concerned over issues surrounding accessibility of treatments and spoke about an unequal distribution of specialist cancer services that provide the most effective treatments leading cancer patients to travel extensively for the best care.

Respondents commonly suggested that an increased number of community-based treatment options would be beneficial.

> *"We would like to see an ambition to ensure that any patient, regardless of where they live, can access all treatments that are clinically beneficial for them. Although some treatments are focussed on a small number of centres of excellence, this should not make a difference in patients being able to access them, if they are prepared to travel to do so. In addition, we would hope this would drive expansion of the services so that they would become more widely available. […]" (Organisation response)*

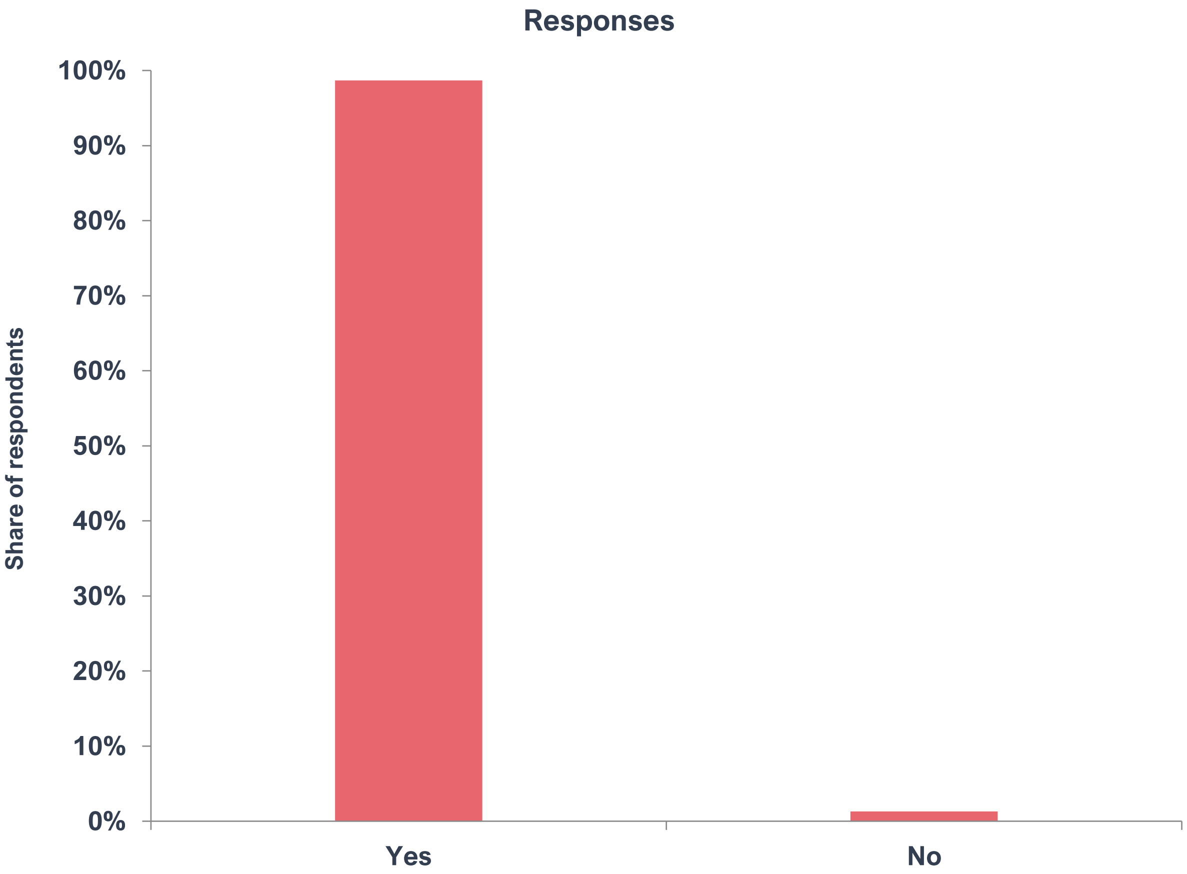
Question 12

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?

Figure 10. Share of Yes/No responses to Question 12



There was a high level of support for the proposed areas of focus among respondents: 99% of respondents agreed with the areas of focus, while 1% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were two open-format questions on the areas of focus for improving quality of life and wellbeing:

- 159 responses to the first question ("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."): 83 from individuals and 76 from organisations.
- 84 responses to the second question ("Please explain your answer and provide any additional suggestions."): 33 from individuals and 51 from organisations.

Management of care services

The most common theme across responses to this question was about the management and delivery of different care services. Respondents highlighted different pathways to achieve a better quality of life and wellbeing. Among others, they considered palliative care, the role of community pharmacies, conducting a Holistic Needs Assessment (HNA), and the interaction between health and social care.

> *"Palliative care - having had to call district nurses out to support with breakthrough care I found a huge variance in their knowledge of palliative care and the required medication which I do believe caused my parent unnecessary pain and distress as I was frequently talked in to them giving lower doses and being told they could come back out in 2 hrs even when this was in the middle of the night, knowing that this would have limited impact" (Individual response)*

Support

The second most discussed theme regarded support. Respondents highlighted different kinds of support, such as mental health and wellbeing support, advice being given to patients as well as to health and care workforce, financial support to patients and to the health and care system, and additional types of support, such as clinical support, or support to families.

> *"It is clear many clinicians are keen to deliver prehabilitation, however lack the resource for the necessary steps such as screening, assessment and personalised signposting to prehab activities in the patient's community. The work done on prehab has been excellent, but without resource, many staff regard this as nice to have but unattainable. Specifically for more specialised patients and complex pathways." (Individual response)*

Research and communication

The next most discussed theme encompassed research and communication. Responses addressing research-related topics included suggestions to listen to the experience of experts and patients, as well as facilitate access to evidence-based rehabilitation considering it helpful in managing side effects of treatment.

> *"More research on pain relief for end of life. There can be a lot of pain experienced by people with cancer and the side effects of pain relief medication for severe pain are not pleasant to say the least." (Individual response)*

Other points regarded data accessibility or collection (e.g. on quality of life). Some responses also stressed the importance of better communication between professional bodies to achieve service integration.

> *"Accessible and understandable information available (for those who have cancer and those who support them, including professionals)." (Organisation response)*

Prehabilitation and rehabilitation

The next most discussed theme included suggestions about prehabilitation and rehabilitation. Respondents stressed the importance of this aspect for the improving quality of life and wellbeing as well as quality of life outcomes. Specifically, they mentioned the necessity for promotion and assessment of prehabilitation activities. They also mentioned that access to rehabilitation and post-treatment support should be facilitated. Responses acknowledged that both prehabilitation and rehabilitation are under-resourced, while some further highlighted that these activities should be fairly delivered across the whole country.

> *"Prehabilitation to specifically meet the needs of older adults should be available. Rehabilitation is particularly important for the older adult as they are prone to functional decline at any point in the cancer journey. We must ensure they have timely access to services that deliver rehabilitation, in a setting suitable for them. This may be in the cancer hospital, at home, in day Hospital or other community settings for example vitality classes in the leisure sector. […]" (Organisation response)*

> *"We would like to see extensive integration of these measures with treatment so that each patient has their unique combination of treatment and support for wellbeing. We particularly welcome the inclusion of prehabilitation and of post-treatment support that helps a patient in coming to terms with, and make the most of, successful cancer treatment." (Organisation response)*

No further suggestions

Some respondents simply stated their agreement or disagreement without elaborating further.

> *"agree with the above" (Individual response)*

> *"Nope, they are all more of the administration that keeps us paying for a huge cancer industry. Not everyone gets these services anyway. People die. What people want is to not die. Not get support to help them while they die." (Individual response)*

Question 13

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:

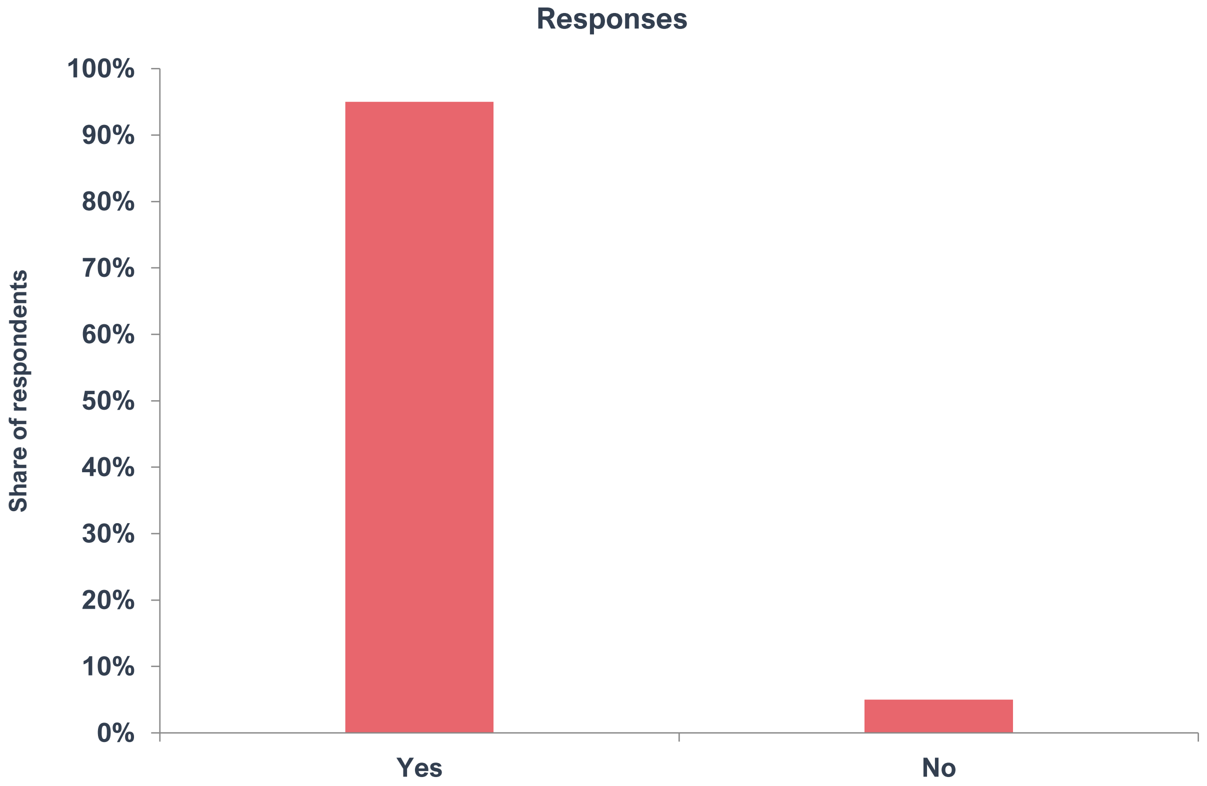
- **Outcomes e.g. recurrence, benchmarking**
- **Scottish Cancer Registry and Intelligence Service (SCRIS)**
- **Quality Performance Indicators (QPIs)**
- **Cancer Waiting Times (CWTs)**
- **Cancer Medicines Outcome Programme (CMOP)**
- **Patient Reported Outcome Measures (PROM)**
- **Multi-disciplinary 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?

Figure 11. Share of Yes/No responses to Question 13



There was a high level of support for the proposed areas of focus among respondents: 95% of respondents agreed with the areas of focus, while 5% did not agree. Respondents were also asked to provide any comments on their response, and the key themes raised in responses are covered below. There were three open-format questions on the areas of focus for data, technology and measurement:

- 161 responses to the first question ("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."): 82 from individuals and 79 from organisations.
- 119 responses to the second question ("Is there any technology you would like to see introduced to improve access to cancer care? Please consider access to screening, diagnostics, results, tracking of your pathway."): 55 from individuals and 64 from organisations.
- 76 responses to the third question ("Please explain your answer and provide any additional suggestions."): 36 from individuals and 40 from organisations.

Data collection and use

The main theme identified regarded the collection of data and how these should be utilised. Respondents stressed the importance of data collection, and many referred to PROMs, QPIs, PREMs and the CMOP as key measures of patient experience and cancer outcomes. Respondents felt that there needed be standardisation of data collection with training for staff to ensure quality. Some responses also suggested that focus needs to be placed on cancers for which there are currently have less data available.

> *"Good data is vital in measuring and assessing quality of care. The regular collection and use of PROMs (Patient Reported Outcome Measures) data in Scotland would be an important step forward in monitoring and improving the quality of cancer care. […]" (Organisation response)*

Respondents also stated that data should be readily accessible and shared with patients so that they can be involved in informed decision-making throughout their cancer journey.

> *"We support access by health professionals to all data that help them manage the diagnosis, treatment and care of patients. We would like all patients to be able to access data to help them understand their condition, if they wish to do so and to help them make informed decisions about future treatments and other options together with health professionals. […]" (Organisation response)*

Patient experience

Another common theme within the responses related to patient experience. Many respondents felt that improved digital provisions and services for patients would be beneficial. A frequent suggestion was for an online hub where treatment plans could be viewed, patients could communicate with clinicians and have their test results posted to reduce waiting times. Respondents acknowledged the need to offer digital skills support to the workforce if implementing this suggestion.

> *"In my experience offering digital support was very beneficial in building knowledge and confidence using devices." (Individual response)*

Respondents also stressed the importance of having non-digital services available as there were concerns that patients already digitally excluded would be left behind, with the examples of older people and those living in remote areas cited frequently. They also felt that face-to-face interactions might be more appropriate for certain aspects of the cancer journey.

> *"At the point where people need cancer services they also need face to face compassion, not technology." (Individual response)*

Cancer detection technologies

The next most frequent theme was the need for improvements in cancer detection technologies. Respondents commonly spoke about screening as needing to be more accurate, timelier, and more accessible, particularly to less engaged groups.

> *"[…] Screening uptake measured by protected characteristics groups would be helpful to direct programmes of work. Average percentages reported back per practice do not allow us to target the population groups who do not take up screening invites (and ensuring health literacy plays a part so that people are making an informed choice if they want to take part or not)." (Organisation response)*

Respondents also frequently felt that diagnostic radiology and genetic/genomic testing were valuable tools in the detection of cancer, and they therefore suggested that more funding be directed towards these technologies in order to develop them further.

> *“A national push on blood screening to detect and diagnose cancers at an earlier stage and incorporate genomic sequencing.” (Individual response)*

Coordination of computer systems

Another theme identified was the need for improved coordination and integration between computer systems. Respondents frequently called for a singular, interoperable system to streamline communication between services and from services to patients.

Respondents suggested that better coordination of systems would mean cancer patients would not have to chase up information and results from multiple services themselves and would allow for pooling of data for rarer or lesser-known cancers.

> *“Far better joined up systems within the NHS and also with private care providers and possibly the third sector with consent. The systems within the NHS do not ‘talk’ to one another and clinical teams are required to send an email/ letter to GPs in order to keep the informed. The onus is on patients to advocate for themselves and ensure lines of communication are clear. That is truly exhausting!” (Individual response)*

Clinical trials and future research

Lastly, the theme of clinical trials and future research was identified. Respondents expressed support for increasing the number and accessibility of clinical trials. They felt that more opportunities should be available for cancer patients to be involved in clinical trials and that this would require increased promotion of them. It was also commonly expressed that more diversity amongst participants would be welcomed.

> *“I think that research and innovation is crucial. Most of the people I know with positive cancer experiences were involved in clinical research.” (Individual response)*
>
> *“We would like to see more support for cancer research, and people with cancer of all ages and backgrounds are given the opportunity to participate in clinical trials. […]” (Organisation response)*

Respondents suggested that any research should be compared to other countries and stated that real-world evidence would also need to be collected. Many respondents also called for the focus of future research to be on less survivable cancers.

> *“Should be connected with European studies and take a wider approach for comparability of data and testing.” (Individual response)*

Question 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 were 164 responses to this question (89 were from individuals and 75 from organisations).

Specific indicators and methods

The most common theme included suggestions on specific indicators and methods for data collection and modelling. Most respondents within this theme felt that QoL, PROMs, and PREMs were the most useful measures of what is meaningful to patients. QPIs were frequently discussed as being useful but require more routine collection to reveal trends in inequalities. It was said that QPIs alone do not collect the qualitative data needed to inform patient-centred care. In addition, the CMOP was referred to as being beneficial in informing practice and identifying subsequent impacts.

> *"We believe that measures such as the Quality Performance Indicators (QPIs) for kidney cancer are extremely valuable. We would like to see more frequent interim progress reports made available at Cancer Regional level regarding the QPIs and combined with action plans to deliver them." (Organisation response)*

> *"Increasing attention to patient's quality of life and satisfaction with services" (Organisation response)*

Patient-specific outcomes and communication

Many respondents suggested that outcomes were based on the experience of patients. According to responses under this theme, the outcomes need to be tailored to each patient's needs and their particular diagnosis. Some respondents also mentioned the use of HNAs or family history.

> *"Talk to patients, follow up. Don't just discharge them." (Individual response)*

> *"As previously stated I believe that a support nurse for each patient will help the patient. It's important for patients to have someone they can rely on to help out rather than a patient having to try and solve a problem." (Individual response)*

While patients' feedback was seen as important by respondents, there was some criticism regarding the current engagement approach. A few responses suggested that surveys may be too cumbersome to be filled by individuals. They proposed that a more joined-up data collection and sharing approach between cancer services would mean patients are not asked the same question more than once. Respondents also suggested that reaching out to carers and families where patients were not able to fill out surveys themselves would reduce the burden on patients.

Time-specific measurements

A large number of responses discussed outcomes as related to time. The waiting times between different procedures (e.g. between diagnosis and treatment or between first referral and diagnosis) were highly stressed. Equally stressed was the importance of an early diagnosis.

> *"Should measure the time to diagnosis, amount of visits and days from first complaint of symptoms to diagnosis, amount of time it takes to see GP to get taken seriously" (Individual response)*

Furthermore, under this theme, respondents suggested periodic checks and frequent updates on indicators.

> *"Patient info - years lived since primary diagnosis. Years before death of secondary diagnosis." (Individual* response)

Aggregate statistics on treatment efficiency

In the next most common theme responses recommended the use of aggregate statistics as indicators of the efficiency of cancer treatments. These included reporting death rates, indicators on survival, incidents and treatment rates. Furthermore, respondents identified recurrence and spread rates also as useful indicators.

> *"Every patient is included and the quality of all cancers are measured (time, survival and experience). Recurrence and spread is also measured. Ideally carers are included too." (Individual response)*

> *"Measure: less people dying from cancer" (Individual response)*

Some respondents further suggested to focus on areas with high health inequalities, while others suggested to compare statistics with international evidence.

Management of relevant bodies and the workforce

Equally prevalent were responses focusing on the management of public bodies and the workforce. Among others, respondents raised the importance of hospital monitoring, training and support of health and care workforce, changes in policies, investment and financial support for specific departments, registration of patients, strategies to achieve cost-efficiency, and investment in research. Furthermore, a few responses underlined the need for accountability of these bodies.

> *"When the hospitals have you in to formally apologise for things having gone wrong and promise to make changes it would be good for a formal body to keep an eye on such changes to ensure they actually happen as all too often there are lots of 'we got it wrong this time and changes have been made' but nothing actually changes. They should be followed up." (Individual response)*

Question 15

Question 15A

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.

There were 206 responses to this question (124 were from individuals and 82 from organisations).

Screening and diagnostic capabilities

The most common theme within the responses related to screening and diagnostic capabilities. Respondents called for expansion of screening services to improve access to timely diagnoses. They felt that screening should be offered to younger age groups as well as encouraged in more at-risk and older populations. Many also suggested that more regular general health check-ups for the whole population that involve testing for cancer would benefit the Earlier Diagnosis Vision.

> *“5-yearly healthy life check-ups offered through Primary Care with a blood test to check for any illness (to detect cancer as soon as possible). This will be supplemented with screening programmes as appropriate. Investigations for all suspicious symptoms (to rule out or diagnose cancer).” (Organisation response)*

> *“Screening starting earlier, potential issues like calcification in breasts monitored more closely. People with headaches or consistent aches screened more often. Make it easier to get screened or medically checked.” (Individual response)*

Respondents also stated that funding should be directed towards innovative diagnostic technologies, commonly citing genetic and genomic testing as areas of interest. They felt that more consideration of methods for timely detection of asymptomatic cancers was needed within the Earlier Diagnosis Vision.

Awareness and education

The theme of awareness and education was the next most frequently cited amongst respondents. They felt that campaigns educating the public about symptoms would lead to greater public awareness and encourage self-referral. Respondents called for education to start at a young age and suggested that a school-setting may be most suitable for this.

> *“Continued education of population for signs and symptoms of cancer to encourage self referral.” (Individual response)*

A common example given of types of symptoms that should be targeted within campaigns was for non-specific symptoms, such as unexplained weight loss, as respondents felt these symptoms often lead to late presentation of patients to cancer services. Respondents also felt that GPs and other staff required further training on identifying indistinct symptoms so that cancer patients are not dismissed or misdiagnosed.

> *"Raise GP awareness. Got to get the referral first. More awareness of cancer symptoms but also the symptoms are not always obvious." (Individual response)*

> *"[…] It is really essential that more education of both GPS and public are better equipped on the awareness of signs. Four of the GPS at my practice missed the signs of my initial breast cancer." (Individual response)*

Accessibility of services and support

Lastly, another frequently discussed theme within the responses for this question was the accessibility of cancer services and support. Respondents felt that for earlier diagnosis to take place, access to diagnostic services needed to be timelier and more equitable. It was often suggested that provisions within local communities, such as community pharmacies, would help with accessibility problems.

> *"More local screening instead of travelling in to Edinburgh." (Individual response)*

Respondents also felt that the Earlier Diagnosis Vision should consider continued support, including psychological, financial and post-diagnosis, considering that any increase in number of diagnoses would lead to a greater number of cancer patients requiring subsequent services and support.

Question 15B

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.

There were 171 responses to this question (103 were from individuals and 68 from organisations). In general, most respondents agreed that a numerical target should be set. Respondents typically expressed general support while providing additional qualifications to their support or details around what a numerical target would look like. Fewer than 5% respondents provided a specific quantitative target, and a slightly larger proportion of respondents explicitly responded "No".

Measurability of targets

The most common theme identified regarded the measurability of targets set for early diagnosis. Respondents felt that any targets set by the Scottish Government would need to relate to decreased mortality rates as well as decreases in late-stage diagnoses as indicators of how successful the Earlier Diagnosis Vision has been.

> *“Increase in earlier diagnosis may not impact on mortality. It would be more appropriate to set mortality reduction targets.” (Organisation response)*

> *“Difficult to set an absolute target - more important to reduce the number of late-stage diagnoses.” (Organisation response)*

Many respondents also highlighted the fact that various types of cancer (examples given including brain and blood cancers) either cannot be staged or are not subject to the same staging as other types. So, they felt that identifying alternative ways of measuring earlier diagnosis progress for these cancers would be important in order for these cancers not to be left behind.

> *“[…] However, many cancers that are common in young people, such as blood cancers, are not currently staged, and so they will not contribute to this commitment. To resolve this, the 10-year cancer strategy should consider proxy measures for cancers that can’t be staged. […]” (Organisation response)*

Targets specific to cancer types

The second most common theme identified within the set of responses was the need for targets to be specific to different types of cancer as respondents felt it would be unrealistic to set the same target for all cancers.

> *“Is it realistic to have the same target for different cancers, some of which may be difficult to diagnose at an early stage? It would make more sense to have a target for each type of cancer. In addition the target should be based on improvement to the current rates of early diagnosis. Ideally the target would be based on what is realistic, plus a little more to give direction to research and improvements in service delivery.” (Individual response)*

Respondents suggested that a generic target would not be comparable across cancer types due to differences in staging, with blood cancer frequently provided as an example. Less survivable cancers were also proposed as types of cancer that should be associated with a specific target as it was suggested this would have the most meaningful impact.

> *“Numerical targets for cancer often overlook blood cancer. Some blood cancers cannot be staged, and so cannot easily be factored into national general targets. Where numerical targets exist, they must acknowledge the differences in data for cancer, and data specific to blood cancer.” (Organisation response)*

Numerical targets are unhelpful

The next most common theme identified was that numerical targets can be unhelpful. Respondents frequently felt that arbitrarily set numerical targets would not benefit the Earlier Diagnosis Vision, with many suggesting that numerical targets can divert attention away from the broader picture and instead expressing the idea that general ‘improvement’ was enough to work towards.

> *"Precise numerical targets are a distraction. Continuous improvement and learning are the key aspects." (Individual response)*

Many respondents were concerned that a numerical target would not prove useful in real-life as well as being difficult to set in the first place, whilst others expressed concern over how service providers would be viewed if they failed to meet strict, numerical targets.

> *"We felt it would be difficult to set a target, justify that target, and then potentially be judged as failure if that aspirational target not achieved. However, there should be targets which may not be numerical." (Organisation response)*

Ambition vs realism when setting targets

Lastly, the need for targets to be ambitious was another theme identified within responses. Of those that agreed with a numerical target being set, the majority expressed that the value of 75% (given in the question example) was too low and needed to be more ambitious. The term 'stretching' was cited often with some respondents suggesting that any percentage below 100% leaves a certain percentage of cancers not diagnosed at an early stage.

> *"I would have the target higher. That's 25% that will have their cancer missed. Strive for a higher number." (Organisation response)*

Within the theme of ambition many respondents also proposed that incremental targets would be beneficial to strive for continuous improvement as the strategy progresses.

> *"Most certainly. It should also be increased at certain stages within the 10 years as through doing something and learning the percentage should get higher." (Individual response)*

Many respondents expressed concerns over keeping targets realistic with feasibility appearing as a sub-theme. Respondents indicated that they want the right balance to be found between ambition and realism when targets are set.

> *"Numerical targets can be very powerful, but they have to be realistic." (Individual response)*

Question 15C

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.

There were 187 responses to this question (115 were from individuals and 72 from organisations). In general, most respondents agreed that the earlier cancer diagnosis vision should focus on specific cancer types. Around 20% of respondents explicitly said "No" in their responses, while the remaining respondents mentioned specific types of cancer or described the criteria they would use (with varying levels of detail) in deciding which cancer types the vision should focus on.

Focusing on specific types of cancer

The most highlighted theme in responses was the view that the Earlier Cancer Diagnosis Vision should focus on specific types of cancer. While some respondents did not specify which types, most of them mentioned different types of cancer that can be summarised into three sub-themes. The first one encompassed less survivable types of cancer[8] as well as dangerous, fast-spreading cancers and cancers with vague symptoms.

> *"Should be: Lung, bowel, stomach (gastric), oesophagus, brain, Pancreatic as if these not diagnosed early then very poor outcome" (Individual response)*

> *"It should be widened to include screening for other cancers where individuals have increased risk factors" (Individual response)*

The second sub-theme included types that are not in the scope of the Less Survivable Cancer Taskforce, such as cancer of blood, breast, skin, head, thyroid, and bladder. For example, a respondent suggested that blood cancer diagnosis is not as developed as the rest.

> *"This vision must focus on blood cancer. As referenced above, blood cancer diagnoses are already significantly lagging behind other cancers. This must be brought up to the national standard and improved upon further. […]" (Organisation response)*

The third sub-theme focused on cancers related to a patient's sex such as uterus, ovary, cervical, and prostate cancer.

> *"What about ovarian cancer or prostate cancer - all easily treatable with early detection. These might make up 45% of cancer but there is another 55% of other cancers being ignored?" (Individual response)*

Not placing focus on specific types

A large number of respondents believed that the Earlier Cancer Diagnosis Vision should not be targeted at specific types. In many cases, respondents appeared to be concerned that focusing on specific cancers would lead to omitting other types (e.g. less common types, such as womb cancer or those that have late-stage diagnoses). For instance, responses raised that focusing on a specific group of patients would be harmful for the rest; instead all types of cancer should be seen important.

> *"No include all so health boards have to treat them all not just focus on the ones with targets and leave the others on the waiting list" (Individual response)*

Time considerations

Some respondents raised the importance of time, mainly in two ways: a) the timing of the diagnosis, especially in terms of the early or late stage of the disease when this takes place,

---

[8] According to the Less Survivable Cancers Taskforce, these types of cancer include cancer in: lungs, stomach, pancreas, liver, oesophagus and the brain.

and b) the age cohort of patients. Early diagnosis was stressed a lot by respondents and was seen as the result of an efficient prevention strategy. On the other hand, cancers usually identified at a later stage were considered to be more dangerous, and hence respondents suggested that they should be at the centre of attention.

> *"The very poor prognosis tumours will see life changing/enhancing/lengthening improvements for a large number of patients if an effective early detection strategy can be found. Even if the numbers are small the outlook is so bleak that this could still be an effective strategy." (Individual response)*

> *"No. I think we should aim to find ways to diagnose all cancers as early as possible, especially those which are often diagnosed very late and which therefore have very poor outcomes." (Individual response)*

A smaller number of respondents raised the importance of the patient's age and the role this can play in the timing of the diagnosis.

> *"Older adults in general should be included in this group are they are more likely to present late and in an emergency setting." (Organisation response)*

Frequency of cancer types

Finally, another prevalent theme underlined the need to focus on cancer types based on how often they are recorded. Interestingly, many respondents suggested that the Earlier Diagnosis Vision should be targeted at the most common types of cancer, without however completely omitting those types that are less common. On the contrary, some respondents mentioned that more emphasis should be placed on rare cancer types.

> *"Common cancers will have the most impact but should not be solely focussed on to the detriment of less common cancers including those which may present with vague symptoms" (Organisation response)*
>
> *"Less well known cancers should be prioritised as some of these have outcomes that have not changed in the last 10 years." (Individual response)*

Question 15D

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.

There were 151 responses to this question (112 were from individuals and 39 from organisations).

Coordination and communication

One of the two themes most commonly discussed by respondents was communication and coordination. Most respondents with lived experience felt that communication from staff to patients and coordination between cancer services had been poor.

> *"[…] It often felt chaotic, instructions were unclear and I spent considerable effort trying to connect dots between oncology, surgery and my GP on different aspects of my treatment. This really knocked my confidence." (Individual response)*

Respondents frequently cited reasons for this being not knowing who to contact, having to chase up information themselves, not having third party support organisations signposted, and having life-changing information conveyed by phone or email. Respondents also felt that coordination between services was poor leading to confusion and delays throughout their cancer journey.

Supporting patients

The other main theme identified regarded the support provided to patients. A little over half of respondents felt that the support they received had been of a low standard. They cited a lack of availability and accessibility, a lack of psychological support, and a lack of follow-ups and aftercare which led to feelings of 'abandonment' post-treatment.

> *"From operation to treatments were good. There should be more information on after care as you go from being treated daily to nothing once you are discharged and is very daunting." (Individual response)*

> *"[…] Regular follow-up was reassuring and appreciated. End of treatment was scary and psychological support at this time would have been welcomed. […]" (Individual response)*

Those that felt support had been good shared good practice examples such as having regular follow-ups which provided reassurance, feeling generally 'looked after' and having access to good quality palliative care.

Timings

The next most common theme related to timings throughout the cancer journey. Just over half of respondents felt that there had been delays in aspects of their cancer pathway frequently commenting that long wait times between testing and results led to worry and anxiety.

> *"Long waiting times for colonoscopy/investigations after GP referral for classic bowel cancer symptoms. Once diagnosed service worked well, clinic and surgeon worked well together and family were involved at all stages. Needs to be speedier investigations for people who have symptoms." (Organisation response)*

Other respondents expressed satisfaction with the speed and efficiency of the process. They commonly referred to the process post-diagnosis as being particularly efficient.

> *"Worked well as my mother was able to get a quick appointment with her GP who then was supported by the system to expedite her case to the central cancer care unit at the [hospital name deleted to retain anonymity]. The speed of diagnosis and then treatment plan meant the mental anguish was reduced." (Individual response)*

Experiences with staff

Another theme identified regarded the staff that patients encountered on their cancer journey. The majority of respondents cited their experience with staff as being positive, with many expressing gratitude for the level of care and compassion they received throughout their cancer journey.

> *"I am currently undergoing treatment for cancer and I would say that the most positive experiences have been from the care, support and attention from nursing staff across departments. This is mainly from ward based nurses, treatment nurses and auxiliary nurses. […]" (Individual response)*

However, some respondents expressed that their experiences with staff were negative, that their access to specialists was limited or that they felt staff appeared to be 'overstretched'.

> *"[…] The consultant who marked me up for the 5th week of radiotherapy left me in tears - no eye contact / told me not to get the mark up wet. I explained I worked full time and would need to shower. Afterwards a nurse took me aside to offer to help and gave me protective tape. […]" (Individual response)*

Diagnosis

Finally, diagnosis was identified as a theme within the responses. A large majority of respondents expressed dissatisfaction with their diagnosis experience and this commonly related to the accuracy and timeliness of diagnosis, and the knock-on effects for their treatment options.

> *"The level of care provided was excellent, however, the diagnosis was made too late which resulted in a rush through toxic treatments the clinical team knew would be unlikely to work. […]" (Individual response)*

Respondents often referred to experiences of being misdiagnosed as a result of their GP not being sufficiently aware of cancer symptoms and being dismissed or diagnosed late because their GP failed to take them seriously.

> *"My cancer diagnosis came from myself knowing my own body, and being aware of problems, almost unknown by GP." (Individual response)*

Question 15E

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.

There were 127 responses to this question (91 were from individuals and 36 from organisations).

Where care should be based

The main theme identified within the responses was the specific location that respondents felt would be the best base for accessing cancer care. Most respondents felt that local, community-based care would be most beneficial for cancer patients.

> *"It would be great to be able to get some access to cancer services at local medical centres." (Individual response)*

Following on from community-based care, respondents most frequently suggested that hospital-based care and GP-based care respectively would be the best options.

> *"For my cancer, the hospital is definitely where I wanted and needed to be during surgery and chemotherapy and radiotherapy. My surgeon was excellent, as were the oncologists and the radiologists. I had confidence in them." (Individual response)*

> *"Personally from a GP that cares and knows me." (Individual response)*

Accessibility of cancer care

The second most common theme identified regarded issues surrounding accessibility. Timely access to cancer care was most commonly cited as a problem that needs addressing, with respondents expressing frustration over delays in the process.

> *"Primary access should be through the GP, and this means that rapid access to GP consultation should be available. The cancer screening programmes should also be able to provide rapid access to diagnostics when a screening test is positive." (Organisation response)*

Distance was the next most frequently mentioned limiting factor associated with accessing cancer care. Many respondents also felt that the difficulties they faced with securing doctors and/or hospital appointments meant that accessing cancer care was not a straightforward process.

> *"Access to the full range of cancer services in the local health board area not hundreds of miles away." (Individual response)*

> *"Access to speak to a real, trained person to discuss concerns and determine whether they need to be followed up and if so, with what urgency. Difficulties in making GP*

> *appointments can be off-putting in making an appointment if there is less certainty around severity. […]" (Individual response)*

Expertise and dedicated care

Lastly, the need for expertise and dedicated care was another theme identified. Respondents suggested that staff should be specialised, highly trained, and knowledgeable so as to provide the best quality of cancer care possible.

> *"I would prefer to access care at a dedicated clinic, this way the staff are trained to a high degree on the specific subject and needs of the patients and more resources, such as counsellors, could be available if the patient is extremely worried or is diagnosed with cancer. GPs are obviously the best first point of contact, but as they are trained to recognise many illnesses but in less detail it is more likely they will miss something important." (Individual response)*

Many respondents also suggested that all aspects of cancer care should be accessed within one, dedicated cancer clinic.

> *"Ideally, a One-Stop Cancer Centre where a speedy diagnosis and treatment can be carried out without referral to a GP." (Individual response)*

> *"A separate unit for diagnostic testing, support, diagnosis and clinical care. Everything cancer care under one roof." (Individual response)*

Question 15F

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.

There were 168 responses to this question (114 were from individuals and 54 from organisations).

Prevention, early diagnosis and efficiency

The most common theme discussed by the respondents was about prevention, timely diagnosis and treatment efficiency. Respondents highlighted the need for detecting cancer at early stages. Early diagnosis was seen as the result of a better prevention strategy and was further linked to better treatment efficiency within responses.

> *"More people being diagnosed when they can be cured" (Individual response)*

> *"A good outcome for me would be to see as a clinician far fewer patients with stage III or IV breast cancer. Not hearing from friends that they were dismissed by GPs and not investigated for non-specific symptoms" (Individual response)*

Quality of life

A large number of respondents discussed the benefits of an earlier diagnosis with reference to the impact this can have on people's quality of life. In particular, respondents associated earlier diagnosis with longer life expectancy, higher survival rates and a better quality of life.

> *"Cancer being a treatable condition, treatments to be curative for all early cancers. When cancer is terminal, better management of side effects to allow best quality of life" (Individual response)*

> *"Fear-free early diagnosis, treatment that takes account of the circumstances of the individual, not just the beliefs of the professionals, and which allows for a sensible compromise between life expectancy and quality of life. QoL must be measured in terms relevant to the individual patient, not by arbitrary standards…" (Individual response)*

Management of health care sector

The next most discussed theme was about the management of health care sector. Among others, respondents discussed issues regarding the accessibility of services, reduction of waiting times and greater access of patients to GPs.

> *"Shorter waiting lists/time." (Individual response)*

> *"The majority of cancers detected before patients even experience symptoms. A proactive NHS in Scotland that provides regular blood screening to detect cancers at the earliest possible stage when curative options or managing the cancer similar to a long-term condition is possible." (Individual response)*

Advanced techniques, and better information and communication

Another theme coming through people's responses encompassed innovative methods to detect and cure cancer alongside a discussion about efficient information and communication between experts and patients.

Responses focused on advanced techniques included suggestions that early diagnosis would lead to a set of new, more efficient, or less harmful methods.

> *"Earlier diagnosis means the greater possibility of a cure or less invasive treatment" (Individual response)*

> *"Improved survival, less treatment related impact on quality of life, state of the art treatment based on evidence, the latest technology and a highly skilled workforce." (Organisation response)*

Responses addressing communication and information included suggestions on better educating experts as well as patients. Responses mentioned that cancer-related topics should be discussed in public settings, such as schools or in the media. Furthermore, respondents raised that, as a result of an efficient diagnosis, patients should be also well-informed.

> *"An honest but compassionate conversation, discussing risks, options, supports and what's important to me. Taking some of the fear away, living positively where a diagnosis is made. Where a patient has every opportunity to live a full life without cancer or with cancer." (Individual response)*

Socio-economic cohorts

The final and the least common theme addressed the benefits of good earlier cancer diagnosis on specific socio-economic cohorts of people, such as young people and vulnerable groups. Respondents acknowledged that an earlier diagnosis could lead to a care plan that can be adapted to each patient's individual needs.

> *"Young people should also feel more empowered to visit primary care and other health professionals when they experience symptoms. In turn, healthcare professionals, young people as well as the public should be better equipped to recognise the first signs of cancer in young people to increase the speed of diagnosis." (Organisation response)*

Question 16

Question 16A

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.

There were 150 responses to this question (87 were from individuals and 63 from organisations).

Age

The most frequently occurring theme within the responses was where respondents would discuss inequalities surrounding age. Many respondents suggested that younger people are disadvantaged throughout the cancer pathway as they are often less aware of symptoms, less engaged with cancer services and experience late-stage diagnoses more frequently.

> *"Younger people often seem to be diagnosed later due to "being too young for cancer"." (Individual response)*

Respondents also felt that older people are disadvantaged by the current cancer system as they are more likely to be at risk for some cancers but are often denied access to some treatments based on their age. There was a general feeling that older cancer patients are less of a priority when it comes to cancer care.

> *"Outcomes for older adults are improving at slower rates, they are less likely to access evidenced based care and are less likely to have access to other services such as specialist nurses. We can ensure that the cancer workforce are educated in looking after older adults. Older adults must be appropriately represented in clinical trials. […]" (Organisation response)*

Ethnicity, culture and religion

The next most common theme regarded ethnicity, culture and religion. Respondents felt that people from ethnic minority backgrounds were less likely to be diagnosed as they believed there to be reluctancy to engage with cancer services and seek screening. Respondents also suggested that individuals from ethnic minority backgrounds may have developed a mistrust of practitioners based on previous negative experiences.

> *"Some marginalised groups such as ethnic minority groups can have a mistrust in medical professionals this can be evidenced in vaccine hesitancy with the Covid vaccination programme, consideration should be given that some of our services are inaccessible for many groups of society. […]" (Organisation response)*

Respondents also felt that certain cultures and religions view cancer as a ‘taboo’ subject which discourages engagement and they called for ‘community champions’ within these groups to help with this issue.

> *“For some religious/belief groups admitting to finding something or going to a doctor’s & discussing very private matters may be very difficult, especially with the opposite sex.” (Individual response)*

Sex and gender identity

Another common theme within the responses related to sex and gender identity. Respondents often cited that women are treated unequally within the cancer system by being misdiagnosed due to not being taken seriously about symptoms.

> *“Woman’s health is still incredibly poorly covered. Symptoms are often dismissed by GPs. Specialist woman’s health services must be developed in local communities.” (Individual response)*

Respondents also commonly suggested that transgender cancer patients can be disadvantaged due to a lack of resources and advice about screening and other diagnostic challenges. They also felt those who have had gender reassignment may be reluctant to engage with cancer services.

> *“Mandatory training to NHS staff around how to be inclusive to transgender population. We had a talk from our professional body that made it change wording on our documentation amongst other things.” (Individual response)*

Communication barriers

Lastly, respondents often commented on the communication barriers that can face some cancer patients. They felt that for patients whose first language is not English, the system can be difficult to navigate, and information is often inaccessible. Respondents suggested that this causes problems with informed consent and leads to a lack of understanding of consequences of treatments.

> *“Timely accessibility of information for people who do not speak/read English as a first language. An accessible catalogue of available resources would be useful, or an IT software system.” (Organisation response)*

Respondents called for a greater number of readily accessible translators and interpreters for those with more apparent communication needs.

> *“Language barriers are difficult. Translators are available in some circumstances but financial pressures mean we are encouraged to use telephone services which lose the human element and no-verbal communication. It is hard to get written information in other languages with only broad topics available. […]” (Individual response*

Question 16B

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.

There were 167 responses to this question (103 were from individuals and 64 from organisations).

Accessibility

The most common theme identified within the responses regarded accessibility issues experienced by those from a lower income socio-economic background. Respondents frequently expressed concerns over the financial, physical and emotional burden of travelling to and from appointments. It was commonly suggested that cancer services should provide patients with transport or reimbursement for the associated costs.

> *"Supporting access for those from lower income households is ensuring services are provided at a local level and not creating a postcode lottery for care. […]" (Organisation response)*

> *"Free public travel for those undergoing treatment and their main support person/carer." (Individual response)*

Respondents also commented on the accessibility of getting appointments, particularly with a GP, stating that the current system of having to call early in the morning did not support those cancer patients that need to work or have other responsibilities.

Education and awareness

The next most frequently spoken about theme related to the need for improved education and awareness amongst those from a low socio-economic background. Respondents suggested that better education and health literacy leads to patient confidence in self-advocating, navigating the cancer system and researching into treatment options themselves.

> *"Health literacy and self-advocacy is lower in patients from more socio-economically deprived areas. Supporting patients with "how to navigate the system" during and after a diagnosis would help address this." (Individual response)*

Respondents frequently suggested that awareness campaigns in local communities should be implemented to improve engagement in the most deprived areas.

> *"Targeted public health campaigns that consider existing health inequalities would be beneficial to improving outcomes for leukaemia and blood cancer patients in Scotland. Tailored awareness campaigns that include communities not fluent in English, not digitally literate and people from deprived areas would make services accessible to all groups." (Organisation response)*

Financial barriers and impacts

Another common theme was the financial barriers to accessing cancer services and the financial impacts of doing so. Respondents stated that patients having to take time off or being unable to work can lead to detrimental loss of income, especially for those from low socio-economic backgrounds.

> *"People from lower incomes households will be affected more by a cancer diagnosis, time off work, less money, difficulty in transport. Lower income households would need more financial support or general assistance." (Individual response)*

It was frequently suggested that more readily accessible financial support should be available to cancer patients from low socio-economic backgrounds. Some respondents expressed concerns over the lack of financial support that is available to those patients that fall outside of the threshold when means-tested.

Question 16C

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.

There were 153 responses to this question (94 were from individuals and 59 from organisations).

Local and accessible cancer services

The most common theme identified within this set of responses related to the need for equitable access to cancer services for patients living rurally or offshore. A prominent suggestion was for more specialist services to be accessible locally for rural and island communities with many proposing that a 'hub and spoke model' would help to achieve this.

> *"Far better outreach and specialist services for rural/island communities. The attitude seems to be they choose to live where they do and if they want support they need to travel. Even a small expert team dedicated to diagnosis and referrals in these communities would support local GPs and the smaller less equipped hospitals." (Individual response)*

Respondents also called for better access to screening and diagnosis centres and frequently suggested that mobile screening units could be beneficial. They also stated that access to local, effective treatments should be improved in rural and island areas, and that availability and location of GP centres needed more consideration.

> *"Mobile screening clinics in areas accessible to people during the course of their day-to-day activities." (Individual response)*

Travel and associated costs

The next most frequently discussed theme was the distances cancer patients have to travel from rural and island areas to access care. Respondents expressed concerns over the physical and emotional impacts that travelling long distances could have on already unwell cancer patients.

> *"Care closer to home: transport and time taken to travel is a financial, emotional and physical burden for people in rural communities and has been consistently reported through patient feedback over time. […]" (Organisation response)*

Respondents also suggested that public transport links should be improved, costs for travel reimbursed, nearby accommodation provided and financial support made available for patients living long distances away from cancer centres. It was suggested that these means of support should apply to a patient's family and carers too to reduce feelings of isolation when travelling away from home.

> *"Support for travel and accommodation if required to attend a big centre for some treatment. It is not possible to bring all treatments out to every centre or community setting so the patient's journey has to be facilitated as much as possible." (Individual response)*

The use of digital provisions

Lastly, the use of digital provisions was commonly discussed by respondents. They stated that the use of telecommunication and implementation of interoperable IT systems would be beneficial for cancer patients living in rural or island communities. Respondents felt this would reduce the need for travel and cited Near Me as a positive example.

> *"There should be continued efforts to mainstream Near Me and associated technology, with virtual consulting as a routine option." (Organisation response)*

However, respondents also expressed concerns over those patients living rurally or offshore who would not have adequate access to devices or broadband to engage with digital solutions. Therefore, they suggested that support would need to be offered to them as well as maintaining a form of face-to-face contact for this group of people.

> *"Yes. Having to travel to Inverness from the Islands is extremely challenging. Even in rural parts, internet connection can be bad so even communicating by email is difficult. Please keep landline and paper communications. And, in an ideal world, a travelling oncologist and Surgeon to do follow ups." (Individual response)*

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.

There were 143 responses to this question (77 were from individuals and 66 from organisations).

Pre-diagnosis cancer care

The main theme identified related to aspects of cancer care pre-diagnosis. Many respondents felt that public awareness of symptoms of cancer and preventative measures was lacking. Respondents gave examples such as encouraging a healthier lifestyle, promoting how to self-check correctly, and improving cancer-related education within schools as ways of improving this.

> *"As a current cancer survivor and hospice nurse, I believe we need to do more to educate people about the importance of screening, self checking and signs and symptoms of cancers and secondary cancers. […]" (Individual response)*

The importance of timely and accurate screening programmes for earlier diagnosis was also cited by many respondents.

> *"[…] Earlier and more accurate detection of cancer is a crucial step in improving survival rates and could be further achieved with the adoption of the latest technologies. In some cases, improvements in screening and surgical processes, as highlighted, could unlock resources, drive workflow efficiencies, and reduce costs. […]" (Organisation response)*

Issues and needs of the workforce

Another theme found within the responses regarded issues surrounding the workforce. This included the need to improve recruitment and retention of highly qualified and compassionate staff.

> *"The need for more fully trained staff is fundamental to cancer services now and for the success of this initiative." (Individual response)*

> *"The most important factor to consider is workforce shortages. Without resolving or mitigating that, nothing else that can be done will improve cancer outcomes or any other health issue." (Organisation response)*

Respondents expressed appreciation for the workforce, and some commented on the need for better pay. Others suggested that more needed to be done to protect the mental health and wellbeing of staff, especially as they felt this can have a direct impact on quality of care provided to patients.

Future investment priorities

The next most common theme identified were priorities that respondents identified for investment. Many respondents felt that funding should be directed towards less survivable and secondary cancers.

> *"Only 5% of funding goes into secondary cancer. It's secondary cancer that kills. There needs to be a higher % put into secondary cancer." (Individual response)*

Other areas for investment that were cited by multiple respondents were clearing backlogs caused by the Covid-19 pandemic, novel treatments and technologies, and infrastructure.

> *"Short-term ambitions need to focus on the funding available at local levels to deal with cancer waiting times and the psychological impact that is so prevalent following the impacts of Covid-19. […]" (Individual response)*

Post-diagnosis cancer care

The fourth most common theme encompassed aspects of cancer care from diagnosis onwards. Respondents brought attention to the importance of effective prehabilitation and increased support provided prior to treatment beginning.

Respondents also felt that effective and accessible treatments and rehabilitation should be highlighted within the new cancer strategy as well as an increased focus on palliative care.

> *"[…] the provision of excellent treatment should be provided in an efficient and effective way even if it requires more information to be provided in languages and formats or screening to be undertaken in more remote locations." (Individual response)*

> *"[…] Palliative care is everyone's responsibility, and each condition specific strategy should be designed to improve the experiences of people living with advanced disease, dying and bereavement." (Organisation response)*

Need for patient-focused care

Lastly, the theme of patient-focused care appeared frequently within the responses. This theme includes respondents calling for more focus on patient mental health and wellbeing.

> *"Much has changed in the past 2 years, yet the feelings of isolation, loneliness, anxiety, and depression felt by many affected by cancer has only increased. Lockdowns and higher impact in cancer have thrown cancer care into turmoil and many are struggling to cope with their mental wellbeing […]" (Organisation response)*

Respondents also felt that patients should be given more autonomy in decisions made about their treatment plans. Overall, a more holistic approach with the patient at the centre was suggested by respondents.

> *"I want my care to be holistic, to look at me as a whole person, not just a cancer. […]" (Individual response)*

Appendix A: Tables

Question 2

Do you agree with a 10-year high-level strategy which will be underpinned by three shorter-term action plans?

Table 4. Breakdown of Yes/No answers to Question 2

Responses	Count	Percentage
Yes	198	86%
No	33	14%
Total responses	**231**	

Question 3

Do you agree with the proposed vision?

Table 5. Breakdown of Yes/No answers to Question 3

Responses	Count	Percentage
Yes	198	85%
No	34	15%
Total responses	**232**	

Question 4

Do you agree with the proposed goals?

Table 6. Breakdown of Yes/No answers to Question 4

Responses	Count	Percentage
Yes	213	91%
No	22	9%
Total responses	**235**	

Question 5

Do you agree with the proposed principles?

Table 7. Breakdown of Yes/No answers to Question 5

Responses	Count	Percentage
Yes	218	94%
No	15	6%
Total responses	**233**	

Question 6

Do you agree with the proposed themes?

Table 8. Breakdown of Yes/No answers to Question 6

Responses	Count	Percentage
Yes	223	95%
No	11	5%
Total responses	**234**	

Question 7

Do you agree with the proposed areas of focus for person-centred care?

Table 9. Breakdown of Yes/No answers to Question 7

Responses	Count	Percentage
Yes	213	94%
No	13	6%
Total responses	**226**	

Question 9

Do you agree with the proposed areas of focus for timely access to care?

Table 10. Breakdown of Yes/No answers to Question 9

Responses	Count	Percentage
Yes	220	96%
No	9	4%
Total responses	**229**	

Question 10

Do you agree with the proposed areas of focus for high quality care?

Table 11. Breakdown of Yes/No answers to Question 10

Responses	Count	Percentage
Yes	217	97%
No	7	3%
Total responses	**224**	

Question 11

Do you agree with the proposed areas of focus for safe and effective treatments?

Table 12. Breakdown of Yes/No answers to Question 11

Responses	Count	Percentage
Yes	214	96%
No	8	4%
Total responses	**222**	

Question 12

Do you agree with the proposed areas of focus for quality of life and wellbeing?

Table 13. Breakdown of Yes/No answers to Question 12

Responses	Count	Percentage
Yes	227	99%
No	3	1%
Total responses	**230**	

Question 13

Do you agree with the proposed areas of focus for data, technology and measurement?

Table 14. Breakdown of Yes/No answers to Question 13

Responses	Count	Percentage
Yes	209	95%
No	11	5%
Total responses	**220**	

Appendix B: Glossary

Hub and spoke model: (as appearing in consultation responses) A central service 'hub' with 'spokes' (branches) coming off into local communities to make services more accessible in rural and island areas.

Palliative care (end of life care): Making a patient with an illness that cannot be cured as comfortable as possible by managing their pain and other distressing symptoms. Palliative care also involves psychological, social and spiritual support for the patient, their family and/or carers.[9]

Postcode lottery: A situation in which access to a type of medical treatment depends on which part of the country one lives in.[10]

Prehabilitation (prehab): Activities that prepare a patient for a medical operation in order to improve their physical strength and help them to recover more quickly after the operation.[11]

Rehabilitation (rehab): Supporting a patient return to a healthy or good way of life after they have been very ill.[12]

Secondary cancer (metastasis): When a cancer that started in one place in the body then spreads elsewhere. The place in the body where a cancer first starts is the ‘primary cancer’.[13]

---

[9] Adopted from: https://www.nhs.uk/conditions/end-of-life-care/what-it-involves-and-when-it-starts/

[10] Adopted from: https://dictionary.cambridge.org/dictionary/english/postcode-lottery

[11] Adopted from: https://dictionary.cambridge.org/dictionary/english/prehabilitation

[12] Adopted from: https://dictionary.cambridge.org/dictionary/english/rehabilitation

[13] Adopted from: https://www.christie.nhs.uk/patients-and-visitors/your-treatment-and-care/types-of-cancer/secondary-cancers-metastases#:~:text=When%20a%20cancer%20starts%20in,is%20the%20'primary%20cancer'.

Scottish Government
Riaghaltas na h-Alba

This publication is available at **www.gov.scot**

Any enquiries regarding this publication should be sent to us at

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

ISBN: 978-1-80525-163-7 (web only)

Published by The Scottish Government, November 2022

Produced for The Scottish Government by APS Group Scotland, 21 Tennant Street, Edinburgh EH6 5NA
PPDAS1183642 (11/22)