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Are you responding as an individual or an organisation?

- Individual
 Organisation

Full name or organisation's name

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- Publish response with name
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We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

- Yes
 No

Questionnaire

Consultation Questions - Overall

Question 1a	What are the most important aspects of the cancer journey you would like to see included in a long-term strategy?
Description	Think about, for example, prevention, screening, diagnosis, treatment, support for people with or affected by cancer, other care.
Answer	A comprehensive strategy should aim to adequately address all the above points.
Question 1b	Are there particular groups of cancers which should be focused on over the next 3 or 10-years?
Description	Examples of groups may include secondary cancers or less survivable cancers.
Answer	<p>Yes - blood cancer. It is the fifth most common type of adult cancer, the third biggest cancer killer, and claims more lives every year than breast or prostate cancer. There are over 240,000 people living with blood cancer in the UK and 40,000 new diagnoses every year across the UK. Yet, despite these facts, blood cancers are often overlooked as they're more challenging to develop initiatives for – this is reflected in this consultation, which doesn't reference blood cancer at all.</p> <p>Blood cancer patients experience significantly worse delays to diagnosis than patients with breast, lung, colorectal and prostate cancers; 3 out of every 10 blood cancer cases in Scotland are diagnosed after presenting to the NHS as an emergency. Therefore, it's unfortunate that the Detect Cancer Early Programme only concentrates on these main four cancers. The BCA urges the Scottish Government to include blood and other cancers to ensure parity in early cancer detection and, ultimately, survival outcomes.</p> <p>Furthermore, the number of patients who had to see their GP five or more times before being referred for specialist treatment is double that of patients with other cancers in Scotland. The Scottish Government should use this strategy to develop initiatives to better prevent and treat blood cancers.</p>
Question 1c	What do you think we should prioritise over the short-term?
Description	Consider what needs addressed within the first 3 years.
Answer	The Alliance would like to see specific action on improving blood cancer diagnosis throughout the consultation, distinct from but with equal prominence to solid tumour cancers. The workforce

	must be radically expanded and upgraded, alongside improved diagnostic infrastructure and pathways that can support an ambitious vision of earlier diagnosis. Delivering patient-centred care is also a priority, and work must also be done to advance clinical trials that were suspended during the pandemic. Kind and effective treatments should be prioritised here.
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Consultation Questions - Type of document

Question 2a	Do you agree with this proposal?
Description	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.
Answer	Yes
Question 2b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer to Question 2a.
Answer	The strategy is thorough in its approach, however it is very top line. The Alliance would like to see increased detail and focus in particular areas. We would urge the Scottish government to be more ambitious, as it is such a long term strategy. In particular, the Alliance is keen to see more focus on blood cancer. Presently, it is not mentioned in the strategy.

Consultation Questions - Vision, aims and principles

Question 3a	Do you agree with this vision?
Description	Do you agree with the proposed vision (51.), please respond yes or no.
Answer	Yes
Question 3b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer to Question 3a.

Answer	The needs of blood cancer patients are distinct from solid tumour cancer patients, and their treatment pathways are often less linear and more complex, and so unique and tailored care is required. This must be developed in partnership with blood cancer patients and the patient advocacy community, to ensure that those lived experiences and issues are fully integrated into plans.
Question 4a	Do you agree with these goals?
Description	Do you agree with the proposed goals (52. a - h), please respond yes or no.
Answer	Yes
Question 4b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer for Question 4a.
Answer	<p>Delayed diagnosis limits treatment options for patients and negatively impacts quality of life and survival for many blood cancer patients. The Blood Cancer Alliance's own research on the unmet needs of people with blood cancer highlights that people with blood cancer are much more likely than other cancer patients to have to see their GP multiple times before receiving an urgent referral, and around 30% of blood cancers are diagnosed via emergency routes, which is much higher than for other types of cancer.</p> <p>It is therefore imperative that the Government deliver earlier diagnoses for blood cancer patients, which is known to be a longstanding challenge and warrants specific attention and action. The Alliance would like to see specific action on improving blood cancer diagnosis throughout the strategy, distinct from but with equal prominence to solid tumour cancers.</p> <p>There are several ways that the Government could take firmer action on blood cancer diagnosis, including:</p> <ul style="list-style-type: none"> ● Implementing early diagnosis targets that include non-stageable cancers, for example introducing a specific target to reduce the proportion of blood cancer diagnoses made in emergency care ● Improving best practice guidelines for diagnosis ● Increasing resources available for, and awareness of, those best practice guidelines ● Improving referral pathways for non-specific symptoms, for blood cancers and solid tumour cancers. This should include expanding Early Cancer Diagnostic Centres.

	<ul style="list-style-type: none"> Investing in improving and growing haematology diagnostic infrastructure, which must include additional funding for haematology consultants, nurses, pathologists, pathway navigators and other personnel; and diagnostic technology such as imaging and pathology services Improved screening for secondary cancers. Provision of routine secondary cancer screening after a primary cancer diagnosis is at present highly variable across geographies. We recommend implementation of a new guideline and KPIs to ensure all patients known to be at higher risk of a secondary cancer are being regularly monitored Additional funding for haematology pathology services to ensure there is capacity to support the volume of diagnostic activity required in the wake of the pandemic as well as to maintain capacity for translational research into blood cancer diagnostic tools and processes
Question 5a	Do you agree with these principles?
Description	Do you agree with the proposed principles (53.), please respond yes or no.
Answer	Yes
Question 5b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer for Question 5a.
Answer	The Alliance agrees with the focus on inequalities however we would like to see what this will look like in practice explained in greater detail. The Alliance also considers the proposed strategy to be reliant on the Scottish government urgently addressing issues facing the workforce, which have not been included in the strategy currently.

Consultation Questions - Scope and Framing

Question 6a	Do you agree with these themes?
Description	Do you agree with the proposed themes (54.), please respond yes or no.
Answer	Yes

Question 6b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer for Question 6a.
Answer	<p>It is crucial that blood cancer patients have equal access to clinical trials, equitable to solid tumour patients. There is also extensive work to be done to remedy the impact of COVID-19 on clinical trials. For example, during the pandemic, patient enrolment for three out of four of Blood Cancer UK's funded advanced clinical trials was suspended, setting these trials back significantly. The Government should provide regular reporting on the number of clinical trials underway in the NHS, identified by condition, phase, and location, and these should be benchmarked to pre-pandemic levels. This information should be provided to all NHS boards, as well as to all blood cancer patients, to deliver greater awareness of, and access to, trial participation.</p> <p>The Alliance would also like to see a pilot for patients to refer themselves to services that aim to speed up diagnosis in Scotland such as Early Cancer Diagnostic Centres.</p>
Question 7a	Do you agree with these areas of focus?
Description	Do you agree with the proposed areas of focus for person-centred care, please respond yes or no.
Answer	Yes
Question 7b	In your experience, what aims or actions would you like to see under any of these areas?
Description	Please focus your response on the person-centred care.
Answer	<p>The Alliance wants to see patients be more involved in decision making about their care, including through the co-production of treatment pathways for blood cancer patients, ensuring that people's lived experiences are considered when designing those pathways. Engaging marginalised communities to develop targeted information campaigns should also be a priority, to ensure harder to reach groups have the proper access to resources and are considered in planning treatment pathways. All patient groups should have access to peer support, as well as access to relevant, up to date information to support informed decision making. Investment in the blood cancer workforce will also be important as some blood cancer patients particularly feel left out of the healthcare system, particularly those living with chronic cancer.</p>

Question 7c	Please explain your answer and provide any additional suggestions.
Description	Please explain your answers for Question 7a and 7b.
Answer	Some measures put in place during the pandemic increased capacity for effective, person-focused care and the Alliance would like to see some of these supportive measures remain, such as providing treatment closer to patients homes, covid-safe centres, access to newer medicines, community testing, and flexibility to access care either in person or remotely.
Question 8a	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?
Description	Please focus your response on the prevention of cancer and inequalities in cancer incidence.
Answer	Raising awareness among the public and primary care workforce about the potential signs and symptoms of blood cancer, and educating and enabling primary care services to act swiftly to refer patients on to the appropriate diagnostic pathway.
Question 8b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer for Question 8a.
Answer	<p>While the underlying causes of solid tumour cancers are relatively well understood, this is not currently the case for many blood cancers. More work must be undertaken to understand this further - particularly if we are to achieve evidence-based strategies and public awareness campaigns on prevention that support reduced incidences for all cancers, including blood cancer.</p> <p>Many blood cancer patients are at heightened risk of secondary cancers, which patients and community and primary care providers must have a better understanding of in order to access or give good information on preventative measures that can reduce patient risk. Solid tumour cancer patients are also at risk of developing blood cancer as a secondary cancer, which must also be effectively communicated. Targeted awareness campaigns at community level should be explored by the Government to address these issues.</p> <p>It is also important to note that awareness alone will not prevent cancer. It is essential that people also have awareness of, and access to support for healthier behaviours which reduce the risks of cancer, such as high-quality nutrition, regular exercise and help to stop smoking. This support needs to be delivered in a way that recognises and targets health inequalities.</p>

Question 9a	Do you agree with these areas of focus?
Description	Do you agree with the proposed areas of focus for timely access to care, please respond yes or no.
Answer	Yes
Question 9b	In your experience, what aims or actions would you like to see under any of these areas?
Description	Please focus your response on timely access to care.
Answer	<p>There are several ways that the Government could take firmer action on blood cancer diagnosis, which we mentioned above. These include:</p> <ul style="list-style-type: none"> ● Implementing early diagnosis targets that include non-stageable cancers, for example introducing a specific target to reduce the proportion of blood cancer diagnoses made in emergency care. The Alliance wants to see the Scottish Government via Public Health Scotland to collate this important data and be responsible for published. ● Improving best practice guidelines for diagnosis ● Increasing resources available for, and awareness of, those best practice guidelines, ● Improving referral pathways for non-specific symptoms, for blood cancers and solid tumour cancers. ● Investing in improving and growing haematology diagnostic infrastructure, which must include additional funding for haematology consultants, nurses, pathologists, pathway navigators and other personnel; and diagnostic technology such as imaging and pathology services ● Improved screening for secondary cancers. Provision of routine secondary cancer screening after a primary cancer diagnosis is at present highly variable across geographies. We recommend implementation of a new guideline and KPIs to ensure all patients known to be at higher risk of a secondary cancer are being regularly monitored ● Additional funding for haematology pathology services to ensure there is capacity to support the volume of diagnostic activity required in the wake of the pandemic as well as to maintain capacity for translational research into blood cancer diagnostic tools and processes

Question 9c	Please explain your answer and provide any additional suggestions.
Description	Please explain your answers for Question 9a and 9b.
Answer	<p>Delayed diagnosis limits treatment options for patients and negatively impacts quality of life and survival for many blood cancer patients. For example, Myeloma UK's recent report "A Life Worth Living" reports new survey findings showing that 49% of myeloma patients who had a delayed diagnosis experienced a high negative impact on their quality of life, compared to 30% of myeloma patients who had a timely diagnosis.</p> <p>It is therefore imperative that the Government delivers earlier diagnoses for blood cancer patients, which is known to be a longstanding challenge and warrants specific attention and action. Given blood cancer is the third biggest cancer killer, and three in ten cases are presently diagnosed in the emergency setting, the Alliance would like to see specific action on improving blood cancer diagnosis throughout the strategy - distinct from but with equal prominence to solid tumour cancers. Investment in ECDCs would support here.</p>
Question 10a	Do you agree with these areas of focus?
Description	Do you agree with the proposed areas of focus for high quality care, please respond yes or no.
Answer	Yes
Question 10b	In your experience, what aims or actions would you like to see under any of these areas?
Description	Please focus your response on quality of care.
Answer	<p>The Alliance is calling for a number of actions to improve the psychological and other support available to blood cancer patients:</p> <ul style="list-style-type: none"> • Better access to written or multimedia information about the impact of coping with diagnosis and treatment • Improved awareness of support or peer support groups • Offering improved support for patients on 'Watch and Wait' – these are patients who have received a blood cancer diagnosis and do not need immediate treatment, but are aware their condition will require treatment at an unspecified point in the future

	<ul style="list-style-type: none"> ● Improved links between specialist haematology and community services to ensure after care and support is seamless and patient centred ● More consistent provision of palliative care and end of life support, including advance planning and bereavement support for families ● After-care services available equitably across the country ● Access to a single point of contact, ideally a specialist CNS, for all blood cancer patients ● Access to specialist haematology clinical psychology for all patients in need in a timely way
Question 10c	Please explain your answer and provide any additional suggestions.
Description	Please explain your answers for Question 10a and 10b.
Answer	<p>The needs of blood cancer patients are distinct from solid tumour cancer patients, and so unique and tailored care is required. This must be developed in partnership with blood cancer patients and the patient advocacy community, to ensure that those lived experiences and issues are fully integrated into plans.</p> <p>A recent UK study also demonstrated that 50% of blood cancer patients reported concerns related to their psychological wellbeing. SCPES data also shows that some people did not receive emotional, financial and practical support, including vital information about their illness. And in 2018, nearly half (45%) of respondents said they weren't supported emotionally or psychologically by healthcare professionals during treatment. Post-pandemic, we gather that this might have increased, and the Alliance want to see the Scottish Government carry out the promised survey and urgently act to rectify these issues.</p>
Question 11a	Do you agree with these areas of focus?
Description	Do you agree with the proposed areas of focus for safe and effective treatments, please respond yes or no.
Answer	
Question 11b	In your experience, what aims or actions would you like to see under any of these areas?
Description	Please focus your response on treatment.

Answer	
Question 11c	Please explain your answer and provide any additional suggestions.
Description	Please explain your answers for Question 11a and 11b.
Answer	
Question 12a	Do you agree with these areas of focus?
Description	Do you agree with the proposed areas of focus for quality of life and wellbeing, please respond yes or no.
Answer	Yes
Question 12b	In your experience, what aims or actions would you like to see under any of these areas?
Description	Please focus your response on quality of life and wellbeing.
Answer	As mentioned above, Myeloma UK's recent report "A Life Worth Living" reports new survey findings showing that 49% of myeloma patients who had a delayed diagnosis experienced a high negative impact on their quality of life, compared to 30% of myeloma patients who had a timely diagnosis. The Blood Cancer Alliance's own research on the unmet needs of people with blood cancer highlights that people with blood cancer are much more likely than other cancer patients to have to see their GP multiple times before receiving an urgent referral, and around 30% of blood cancers are diagnosed via emergency routes, which is much higher than for other types of cancer.
Question 12c	Please explain your answer and provide any additional suggestions.
Description	Please explain your answers for Question 12a and 12b.
Answer	It is imperative that the 10 Year Cancer Strategy prioritises stopping blood cancer patients from being diagnosed as emergency presentations – as outlined in the previous answer this has a deeply negative impact on patient's experience and can be rectified with proper processes. Whilst additional funding to tackle the overall NHS backlog is welcome, targeted action is needed to ensure more blood cancer patients are diagnosed

	sooner, and to tackle long waiting lists for blood cancer treatments.
Question 13a	Do you agree with these areas of focus?
Description	Do you agree with the proposed areas of focus for data, technology and measurement, please respond yes or no.
Answer	Yes
Question 13b	In your experience, what aims or actions would you like to see under any of these areas?
Description	Please focus your response on data, technology and measurement.
Answer	<p>The Alliance wants the Government to support NHS Scotland in regularly updating and reporting data on blood cancer.</p> <p>Ensuring data collected can be shared in a timely, efficient way would also contribute to better understanding of blood cancer, and so the Alliance would like to see the Government invest in development systems which can share that data efficiently by making it as public as possible. We'd like to see the Government invest in putting those systems in place without delay, incorporating new technology, personnel, and processes. The fact that some blood cancers cannot be staged must be considered when developing these new data systems. The Alliance would like to see this incorporated by ensuring that early diagnosis targets which focus on staging data include data specific to blood cancers, or, have separate blood cancer measures created.</p> <p>Finally, we want to see the Government standardise the data collected on blood cancer across the NHS, delivering a clear definition of 'blood cancer' which is consistent across all data sets. This should be in consultation with the blood cancer patient and clinical community. From here, we would like to see this data be aggregated by stage and type, and broken down by demographics including age, gender, ethnicity and location. This improved data collection and reporting must then be used to inform development of new, innovative treatments.</p>
Question 13c	Is there any technology that you would like to see introduced to improve access to cancer care?
Description	Please consider access to screening, diagnostics, results, tracking of your pathway.
Answer	

Question 13d	Please explain your answer and provide any additional suggestions.
Description	Please explain your answers for Question 13a, 13b and 13c.
Answer	
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?
Description	Please focus your response on cancer care and outcomes.
Answer	The Alliance want to see an end to blood cancer patients being diagnosed as emergency presentations – as outlined in a previous answer this has a deeply negative impact on patient's experience and can be rectified with proper processes

Consultation Questions - Earlier Diagnosis Vision

Question 15a	What would you like to see an Earlier Diagnosis Vision achieve?
Description	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
Answer	<p>Around 30% of blood cancers are diagnosed via emergency routes, which is much higher than for other types of cancer.</p> <p>It is therefore imperative that the Government deliver earlier diagnoses for blood cancer patients, which is known to be a longstanding challenge and warrants specific attention and action. The Alliance would like to see specific action on improving blood cancer diagnosis throughout the strategy, distinct from but with equal prominence to solid tumour cancers.</p>
Question 15b	Should the Earlier Diagnosis Vision set itself a numerical target?
Description	For example, 75% of all cancers diagnosed at an earlier stage. Please provide any suggested target you have.
Answer	Some blood cancers cannot be staged. The Alliance would like to see this addressed by ensuring that early diagnosis targets which focus on staging data include data specific to blood cancers, or, have separate proxy blood cancer measures created.

Question 15c	Should the earlier cancer diagnosis vision focus on specific cancer types?
Description	The current programme focusses on lung, bowel and breast cancers that account for 45% of all cancers diagnosed in Scotland.
Answer	<p>Blood cancer is the fifth most prevalent cancer and the third biggest cancer killer, and yet it is not mentioned in the Scotland Cancer Strategy. The Alliance would particularly like to see an increase in the awareness of the signs and symptoms of blood cancer among GPs. Where routes to diagnosis are clear, for example the simple blood tests available for leukaemia, it should be ensured that wider policies and challenges do not prevent this from happening. Examples here include ensuring adequate awareness of symptoms and appropriate actions among GPs, and ensuring that practical or logistical challenges such as shortages of blood test tubes do not have a negative impact on diagnoses.</p> <p>We would also like to see more funding and resources put toward increasing usage of ECDCs in primary care settings by expanding the initiative. Awareness of ECDCs among GPs should also be increased. These changes would be beneficial for both blood cancer patients and solid tumour patients.</p>
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?
Description	Please refer back to your personal experience to identify how services worked well and where improvements could be made.
Answer	
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?
Description	Please identify where you would like to access care differently to your experience.
Answer	
Question 15f	What does good earlier cancer diagnosis look like for you?
Description	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

Answer	<p>As mentioned in previous answers, the Alliance want to see a significant reduction in blood cancer patients being diagnosed as emergency presentations at A&E. As mentioned above, the Alliance are advocating for adequate awareness of symptoms and appropriate actions among GPs, and ensuring that practical or logistical challenges such as shortages of blood test tubes do not have a negative impact on diagnoses.</p> <p>We would also like to see more funding and resources put toward increasing usage of ECDCs in primary care settings by expanding the initiative. Awareness of ECDCs among GPs should also be increased. These changes would be beneficial for both blood cancer patients and solid tumour patients.</p>
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Impact Assessments

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?
Description	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.
Answer	<p>Different ages, genders and ethnicities experience different signs and symptoms of blood cancer and may require uniquely targeted awareness campaigns as a subsidiary of a national awareness campaign. For example, blood cancer is predominantly experienced by older patients, and awareness campaigns should therefore in principle be targeted at people with older age groups. Leukaemia is also the most common childhood cancer, and therefore a campaign targeted toward parents on the signs and symptoms of the disease would be effective.</p>
Question 16b	Similarly, is how we manage cancer different for wealthy or poor people? What could be done to do this better?
Description	Please consider the impact of socio-economic inequality.
Answer	<p>As mentioned in earlier answers, a targeted public health campaign would be beneficial to improved outcomes for blood cancer patients in Scotland. This must however take into account existing health inequalities, and be accessible to all groups. Careful targeting and tailoring will be necessary to make sure any public awareness campaigns include those who are not fluent in English, those who are not digitally literate, and people from disadvantaged socio-economic groups.</p>
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?

Description	Please consider the impact of rurality on access to and quality of cancer services.
Answer	

Conclusion

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