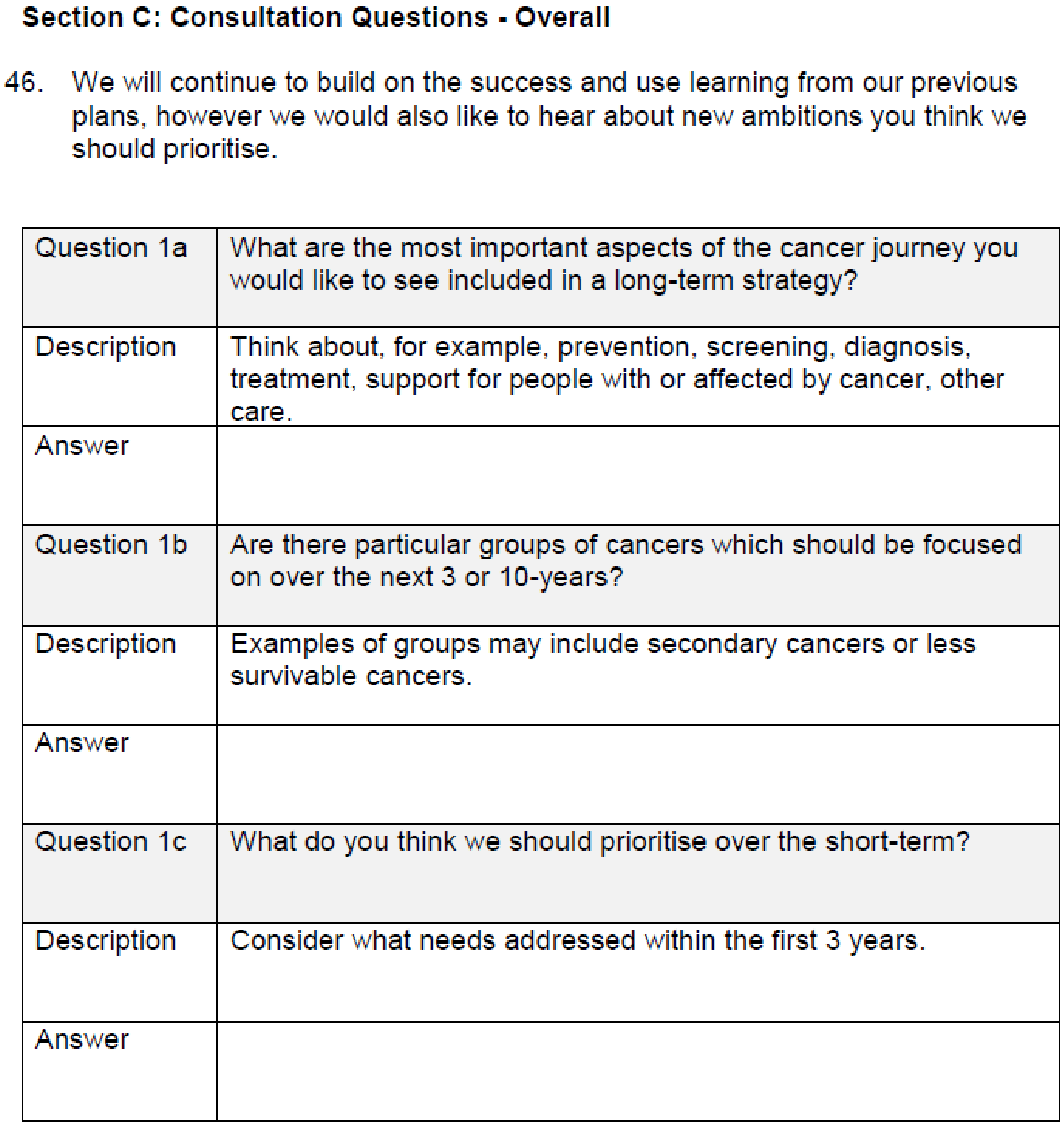
SPPC Response to SG Consultation on a New Strategy for Cancer Services

(the consultation is an online survey. For ease of reading and to provide context to our answers this document extracts some of the background from the consultation document and shows SPPC's responses in larger bold text)



Section C: Consultation Questions - Overall

46. We will continue to build on the success and use learning from our previous plans, however we would also like to hear about new ambitions you think we should prioritise.

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	
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	
Question 1c	What do you think we should prioritise over the short-term?
Description	Consider what needs addressed within the first 3 years.
Answer	

1a

57% of men and 49% of women diagnosed with cancer will not survive 5 years. One in three people with cancer lives for less than a year following

diagnosis. The absolute number of people with cancer who need palliative care is set to increase very substantially in the next two decades. There is evidence that timely involvement of palliative care (specialist and/or generalist can improve outcomes for people with cancer and their families. In a study of people with metastatic lung cancer early involvement of palliative care led to significant improvements in quality of life and mood. As compared with patients receiving standard care, patients receiving early palliative care had less aggressive care at the end of life but longer survival. The forthcoming cancer strategy should therefore include a prominent, clear and explicit commitment to improving the outcomes and experiences of people who would benefit from palliative care.

To achieve this aim will require a breadth of work, and in our response SPPC has suggested how the strategy could reflect this within many of the themes identified in the draft (person-centred care, timely access to care, high quality care, improving quality of life and wellbeing, data and measurement, and outcomes).

The term “palliative care” is not always well understood. Though more specific definitions can be helpful, one way of thinking about ‘palliative care’ is to talk in terms of providing ‘good care’ to people whose health is in irreversible decline or whose lives are coming to an inevitable close.

Perhaps what differentiates ‘palliative care’ from ‘just good care’ is the awareness that a person’s mortality has started to influence clinical and/or personal decision-making.

However, palliative care is not synonymous with death – it is about life, about the care of someone who is alive, someone who still has hours, days, months, or years remaining in their life, and about optimising wellbeing in those circumstances.

Palliative care interventions are holistic and aim to modify the impact of illness/disease by addressing symptoms and should be delivered alongside treatments aimed at controlling or modifying the underlying condition(s). Palliative care can and should be provided alongside treatment aiming to cure or remove the underlying illness/disease where such treatments exist.

Palliative care includes, but is not exclusively about, end of life care. End of life care is a core part of palliative care which should follow from the diagnosis of someone entering the process of dying, whether or not they are already in receipt of palliative care. This phase could vary between months, weeks, days or hours in the context of different disease trajectories . There can be uncertainty involved in identifying when someone might be expected to die – illness can be unpredictable, and changes can occur suddenly and unexpectedly.

Most of the palliative care provided to people with cancer will be provided by generalists in primary acre, care homes and on hospital wards.

Specialist palliative care can help people with more complex palliative care needs and is provided by specially trained multi-professional specialist palliative care teams who are generally based in a hospice, an NHS specialist palliative care unit or an acute hospital, but whose expertise should be accessible from any care setting and at any time. Services labelled 'palliative' are usually specialist palliative care. Key contributions of specialist palliative care include:

- assessment and management of complex physical, psychological and spiritual symptoms
- supporting complex clinical decision-making, seeking to apply relevant ethical and legal frameworks alongside clinical assessment and respect for personal autonomy and values
- direct provision and management of symptom management interventions
- providing care and support to those important to the person receiving care, including facilitating bereavement care
- providing specialist advice and support to the wider care team which is providing direct care to the person
- liaison with and between different settings
- providing formal and informal education and training for the wider health and social care system
- attending and providing input to multidisciplinary team meetings, including key decision-making contributions
- providing strategic expertise and leadership to support the health and care system to recognise and meet the needs of people approaching the end of their lives.

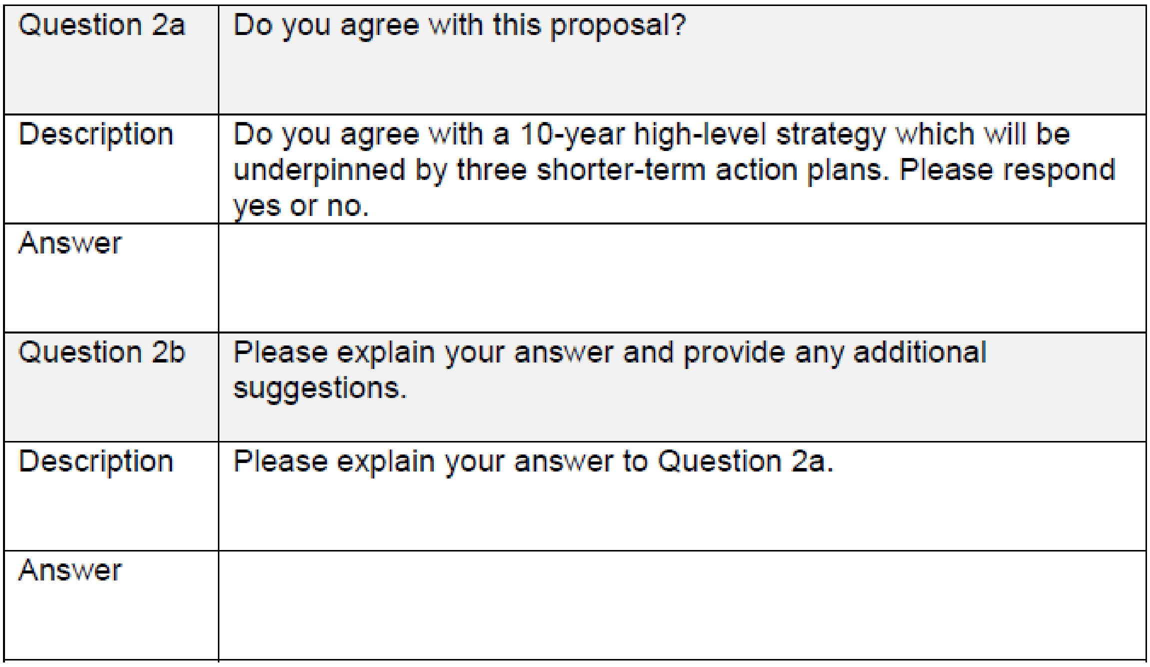
There are different models through which palliative care can be provided. It is important that the roles of and relationships between oncology, specialist palliative care and generalist palliative care are clear and pathways are identified.

Scottish Partnership for Palliative Care's recent report *Every Story's Ending*, is a comprehensive review of what actions should be taken to improve people's experiences of living with serious illness, dying and bereavement. The report explores many of the issues presented in this submission and provides references. It can be downloaded at https://www.palliativecarescotland.org.uk/content/everystorysending/

1b

1c

There is a need for early action on the integration of supportive/palliative care into treatment of recurrent disease.



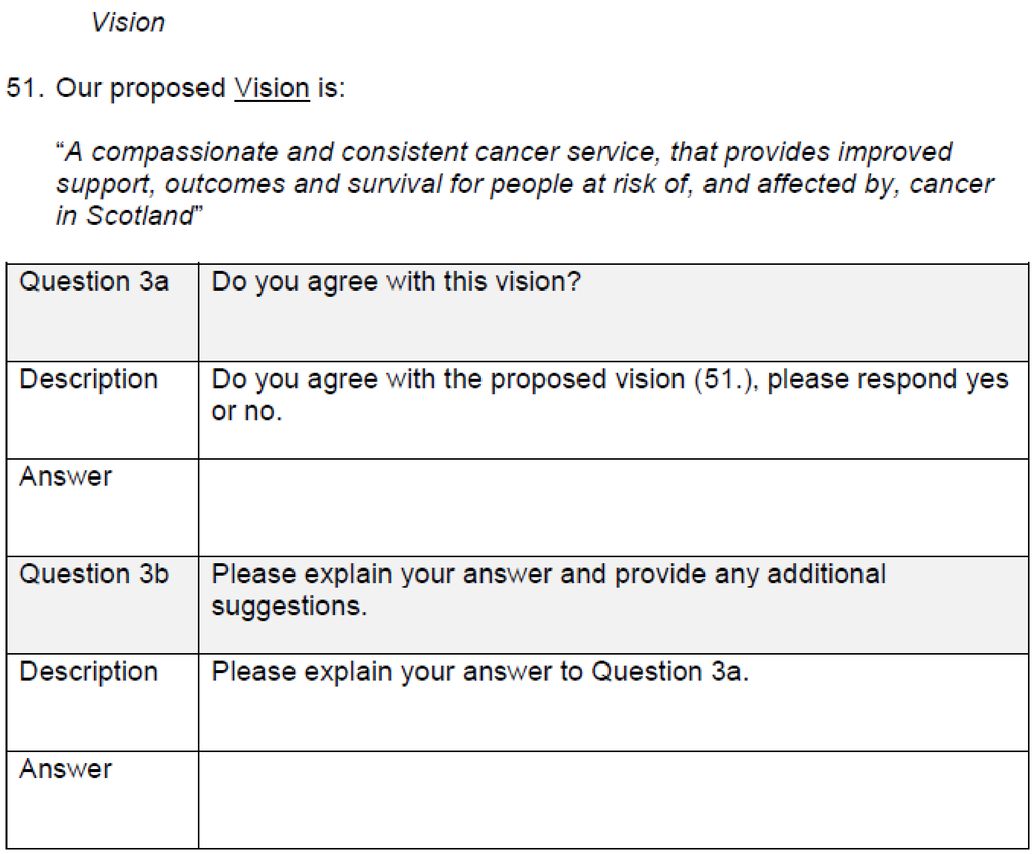
Question 2a	Do you agree with this proposal?
Description	Do you agree with a 10-year high-level strategy which will be underpinned by three shorter-term action plans. Please respond yes or no.
Answer	
Question 2b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer to Question 2a.
Answer	

2a

Yes.

2b

The suggested approach can combine long term goals with the ability to develop plans over a shorter period allow adaptation to reflect changing circumstance and degree of progress.



Vision

51. 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"*

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

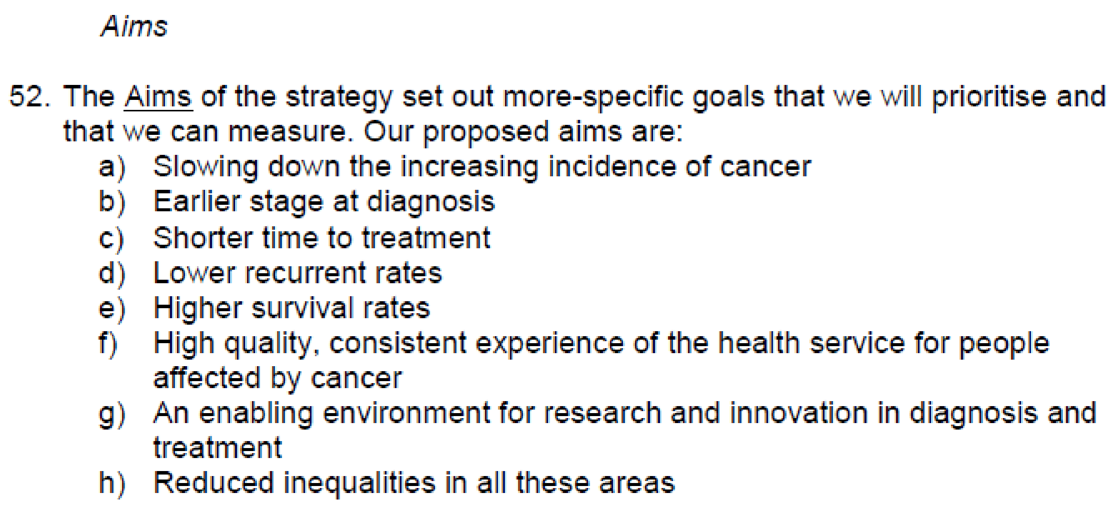
3a

No.

3b

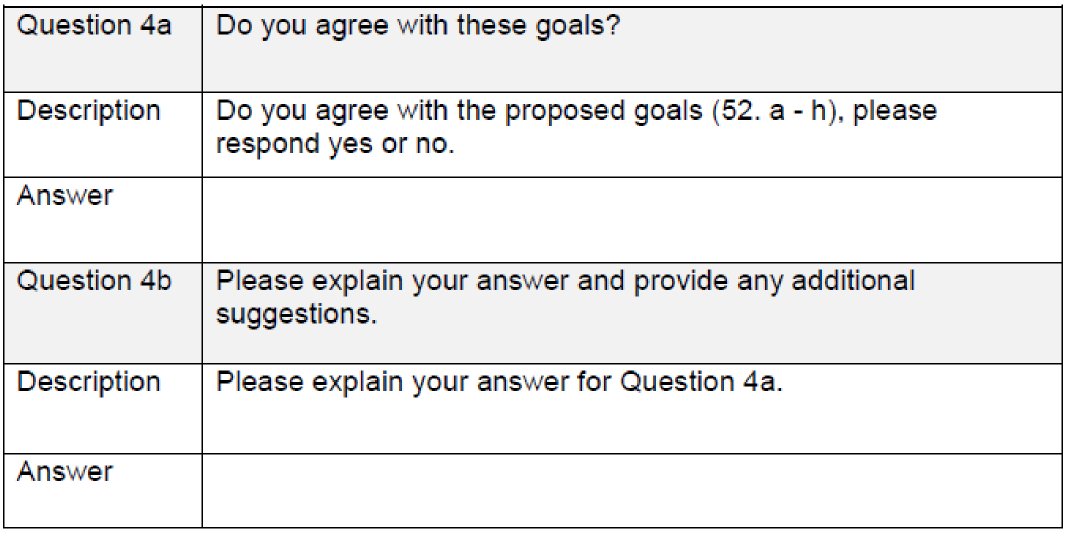
SPPC suggests that the vision should be reworded so as to be clear that survival is one outcome, but that there are also other outcomes which are valued and which can be improved. The vision could be worded like this:

"Compassionate and consistent services, that provide improved support, survival and other valued outcomes for people at risk of, and affected by, cancer in Scotland."



Aims

52. 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



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	
Question 4b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer for Question 4a.
Answer	

4a

No

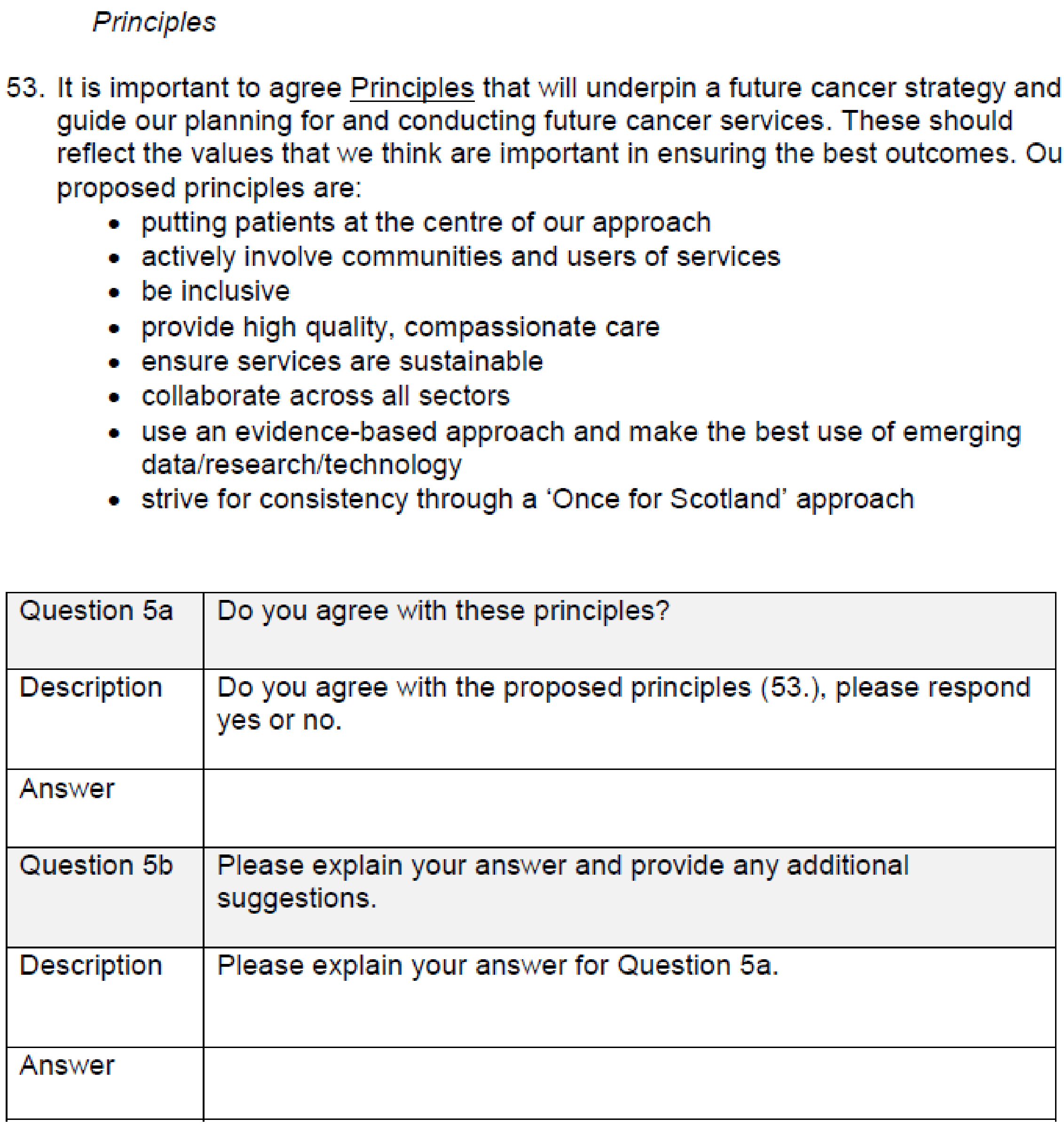
4b

We would like to suggest an additional goal/aim.

Timely receipt of palliative care (including access to specialist palliative care where appropriate).

Alternatively, timely receipt of palliative care (including access to specialist palliative care where appropriate) could be explicitly included in f)

Within g) the scope of research should go beyond diagnosis and treatment to include care/support, health services research and public health research.



Principles

53. It is important to agree <u>Principles</u> 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

Question 5a	Do you agree with these principles?
Description	Do you agree with the proposed principles (53.), please respond yes or no.
Answer	
Question 5b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer for Question 5a.
Answer	

5a

No

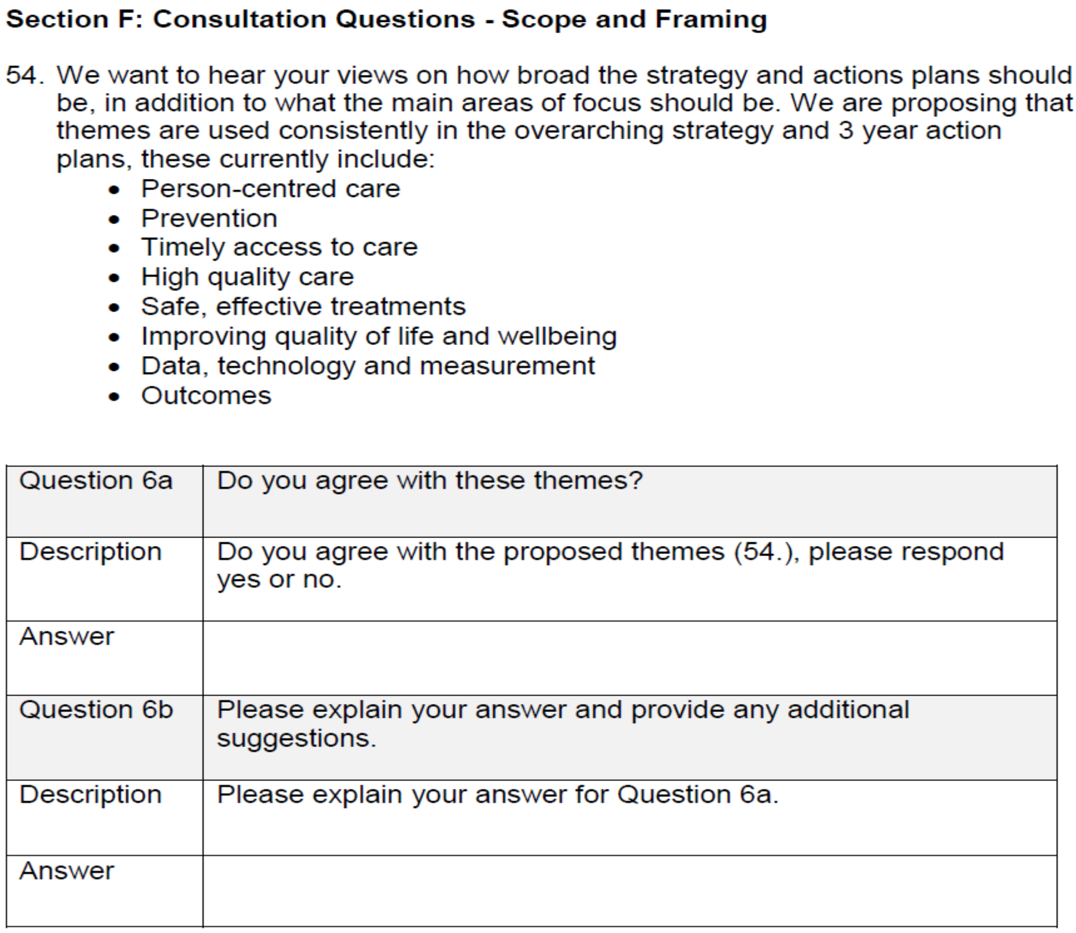
5b

In the first bullet we suggest "patients" should be replaced with "people affected by cancer", and reference made to shared decision making. We would also suggest explicit reference to "timely, honest and sensitive conversations" which are at the heart of a person-centred approach.

In the fourth bullet we would like to see reference to "high value" care included. High quality care or safe/effective care, if given to the wrong person or at the wrong time or in the wrong place, is still low value care. For example those patients (typically with advanced cancer) who undergo

systemic anti-cancer treatment but subsequently experience treatment regret, often because what they have gained by the end of treatment is outweighed by what they have given up (and this is probably because the "shared decision" taken at the outset had not fully considered the extent to which a treatment aligned to the person's priorities and preferences). The strategy document should highlight value as a separate but important pillar alongside quality, safety and effectiveness. This would resonate very closely with palliative care approaches and Realistic Medicine's philosophy.

We would like to see wording which more strongly reflects the importance of integrated services, acknowledging that most care for people affected by cancer is provided outwith "cancer services"



Section F: Consultation Questions - Scope and Framing

54. 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

Question 6a	Do you agree with these themes?
Description	Do you agree with the proposed themes (54.), please respond yes or no.
Answer	
Question 6b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer for Question 6a.
Answer	

6a

No

6b

We would like to see a statement prefacing these themes which makes it clear that they apply across every stage of illness. There is a need to ensure an evidenced and realistic approach to ongoing management when

oncological treatments are not longer effective. The themes all have clear applicability to the aim of improving palliative care. [This may seem counterintuitive for the "prevention" theme. However, within palliative care "prevention" refers to preventing avoidable suffering through the management of symptoms (including side effects of treatment) and also the prevention of avoidable psychological, social and spiritual harms and suffering associated with inadequate support for people living with advanced disease, dying and bereavement].

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

50. Under Person-centred care we are considering:

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

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	
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	
Question 7c	Please explain your answer and provide any additional suggestions.
Description	Please explain your answers for Question 7a and 7b.
Answer	

7a

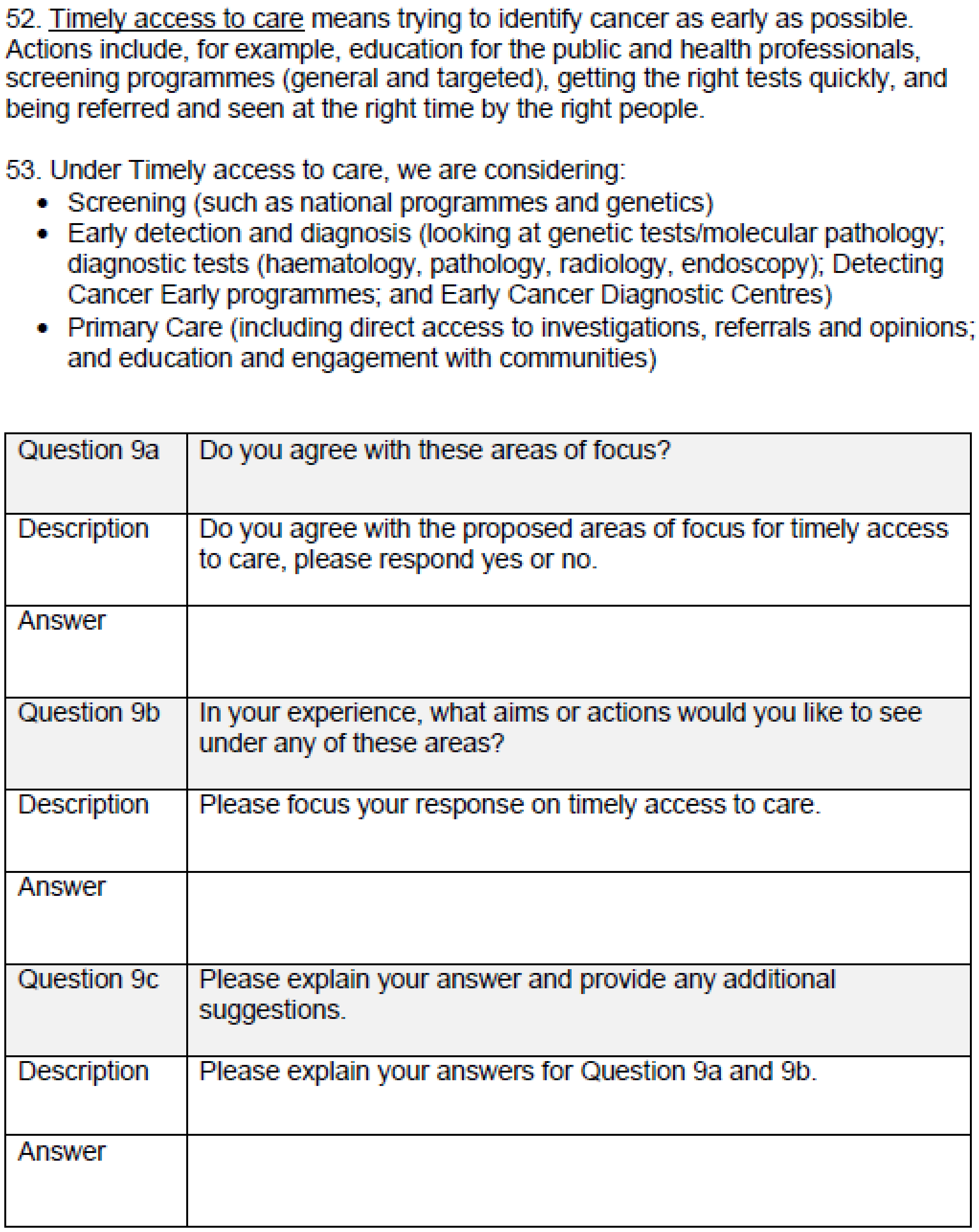
No

7b

We would like to see “Wider support for people living with and beyond cancer…” broadened to include support for people who are dying with cancer.

7c

(Q 8 omitted – it is about cancer prevention)



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

53. 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)

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	
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	
Question 9c	Please explain your answer and provide any additional suggestions.
Description	Please explain your answers for Question 9a and 9b.
Answer	

9a

No

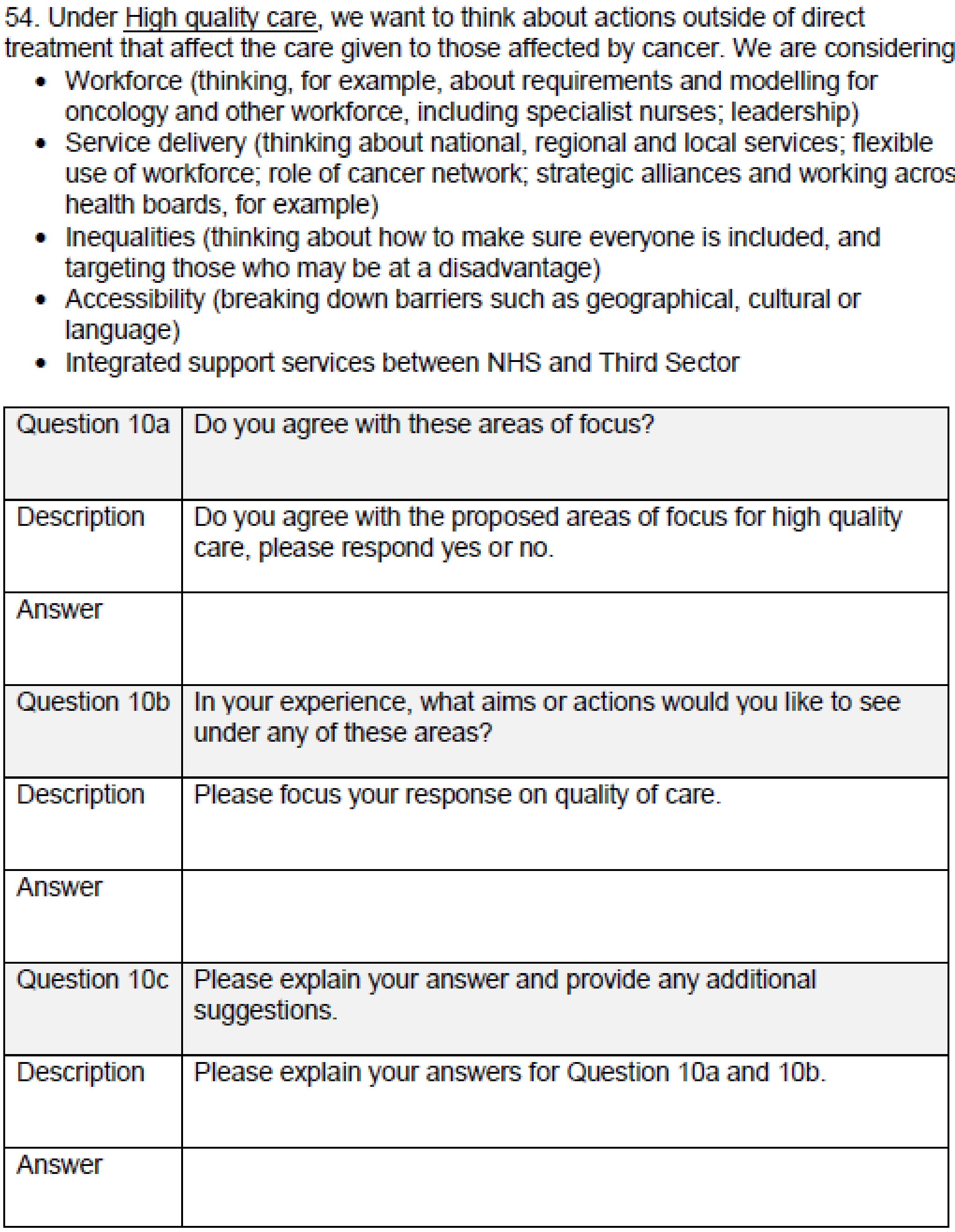
9b

We would like to see timely receipt/involvement of palliative care as an area of focus.

9c

There is evidence that earlier involvement of palliative care can improve outcomes for individuals, and improve allocation of resource to care and treatment which is valued by them.

As we argued in Q1 a large percentage, and growing absolute number, of people receiving a cancer diagnosis will need timely palliative care.



54. 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

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	
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	
Question 10c	Please explain your answer and provide any additional suggestions.
Description	Please explain your answers for Question 10a and 10b.
Answer	

10 a

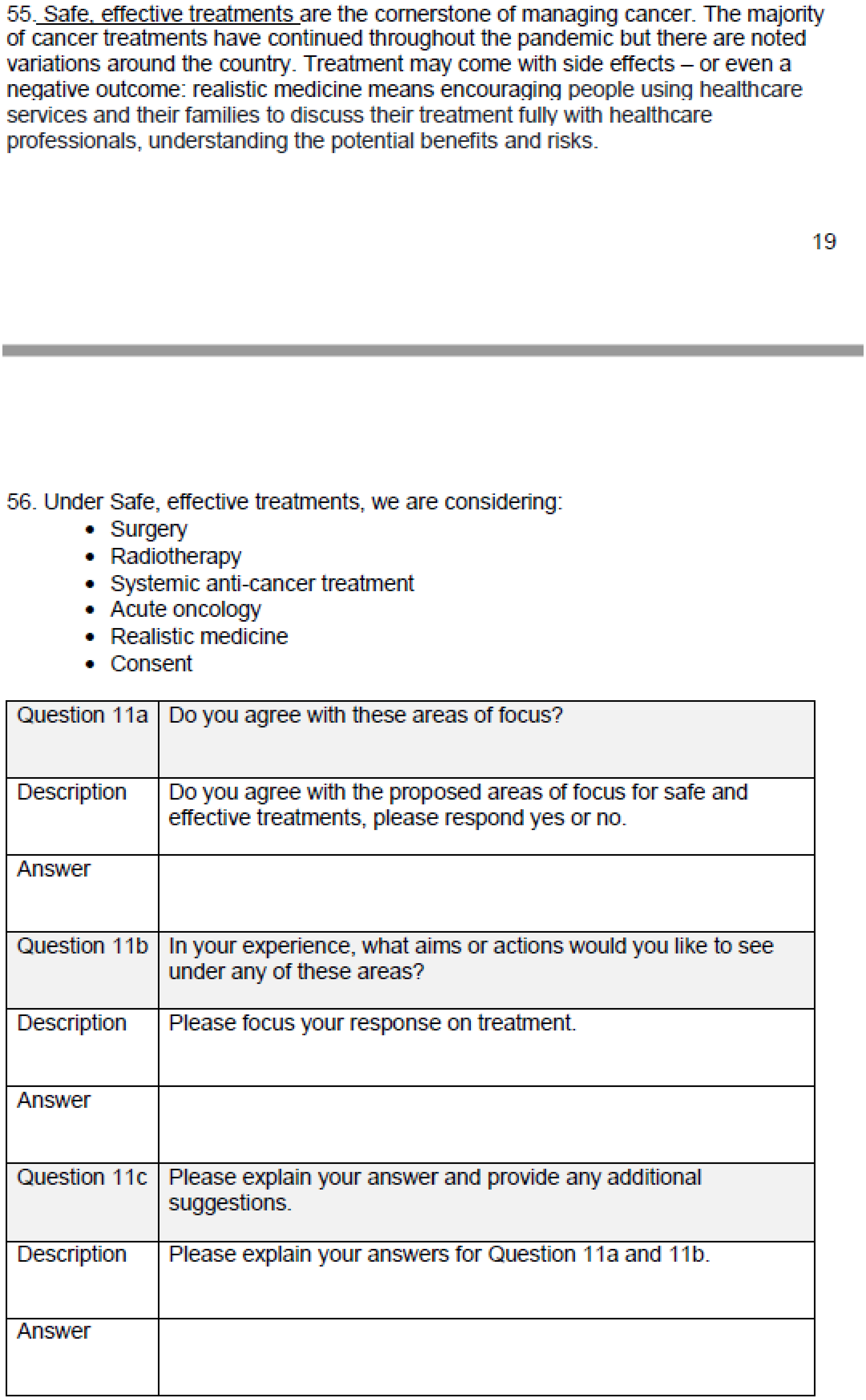
No

10b

Within each of the proposed areas we would like to see the explicit inclusion of palliative care.

10c

As set out in our response to 1) a large percentage of people diagnosed with cancer will need palliative care. Therefore, the scope of work to deliver high quality care must include palliative care.



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

56. Under Safe, effective treatments, we are considering:

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

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	

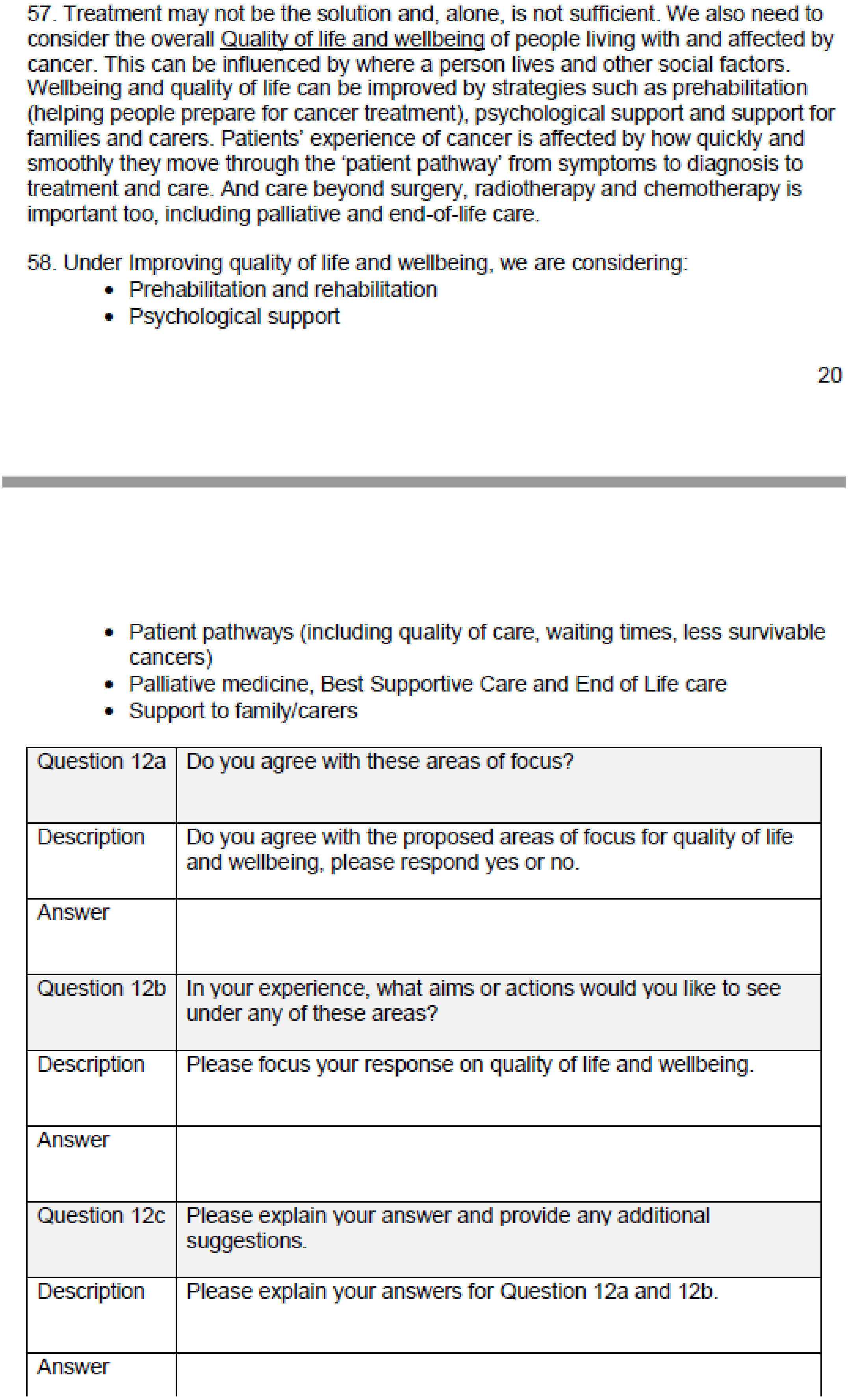
11a

Yes

11b

We would like to see action around open, honest and sensitive conversations about treatment options as part of the Realistic Medicine focus. Such conversations are at the heart of person-centred care, and support shared decision-making. Ensuring safe effective treatments should include avoiding oncological treatments that are no longer safe or effective and promoting alternative holistic approaches e.g. palliative care.

11c



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

58. 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

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	
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	
Question 12c	Please explain your answer and provide any additional suggestions.
Description	Please explain your answers for Question 12a and 12b.
Answer	

12 a

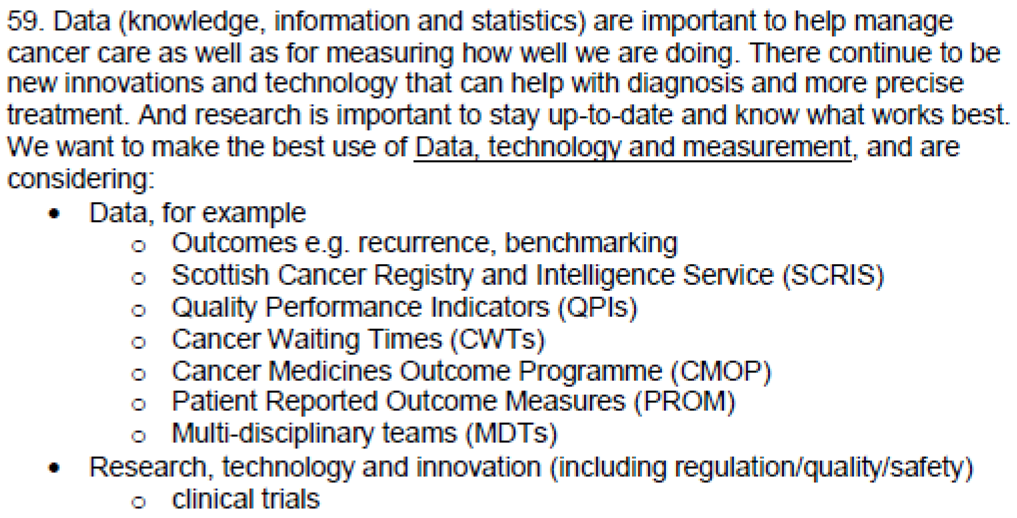
Yes

12 b

We support the intended focus on palliative care and the focus on patient pathways. We would like to see work to support greater use of anticipatory care planning, 24/7 access to generalist and specialist palliative care support, and as mentioned elsewhere better integration of palliative care.

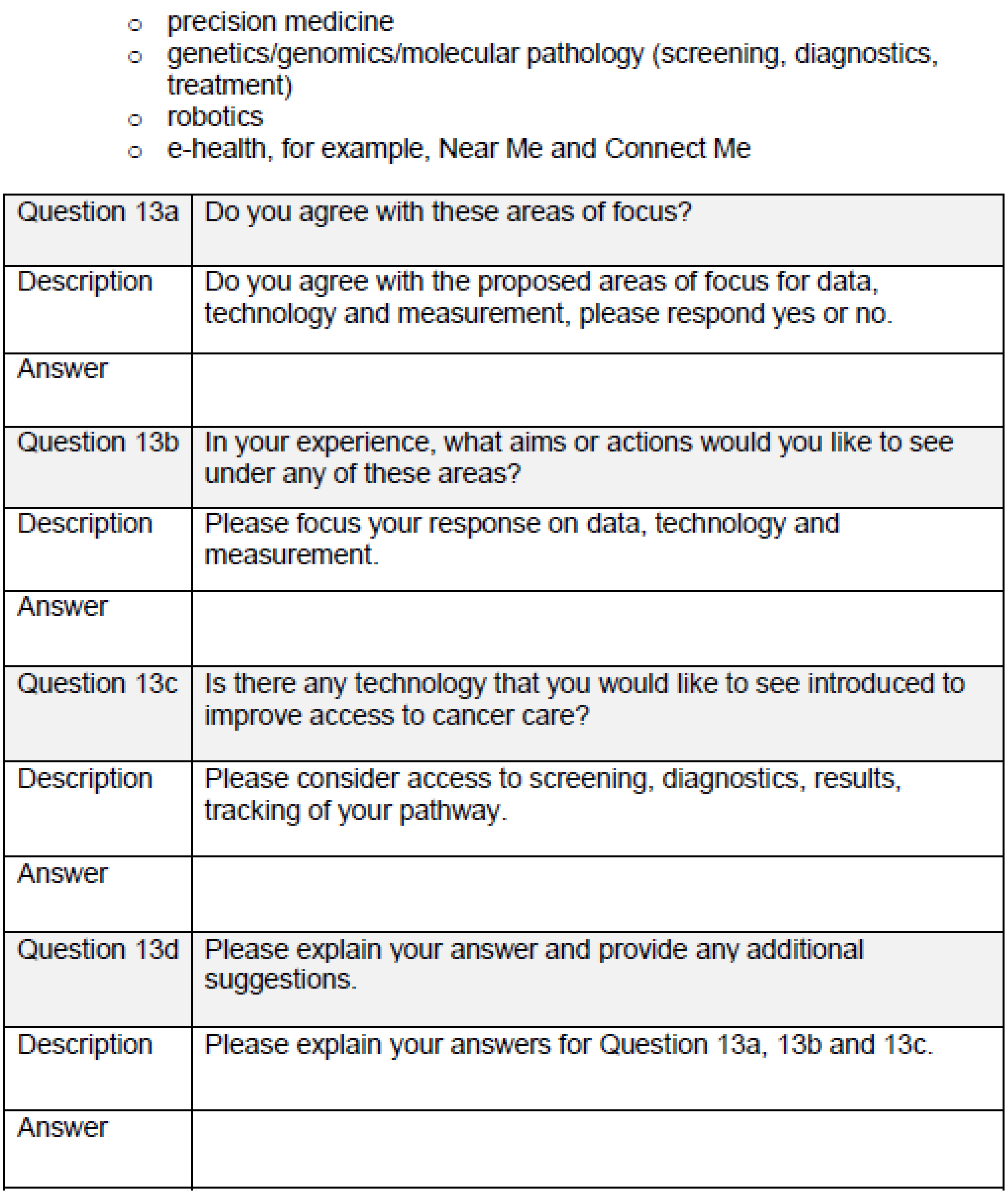
12 c

The terminology used in the 4th bullet "Palliative medicine, Best Supportive Care and End of Life care" should be clarified. We have provided explanations of palliative care in section 1a. Palliative medicine is one component of specialist palliative care which is provided by multidisciplinary teams. End of life care is one part of palliative care. There are similarities and overlaps in the scope, aims and philosophy of palliative care and Best Supportive Care (and "supportive oncology". The strategy should prompt and support clarification of terminology and desired models of care on the ground.



59. 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

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	
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	
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	

13 a

No

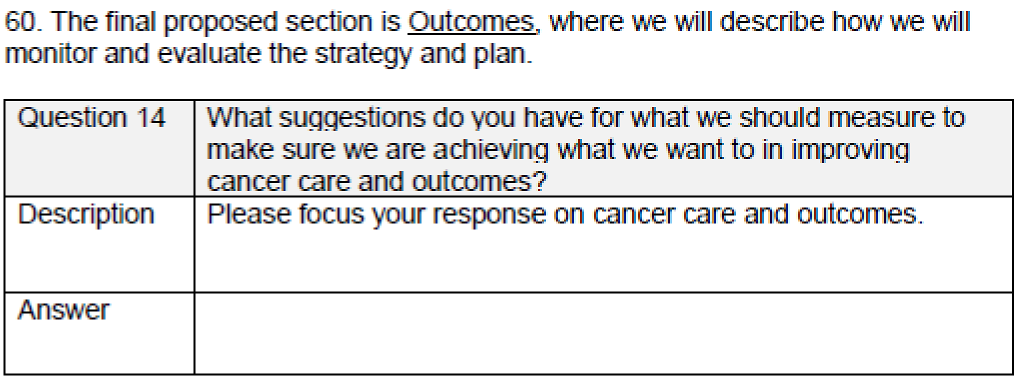
13b

Under Data we would like to see measurement of the experiences and outcomes of people approaching the end of life. The current Cancer Experience Survey, and the Health and Care Experience Survey do not capture information about this part of the pathway. We would like to see some process measures and also feedback from people with advanced disease and from bereaved carers. Within this we would like to see better

data to describe and understand health inequalities relating to palliative care.

In Chapter 10 of SPPC's report Every Story's Ending we make detailed recommendations about the development of data to support improvement in palliative care.

13 c



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

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	

14

We would like to feedback from people with advanced disease and also from bereaved carers about their experience of care as a key outcome.

At a more detailed level we would also like to see a range of process measures which provide insight into intended positive change. Examples could include: presence, timing and completeness of ACP; presence of CSNAT carer assessment; anticipatory prescribing in last days/weeks of life; rollout of Improving the Cancer Journey.

16 a

Yes. There is evidence of worse access to, and/or experiences of, palliative and end of life care relating to the protected characteristics.

16b

There is evidence of worse access to, and/or experiences of, palliative and end of life care relating socio economic deprivation, including people in prison and people who are homeless.

Inequalities towards the end of life generally reflect patterns of inequality and discrimination within wider society. Societal approaches which tackle inequality, poverty and discrimination are fundamental to improving experiences and outcomes at the end of life. There is now good evidence for how governments can address poverty-related health inequalities by addressing the wider social determinants of health . Social movements, properly enforced equalities legislation and society-wide campaigns are the basis for challenging discrimination and stigma at societal level.

Measures which aim to make general services more accessible and person-centred will help to address inequalities in palliative and end of life care – for example work currently being done under the banner of health literacy .

In Chapter 14 of SPPC's report Every Story's Ending we make detailed recommendations about reducing inequalities specific to palliative care.

Section I: Conclusion

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

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	

17

You will be aware that SG colleagues are just embarking on developing a strategy for palliative and end of life care.

SPPC is very keen that the cancer strategy itself should fully engage with, address and embed necessary action to improve palliative care for people with cancer.

Occasionally, "condition-specific" strategies merely reference the existence (or forthcoming existence) of a national strategy/framework for palliative care, instead of setting out how the condition specific strategy itself will improve palliative care. {obviously we're talking about specific conditions which can shorten life}.

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.