Cancer strategy: draft vision, aims and priority areas

Scottish Government
Riaghaltas na h-Alba
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Full name or organisation's name

Royal College of Speech and Language Therapists

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	The Royal College of Speech and Language Therapists (RCSLT) welcomes the opportunity to respond to this consultation. Speech and language therapists (SLTs) have an important role to play in supporting better outcomes for cancer patients. A new cancer strategy provides an excellent opportunity to recognise and maximise the role of SLTs in cancer care and service development. We have worked closely with our members working in cancer care to inform our response. SLTs have expertise in assessing, diagnosing and managing disorders of communication, speech, voice and swallowing in children and adults. In cancer care, they are responsible for assessing and managing any cancer patient referred who presents with swallowing and/or communication dysfunction. Through identifying risk and impact for individuals and enabling supported management, SLTs are uniquely placed to gather a patient's story and support identification of personal outcomes – what matters to them.

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	While SLTs work with patients with a wide range of cancers, including lung, brain, oesophageal, haematological and patients with metastatic disease, the majority of those referred have head and neck cancers. SLTs see first hand how access to services

	varies greatly for those with head and neck cancers from those with other cancers, despite the increasing prevalence and significant changes in quality of life that can result after treatment. Head and neck cancer is the 8th most common cancer in the UK and 4th most common in males (Cancer Research UK, 2016-2018). While statistics like these are useful in trying to quantify the impact of certain cancers, we are aware of shifting demographics in those presenting with head and neck cancers based on feedback from our members in different areas. In this sense, we would urge health professionals not to overly rely on published statistics as this may lead to overlooked symptoms in patients who are atypical in statistical terms and result in delayed diagnosis. Likewise, there is a growing body of evidence that Human papillomavirus is linked to some head and neck cancers, and we think there is merit in a public awareness campaign that could hopefully lead to greater prevention with take up of the HPV vaccine. Treatments for head and neck cancers often significantly impact on quality of life, commonly affecting a person's ability to swallow, speak, use their voice, smell and breathe. Left unsupported, these difficulties can also affect a person's ability to participate in social activities and return to work. The effects of treatment can continue for many months and years following treatment and for some patients effects will be long-term. These patients require ongoing access to speech and language therapy for support and intervention at times right for them.

Question 1c	What do you think we should prioritise over the short-term?
Description	Consider what needs addressed within the first 3 years.
Answer	We believe access to care across the cancer journey post-diagnosis (prehabilitation, treatment, recovery/rehabilitation) needs to be prioritised. Feedback from our members suggest that while the national cancer managed clinical networks offer a great platform to provide high quality care and treatment where specialties are concentrated and accessible at regional hubs, more needs to be done to address the gaps in continuity of local care pre and post treatment. SLTs work with head and neck cancer patients who will require ongoing access to support for the effects of treatment for months

	and years, and the risks increase when this vital rehabilitation is lacking. For instance, swallowing difficulties (dysphagia), which 50-60% of people with head and neck cancer experience, can result in numerous comorbidities including dehydration, aspiration, potential aspiration pneumonia and poor nutrition requiring long term non-oral feeding. Appropriate and timely intervention with an SLT will greatly decrease the chances of having these comorbidities impacting further on the patient's quality of life. Head and neck cancer patients work with an SLT while undergoing treatment overseen by the regional network, however once a patient is discharged following treatment they are referred back to an SLT in their local health board. While the local SLT referred to does not need to be experienced in cancer care to continue supporting the patient, some of our members have raised concerns about patients being delayed in seeing an SLT once home, either through administrative issues in the health board or a lack of staffing to meet the demand in referrals more widely to speech and language therapy. There are aspects of this that relate to a national unmet demand for SLTs in Scotland, which RCSLT is regularly engaged with, however we believe there needs to be a stronger, joined-up approach to referring cancer patients to all local services post-treatment. Continuity of care is vital, especially in cancers like those of the head and neck, which often have a long-lasting impact post-treatment compared to any other time in the cancer journey.

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	Somewhat
Question 2b	Please explain your answer and provide any additional suggestions.
Description	Please explain your answer to Question 2a.
Answer	We see the merit in a 10-year strategy in that it will allow time to develop shifts in service delivery that couldn't otherwise be achieved in a shorter strategy. One area we'd like to see addressed in a 10-year cancer strategy is addressing the

	tendency of these to focus only on specialist services, at the expense of the important cancer care received through community services in local health boards. A high-level strategy could strengthen a commitment to person-centred care in all stages of the cancer journey. This would facilitate better coordination of care planning across acute, specialist services and community based, ongoing care for cancer patients. However, we also have reservations about a 10-year strategy, as with less urgency to deliver, services may not act at appropriate speed to address the real challenges faced in cancer care. The shorter-term action plans would need to be robust and as effective as a shorter term strategy in prompting delivery of meaningful change. We believe Allied Health Professionals (AHPs) should be involved in the planning and development of these plans from the outset.

Consultation Questions - Vision, aims and principles

Question 3a	Do you agree with this vision?
Description	Do you agree with the proposed vision (51.), “A compassionate and consistent cancer service, that provides improved support, outcomes and survival for people at risk of, and affected by, cancer in Scotland”, 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	We agree that cancer care should be consistent in order to provide a compassionate service, and this requires overcoming structural barriers. For instance, SLTs play a crucial role in care for head and neck cancer patients, helping them pre-treatment, during treatment and in recovery for as long as the patient needs them. However, in many areas, there is no specific cancer funding provided to speech and language therapy services to meet the demand, forcing services to divert resources from existing finite budgets. SLT services often find their person-centred, holistic approach to patient care runs into conflict with the traditional medical model approach in cancer care. This imprints on the treatment pathways that have been developed without SLT or allied health professional (AHP) involvement, creating further barriers to consistent cancer care in the

	community through delayed transfers or inability to share care plans across teams. We also believe that in order to see improved outcomes in cancer care, we need better tools to measure these outcomes. The current Quality Performance Indicators do not provide the qualitative data and we would prefer to see patient reported outcome measures included in any future data gathering. This will be crucial to providing true person-centred care. These issues need to be addressed in order to deliver on this proposed vision.

Question 4a	Do you agree with these goals?
Description	Do you agree with the proposed goals (52. a - h), 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 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	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.

Question 5a	Do you agree with these principles?
Description	Do you agree with the proposed principles (53.), 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 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	We are pleased to see a commitment to be inclusive. SLTs are specialists in identifying and working with individuals with communication difficulties, enabling them to communicate effectively, access information for health and wellbeing and advising and supporting others to do the same. Around 1 in 5 people are estimated to have a communication support need at some point in their life. For those with additional communication needs, such as individuals with learning disabilities or dementia, being diagnosed with or living with cancer can lead to inequality in access through lack of understanding and difficulty utilising services. Some individuals can be more vulnerable during health care interactions due to their communicative disadvantage, impacting on complex decision-making relating to their own health. SLTs are in a unique position to support and facilitate communication between health care professionals and these patients where this is possible. In order to truly improve access to care for everyone, we believe a new cancer strategy should adopt an inclusive communication approach to ensure no one is left behind. SLTs can support the implementation of inclusive communication through increasing the awareness, skills and knowledge of others in the public, private and third sectors and promoting communication inclusion, both at an individual level and at wider organisational or population levels.

	Better access to cancer care would include the provision of accessible information and resources for cancer patients throughout the cancer journey (prevention, screening, diagnosis, treatment, post-treatment). This would aid understanding, self management and enable decisions about their own health care. It would also be useful to consider additional training for healthcare staff regarding the impact of communication difficulties during health care interactions. SLTs are able to provide or support this training through a specialist, targeted or universal model of service delivery.

Consultation Questions - Scope and Framing

Question 6a	Do you agree with these themes?
Description	Do you agree with the proposed themes (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 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	While we agree with all of the themes, we would prioritise person-centred care (see our response to question 3.b), improving quality of life and wellbeing and outcomes (see also answer to question 3.b). Speech and language therapists (SLTs) play a crucial role in supporting cancer patients to continue what we normally think of as basic life functions of communicating with others and swallowing food and drink – functions that can often be greatly

	impaired by cancer or cancer treatment. The average length of time patients are seeing an SLT also lends to their very important role in mental and emotional support to the patient, as they often see a patient through from diagnosis to treatment to post-treatment recovery for however long that takes. The problem we are seeing is that not all health boards are able to ensure that an SLT is available (due to local/national supply issues) or can be referred in a timely manner (due to staffing prioritisation) to ensure continuity of care from the on-treatment phase to further support in the community. We think more needs to be done from the top level to ensure quality of life and wellbeing is prioritised beyond the sometimes short window in which patients are on treatment. Allied health professionals (AHPs) have important roles to play in cancer care, yet their involvement is often treated as an afterthought when it comes to care planning. AHPs must be included in cancer care planning nationally and in local health boards to ensure that appropriate workforce planning and continuity of care is prepared for and available to cancer patients.

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	In our view, the current Quality Performance Indicators do not provide the qualitative data we want to see in cancer care. As we are keen to emphasise person-centred care, we think an outcomes measure should be developed that takes into account direct feedback from the patient. This will help us understand better if we've met their needs immediately and in the long-term. We want to know how patients are surviving, and strong quality of life measures can help us understand this better.