



The Royal College of Speech and Language Therapists NI response to the consultation on the draft Northern Ireland Cancer Strategy 2021-31

October 2021

Speech and Language Therapists (SLTs) have an important role to play in supporting better outcomes for cancer patients. The draft cancer strategy provides an excellent opportunity to recognise and maximise the role of SLTs in cancer care and service development. We wish to express our thanks to the team at the Department of Health for the work involved to bring this strategy to this point and for the open consultation engagements events which we have been able to contribute to.

We have worked closely with our members working in cancer care to inform our response. Our comments below highlight the areas in which SLT can make a unique contribution to achieving the strategic priorities, as well as opportunities for improving the accessibility of all cancer services, particularly for the most vulnerable in our society.

We are hopeful that this cancer strategy offers an opportunity to review and improve the availability of specialist SLT oncology workforce across Northern Ireland. This is required in order to deliver sustainable, high-quality services for patients.

We look forward to continuing to engage with the Department on the implementation of the strategy in the future. For further information or any queries, please contact Vivienne Fitzroy, RCSLT NI Policy Adviser, Vivienne.fitzroy@rslt.org.

Consultation Questions

Strategic priorities

1 Do you agree that the strategy has identified the correct strategic priorities?

Yes/No

Do you have any further comments? **Yes – see below**

Accessible Communication and Health Inequalities – whole strategy

The Royal College of Speech and Language Therapy (RCSLT) welcome recognition of health literacy and poorer communication with health-care professionals as part of the health inequalities discussion within the strategy. However, we would welcome a much broader reference to people with communication needs, including those with a learning disability, on page 15.

Who is affected by communication needs?

Speech, language and communication needs can be lifelong and present from birth - as part of a learning or physical disability, or a stand-alone communication difficulty, such as a stammer.

Communication difficulties can also be acquired at any age, because of a head injury, dementia, stroke, a degenerative neurological condition, mental ill health or cancer.

Almost 30,000 people in NI report living with a long-term communication difficulty (NISRA 2011 NI Census).

Communication difficulties are also associated with socioeconomic disadvantage. 10% of all children will have a lifelong communication need, however in areas of high social disadvantage in NI around 50% of children start school with delayed language and other identified communication needs (Law, J., McBean, K and Rush, R. 2011; Jordan, J., Coulter, L., McKeever, A and Dowling, C. 2013).

As the strategy recognises, healthcare is highly dependent on good communication. People with communication difficulties are at a disadvantage when it comes to access and safety in healthcare encounters:

- 50% of those with intellectual or learning difficulties report challenges accessing health services due to difficulties making appointments via telephone and a lack of support and accessible information when navigating health settings (Allerton & Emmerson.2012)
- Research in Scotland in 2018 found that only 73% of service users agreed that they easily understood information given to them, about their care, by their GP (University of Strathclyde, 2021)
- A study in Canada reported that adults with communication impairments had a three-fold increase in the risk of experiencing an adverse healthcare event (for example medication errors, delay in treatment) than those without communication impairments (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008).
- People with severe aphasia are often marginalised in healthcare and are more likely to receive inadequate care (Parr, 2004).
- Negative health outcomes linked to difficulties communicating in healthcare contexts are also reported for those with communication disability (Hemsley, Werninck, & Worrall, 2013; Dinsmore, 2012).

People with communication difficulties – those with learning difficulties, mental health difficulties, dementia for example - often require more frequent interactions with health services, but may have greater difficulty accessing these services. Some individuals with communication needs may be more vulnerable during some healthcare encounters.

Accessible information and resources are important and we welcome references to these within the strategy. However accessible resources should be complimented by an awareness training among HSC professionals and service providers of the nature and impact of communication difficulties, and how these might impact on a patient's cancer journey and their interaction with services. Speech and language therapists are experts in communication and therefore best placed to provide or support this training delivery.

An important aspect of addressing health inequalities within the cancer strategy should include an explicit commitment to providing accessible services in relation to cancer prevention, treatment, living well and dying well to those who need it.

The RCSLT believe a number of recommendations within the strategy should be strengthened to support the focus of reducing health inequalities by making a more explicit commitment to accessible and inclusive services as well as information and resources. These are outlined below.

Recommendation 9: insert the word, ‘accessible’ as highlighted below in italics -

9. We will ensure that all people diagnosed with cancer have appropriate, *accessible* and targeted information and support to live well and reduce the risk of long term consequences and developing second cancers.

The RCSLT welcome the acknowledgement in the body of the strategy of the need to work in partnership with the community and voluntary sector in providing accessible resources and reaching all sections of our community when raising public awareness. The RCSLT would ask to see this commitment reflected in the recommendation 9 as outlined above.

Recommendation 24: insert the word ‘inclusive’ as highlighted below in italics.

24. We will agree a person-centred model of care, which is effective, *inclusive* and efficient, and which is built on learning from COVID 19 with increasing use of telehealth and technology and with standard operating procedures by 2022.

While there are positive benefits to the use of telehealth, it is essential that the following are taken into consideration to reduce the risks of health inequalities:

1. Issues accessing digital technology, including data usage (digital poverty)
2. Difficulties accessing digital technology as a result of communication needs
3. Literacy or language barriers.

Telehealth may be more challenging for those with a communication difficulty and some adaptations may be required in line with COVID-19 learning and best practice guidance. The RCSLT has developed telehealth guidance for our members. It provides practical guidance and examples of best practice for delivering speech and language therapy remotely and enables individuals/organisations to understand telehealth options, help to justify their decision making and support the implementation at a local level. [Telehealth as a model of service delivery in adult speech and language therapy services during the COVID-19 pandemic | RCSLT](#)

Recommendation 36: insert the word ‘accessible’ as highlighted below in italics and include a sentence within the text to expand on the meaning of the phrase “people seldom heard” to make it more accessible to a wider audience.

36. We will ensure the development of appropriate pathways and *accessible* services for older people with cancer, rarer cancers, teenage and young adults and people seldom heard.

Older people and people “seldom heard” will include people who have significant communication needs, for example associated with learning or physical disabilities, or co-morbidities such as dementia. As outlined above, if communication difficulties are not considered, this can potentially exacerbate health inequalities for some of our most vulnerable patients.

A commitment in the strategy to providing communication accessible cancer services in Northern Ireland could be achieved through a tiered approach to awareness raising and training for staff and partners supporting the most vulnerable cancer patients. This could be achieved through Communication Access UK (CAUK). CAUK is a free scheme open to all services, providers and individuals via a free e-learning course and subsequent accreditation. Upon completion of the 90 minute e-learning course services and individuals are able to display the CAUK symbol and are

empowered to support individuals with communication needs more confidently. More information on CAUK is available here. [Communication Access UK – Inclusive communication for all \(communication-access.co.uk\)](http://communication-access.co.uk).

The aim of accessible communication is to reduce communication barriers and subsequent prejudice and exclusion from society. By making some small adjustments to how we provide services and make information available, we can make a big difference in the lives of many people and families in NI. It is also vital that where there are concerns about a cancer patient's ability to understand their diagnosis and treatment options, express their wishes and feelings, or consent to treatment, that staff are aware of how to refer to SLT for support and where required, mental capacity assessments and advice. It is critical that the SLT workforce are commissioned to support cancer patients in this way.

Theme 1: Prevention

2 Do you agree that these recommendations will reduce the number of preventable cancers in NI?
Yes/No

Do you have any further comments? **Yes** - See above comments on addressing health inequalities.

Theme 2: Diagnosis and Treatment

3 Do you agree that these recommendations will improve outcomes for people living with cancer?
Yes/No - **somewhat**

Do you have any further comments? **Yes – see below**

The RCSLT are concerned that SLTs are not mentioned in the document and that Allied Health Professionals (AHPs) are not specifically referenced within the strategy recommendations. There is also concern that the discussions do not reflect some of the most pressing challenges for SLT and AHPs in meeting the needs of patients. We have made a number of suggested amendments to the text and recommendations that seek to address these concerns (in blue) and provided the supporting evidence for our asks.

Cancer – role of SLT

Speech and language therapists (SLTs) have expertise in assessing, diagnosing and managing disorders of communication, speech, voice and swallowing for both children and adults.

SLTs are responsible for assessing and managing any cancer patient referred who presents with swallowing and/or communication dysfunction. While head and neck cancers make up a significant proportion of the SLT caseload, it is not a homogenous patient group; patients with various cancers including, but not exclusive to, lung, brain, oesophageal, haematological and patients with metastatic disease are also referred. Equally, patients who are deconditioned due to illness or patients who have co-morbidities making them susceptible to swallowing and/or communication impairments are also reviewed by SLT. There is emerging evidence demonstrating the need for more frequent SLT screening and intervention of patients with lung and oesophageal cancer.

There has been recent investment in AHP within the Royal Belfast Hospital for Sick Children (RBHSC) cancer service recognising the need for optimising the potential of the child or young person to live and develop well throughout their cancer treatment. SLTs work directly with children and younger people and support families during all phases of care, liaising with regional specialist services in RBHSC and local paediatric services within child development, complex needs, school and community sectors.

Head and Neck Cancer

There is a significant body of evidence and UK published guidance (NICE Improving Outcomes In Head And Neck Cancer Guidance 2004, 2015; ENT UK Guidance 2016) demonstrating the need for holistic SLT intervention with head and neck cancer patients, at all stages of the cancer journey:

- SLTs develop and support the communication skills of both the patient and communication partners.
- SLTs have a unique and essential role to help facilitate laryngeal voice restoration post laryngectomy.
- SLTs contribute to the decision-making process regarding selection of prosthesis, care and management in Surgical Voice Restoration service (SVR) post laryngectomy.
- Early SLT intervention for swallowing problems associated with head and neck cancer requires a thorough assessment that may include both videofluoroscopy and/or FEES (fiberoptic endoscopic evaluation of swallowing) in addition to clinical assessment of swallowing which may take place prior to any treatment. 50-60% of people with head and neck cancer experience swallowing difficulties.
- Patients continue to experience dysphagia (swallowing difficulties) following head and neck cancer treatment and this can have a negative impact on quality of life. The ability to swallow is rated by patients as a high priority up to 12 months following treatment. (Roe *et al.* 2014)

Early intervention

Early intervention has a significant impact on achieving the best outcome for patients including improving quality of life, management of symptoms and the consequences of treatment. SLTs have a significant role in early intervention.

Swallowing difficulties can be a sign of head and neck cancer, so greater understanding of swallowing needs is crucial. This needs to be communicated to the public but also to GPs and other health professionals who may be the first port of contact.

Making every contact count by ensuring that all staff are aware of the signs of early cancer. AHPs and speech and language therapists in services outside of oncology can assist by being aware of the signs of cancer for prompt referral.

Challenges for SLT oncology services in Northern Ireland

Currently in Northern Ireland, the specialist oncology SLT workforce is extremely small and in some areas services continue to lag behind other parts of the UK.

- Staffing levels and service provision are not commissioned in line with NICE guidelines referenced above. This has resulted in regional variations in the availability, access and quality of SLT interventions for patients.

- *The SLT service at North West Cancer Centre (NWCC) Altnagelvin Hospital is commissioned for patients on a radiotherapy / chemotherapy pathway up to six weeks post treatment. However, this does not take into account patient needs at multiple other points on their cancer journey such as diagnosis/pre-treatment, prehabilitation/early intervention, rehabilitation beyond 6 weeks post-chemo/radiotherapy and promotion of survivorship or palliative care/end of life support.*
 - *Altnagelvin hospital is a centre for oral and maxillofacial (OMFS) and ear, nose and throat (ENT) head and neck cancer surgery. There is currently no funded SLT service to review these patients pre-surgery, acutely post-surgery or to provide any rehabilitation post-discharge from hospital. This poses a substantial risk to this patient group who often present with significant swallowing and communication impairments.*
- SLT-led instrumental assessment (videofluoroscopy and FEES) is not currently available in every trust. As such not every cancer patient has access to the gold standard in diagnostic and therapeutic SLT management of dysphagia. This is a patient safety and quality issue given the high risk of silent aspiration within this client group and subsequent aspiration pneumonia and its' consequences if left undetected and unmanaged.
 - As with other HSC professions, there is a scarcity of SLT specialist oncology clinical skills required to ensure resilient and sustainable SLT oncology services. However, these do not exist in isolation and any cancer strategy workforce planning needs to be joined up with the wider AHP workforce planning by the Department.
 - *Regionally SLTs provide a service, across a number of locations, supporting a large long term caseload in RVH & NICC. Some Head & Neck patients require specialist SLT management for life, for example for ongoing voice prosthesis and airway management and review following laryngectomy. Despite the limited capacity of this service, a lack of available advanced clinical skills in instrumental assessment across non-oncology services, instrumental cover is also provided to other SLT caseloads which places further pressure on availability of SLT for cancer patients.*
 - SLT is a small profession. We would welcome more information on how small professions can be supported to ensure that the clinical specialisms needed for effective cancer services can be planned for and maintained. It is our members' experience that supporting the best patient outcomes is often reliant on staff working far beyond their commissioned capacity. We are aware that this situation is not unique to SLTs, nonetheless it is unsustainable for patients and services and detrimental to staff well-being and retention.

Treatment

The RCSLT welcomes the move to enhance and increase accessibility of surgical and non-surgical treatments, including plans to implement the oncology transformation project and haematology stabilisation plan. However, it is important to note that these commitments will increase demand for SLT prehabilitation, diagnostic and rehabilitation services, particularly in the area of head and neck cancer. This is not acknowledged within the body or recommendations of the strategy and the RCSLT ask that this is included going forward.

Prehabilitation & Enhanced Recovery after Surgery

We welcome the inclusion and recognition of prehabilitation in the strategy and support recommendation 21. We also welcome the recognition that these are led by AHPs.

However the RCSLT would welcome the adoption of a broader definition of prehab in relation to being prior to any cancer treatment – surgical and other - not just the first cancer treatment (*Macmillan Prehabilitation for People with Cancer*, 2019). This is particularly relevant to SLT prehabilitation for head and neck cancer patients who often follow a combined pathway of treatments and prehabilitation needs are distinct for differing treatments and are also time sensitive.

It is also important to note that prehabilitation benefits are not limited to surgery. There are prehabilitation benefits for radiotherapy patients also. SLT therapeutic preparation for patients with head and neck cancer can help to achieve better patient outcomes – as discussed below. SLT also play a significant role in enhanced recovery after surgery in terms of swallowing rehabilitation which reduces the length of stay in hospital and work with patients to maximise communication function which play a huge part in quality-of-life outcomes.

Recommendation 21: The RCSLT would welcome a more detailed discussion within the strategy of how recommendation 21 will be taken forward; a clearer definition of prehabilitation; and a commitment to the inclusion of prehabilitation for non-surgical patients.

CASE STUDY: Benefits for Prehabilitation for Head and Neck Cancer Patients

SLTs at the North West Cancer Centre (NWCC) have co-produced a successful multidisciplinary head and neck cancer prehabilitation pilot project involving radiography, dietetics, speech and language therapy and clinical nursing specialists.

The impact of radiotherapy treatments for head and neck cancer patients can be severe and lifelong, commonly affecting a person's ability to speak, use their voice, swallow, smell and breathe, significantly affecting quality of life. There are potentially high risks around aspiration and well-being with the psychological impact often leading to poorer rates of return to work for head and neck cancer patients.

The NWCC head and neck cancer radiotherapy prehab project contrasted the experience and outcomes for patients with and without access to prehabilitation and found that patients were better supported through early intervention, exercises to prepare for treatment side effects and better patient outcomes.

Patients were supported to identify person-centred outcomes and strategies put in place to support this. Patients were empowered to be aware of and report worsening or unusual symptoms early, begin mouth and swallowing exercises to support recovery, to prepare for treatment sides effects, particularly how this would impact on their communication and ability to eat and drink, and take action to reduce anxiety and receive counselling support.

Despite delivering positive patient outcomes, endorsement from patients and staff, and being shortlisted for a Macmillan Professional Excellence Awards, nominated in the Innovation category, the project concluded in 2020 due to staff shortages. Project evaluation demonstrated favourable outcomes for patients, clinicians and the wider health system, including reducing admission to hospital and shortening length of stay.

Developing Prehabilitation and Rehabilitation services

AHPs need to be central in the planning process to developing regional prehabilitation services so that the benefit to patients can be maximised and evidenced best practice used to inform the nature and shape of services. However as outlined above there are significant challenges for the SLT workforce in meeting current demand with no capacity to absorb additional service delivery without appropriate commissioning. As such the RCSLT would ask that recommendation 21 is amended as follows:

Recommendation 21: expand this recommendation to provide a clearer indication of how this will be implemented, we have suggested wording below in italics.

21. We will develop and implement prehabilitation and rehabilitation services on a regional basis for all those who will benefit. *Service development will be informed by a review of AHP demand and capacity and learning from evidence-based practice from NI and elsewhere.*

Radiotherapy

The RCSLT would welcome the supplement of an additional paragraph within this section to highlight the specific impact of radiotherapy on swallowing and communication for cancer patients- some wording is suggested below.

Head and neck radiotherapy treatment has a significant effect on communication and swallowing function. Patients require significant support before, during and after treatment by speech and language therapists to manage the side effects of treatment. A growing body of evidence supports introduction of swallowing exercises before treatment with emphasis that completion during and after treatment leads to more efficient swallowing function in the long- term.

Adults with Learning Disabilities and chronic mental health conditions

The RCSLT welcome the broad reference to communication issues within this section (pg 64). As outlined previously, adults with communication difficulties includes but is not limited to those with a learning disability. It also includes all individuals with communication difficulties such as patients with ASD, physical disabilities, dementia, stroke, MND, Parkinson's disease and mental ill health.

The RCSLT suggest that the title of this section be amended as below, in italics, to be inclusive of all adults with communication needs who may require some reasonable adjustments to access cancer treatment and care in NI.

“Adults with learning disabilities, *communication needs* and mental health conditions”

The RCSLT feel this section of the strategy could be strengthened by including an indication that some patients may require onward referral for communication support to exercise their capacity and/or receive a mental capacity assessment.

Multidisciplinary teams

The RCSLT welcome the space given in the strategy reaffirming the commitment to MDTs. This could be improved further by including a reference to 'medics, nurses and AHPs' within the text.

Theme 3: Supporting People

4 Do you agree that these recommendations will deliver person centred care?

Yes/No - **unsure**

Do you have any further comments? **Yes**

Support from Healthcare Professionals

The RCSLT welcome the recognition for Clinical Nurse Specialists (CNS) in Recommendation 45: We will ensure that all patients, including children and young people, diagnosed with cancer have access to a Clinical Nurse Specialist throughout the entire care pathway. As outlined in the above case study, AHPs play a vital role alongside CNS as part of the core multidisciplinary team and as such we would welcome that this recommendation is expanded to include AHPs in recognition of the MDT approach set out in the strategy.

Recommendation 45: expand this recommendation to include AHPs as outlined below in italics.

We will ensure that all patients, including children and young people, diagnosed with cancer have access to a Clinical Nurse Specialist *and AHPs* throughout the entire care pathway.

There is further opportunity for the development of transdisciplinary working with AHPs in this area, for example advanced practice SLTs are trained in nasendoscopy and can utilise such clinical skills to support triage, diagnosis and treatment thereby maximising support for medical and nursing colleagues.

The RCSLT is interested in whether there will be scope to open up some of these roles to other health care professionals with the relevant skills and experience. AHPs working at advanced practitioner level should be considered to look at workflow and innovative ways of supporting people with cancer. The SLT-led ENT parallel clinic operating in SEHSCT is an excellent example of this type of approach. This clinic enables the SLT to undertake scoping and triaging of patients referred to ENT and SLT, thereby reducing waiting times for patients, and in discussion with the ENT consultant at the time of appointment, ensure that patients are referred appropriately for onward investigation, care and management. This has had an immediate benefit to patients as waiting time is reduced and appointments are condensed. Furthermore it delivers service cost savings – every two SLT led parallel clinics reduces the need for one ENT consultant led, benefitting the ENT and SLT services.

Support from Allied Health Professionals

The RCSLT would welcome a more detailed outline of the role of AHPs in cancer care within this section, including SLTs. However we recognise the limitations within a document of this nature. Notwithstanding this we believe this section offers the opportunity to acknowledge some of the challenges for key AHP members of the oncology MDT team – as outlined for SLT above.

The RCSLT request a review of this section to better reflect the essential AHP role in diagnosing cancer, in the delivery of cancer treatment, supporting people through treatment, leading the delivery of prehabilitation and rehabilitation services and providing palliative and end of life care. AHPs are essential in ensuring patient safety and quality of life at every stage.

In addition, we request the inclusion of a specific recommendations as outlined below.

The RCSLT would welcome the inclusion in this section of an additional recommendation, with suggested wording below:

Additional recommendation – “we will ensure that patients have access to equitable AHP cancer support services, in line with relevant NICE and professional guidance”.

Supporting people with head and neck cancer

As highlighted above, treatments for HNC commonly affect a person’s ability to swallow, speak, use their voice, smell and breathe, significantly affecting quality of life. Left unsupported, these difficulties can also affect a person’s ability to participate in social activities and to 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 speech and language therapy support and intervention. Swallowing difficulties (dysphagia) can result in numerous comorbidities including dehydration, aspiration, potential aspiration pneumonia and poor nutrition requiring long-term non-oral feeding,

With the introduction of advanced surgery, radiation therapy and targeted treatments, people are living longer after cancer with the consequences of their treatment.

Macmillan data shows increased demand for speech and language therapy for patients following initial treatment (due to patient living with long term effects of cancer treatment). This shows a need for longer term intervention and follow up support. This long-term support can be for swallowing difficulties (dysphagia) which can persist up to one year after cancer treatment is completed and beyond. Late onset dysphagia is also a significant consequence of head and neck treatment and can occur many years following treatment. Dysphagia can have a significant impact on patient safety and quality of life. Long-term support is also needed for communication problems as a result of radiation treatments or surgery such as laryngectomy and oral surgery.

The RCSLT support recommendation 50 but feel that the long-term consequences for head and neck cancer patients are not reflected well enough in the supporting discussion.

The RCSLT would welcome the inclusion of a paragraph, as set out below, on the consequences of head and neck treatment to swallowing and communication under the section “Supporting people to live well” (pg 91-97).

The consequences of head and neck cancer treatment:

Head and neck cancer treatment can have a significant negative impact on the everyday functional activities of swallowing and communication. Acute effects of chemotherapy /radiotherapy for head and neck cancer include pain, mucositis, xerostomia, odynophagia, and loss of taste. This can result in the need for nutritional supplementation and non-oral tube feeding. Persisting and late treatment effects include xerostomia, food sticking, difficulty maintaining weight, intermittent coughing, silent aspiration, aspiration pneumonia and potential need for the re-insertion of non-oral tube feeding.

Fibrosis and stricture can occur as a result of treatment and can contribute to the late onset of swallowing difficulties. Surgical treatment for head and neck cancer can have life changing consequences to both communication and swallowing. Access to long-term specialist speech and language therapy follow up is essential.

Palliative Care

The RCSLT are concerned regarding the lack of reference within this section to the requirement for funding for palliative services. Currently a large number of specialist palliative care roles are at least in part charity funded. AHPs are often funded by Macmillan, and we are aware that nursing services are also often funded or rely on charitable organisations (e.g. NI Hospice and Marie Curie). It is important to acknowledge within the strategy that commitment to increased funding is required to provide the necessary services to meet the needs of all palliative patients and their loved ones, in a timely and holistic way.

Risk stratified follow-up

It is our members experience that better follow-up post treatment is needed with improved follow-up and handover to primary care (GP/DNS) particularly within palliative care where GP/DNS are identified key workers.

The table on page 80 states risk stratified follow-up should be given to those with both curative and palliative disease, however, the elaborative section on risk stratified follow-up does not detail how this should look for palliative patients. Timely, clear handover to primary care (GP/DNS) as well as detailing any current or anticipated need relating to AHP roles would enable individuals to be referred to services in a timely way to receive optimum support for symptom management and to maximise quality of life, for the remainder of their life.

SLTs currently working in this area request increased clarity from oncology/diagnostic team as to whether/when the disease is considered palliative. This is not always clear which can delay appropriate referrals to specialist palliative care services. In the case of a person with palliative disease, it would likely lead to better patient care (and less burden on oncology services) to discharge from oncology when further treatment is not indicated, but with clear channels of timely re-referral if/when indicated for symptom management. This would avoid recalling patients, thereby reducing the need for attending these appointments, which can be burdensome for palliative patients. It is vital that clear handover at this stage to primary care clarifies the key support team for the person, rather than ambiguity of who can support and when.

Psychological support

The RCSLT welcome the recognition that people with palliative disease need timely psychological support. It is also important to highlight timely support for their loved ones/carers as emotional and psychological burden can be very high for them.

Caring when cancer can't be cured

The RCSLT welcome the reference to MDT on page 108 including AHP services. However, it would be beneficial here to acknowledge the constraints and opportunities regarding the availability of specialist AHP palliative care services where indicated – it is our understanding that these are not consistently available in all trusts at present.

There is a clear need for ongoing education regarding palliative care. SLTs are part of the MDT team in SEHSCT that run training on foundations of palliative care, advanced care planning, advanced communication skills, sage and thyme, as well as profession specific palliative care training.

Communication between acute services and out of hospital primary care services could also be improved and highlighted in this section. A key information summary on electronic care records should be mandatory for all palliative patients. Priority needs to be given to implementing the RESPECT document for documentation of key palliative decisions (including DNACPR) which will follow the individual in community and in hospital.

Advance care planning

SLTs can use their specialist skills to support people with communication difficulties to understand and engage in advance care planning. These are often the most vulnerable patients who require support to ensure they understand and can participate in complex decision-making discussions and can express their wishes.

SLTs can support advance care planning discussions in relation to eating and drinking as part of the MDT. The RCSLT has developed multidisciplinary guidance '**Eating and drinking with acknowledged risks 2021**' as an adjunct to the Royal College of Physicians (RCP) document '**Supporting people who have eating and drinking difficulties**' (2021), the primary guidance for care and clinical assistance towards the end of life. The decision-making process requires a person-centred problem-solving approach from the range of professionals involved in the individual's nutritional management and care – a reference to the Macmillan resource '[Your life and your choices: plan ahead Northern Ireland](#)' may be useful addition. SLTs may need to be involved for communication support and /or eating, drinking and swallowing management advice.

The RCSLT support recommendation 56 but would welcome recognition within this section that people with communication difficulties may need support to make informed decisions or communicate their wishes about advance care planning.

Theme 4: Implementation 11

5 Do you agree that these recommendations will enable delivery of the 10 year strategy?

Yes/No - **somewhat**

Do you have any further comments? **Yes**

Governance

Recommendation 58: *We will set up a clinically led, managerially supported NI Cancer Programme with sufficient resources to oversee the implementation and delivery of the cancer strategy*

implementation plan. This will be data driven and will include commissioning of cancer services and further policy development.

Greater detail is needed to understand how SLTs can inform the implementation and delivery of the cancer strategy.

- Will AHPS be represented on the managerial group?
- Will there be an opportunity for SLTs to inform the commissioning of head and neck cancer services?

Workforce

It is our understanding that SLT were not included in the Oncology Services Transformation work in 2019 and we would welcome clarity on whether SLT are included in the workforce review referenced in Recommendation 60.

The RCSLT welcome the statement that “allied health professionals have a key role across the cancer pathway including diagnostics, the provision of prehabilitation and rehabilitation services, providing palliative care and support for people at the end of life”. However as outlined above this does not convey the challenges facing SLT oncology services, nor is there commitment to ensuring access to these services for patients. *It is crucial that the capacity of AHP services to deliver on the implementation of the strategy is considered and that an AHP workforce analysis also informs delivery plans.*

Workforce planning needs to consider the vulnerability of service delivery of SLT resulting from a small staff pool with relevant specialist competencies and skills required to manage the long term needs of Head and Neck cancer patients.

Thank you.