10-Year Cancer Plan

Department of Health and Social Care - call for evidence

About The Royal College of Speech and Language Therapists

The Royal College of Speech and Language Therapists (RCSLT) is the professional body for speech and language therapists across the United Kingdom. The RCSLT currently has over 20,000 SLT members, including student members. We promote excellence in practice and influence health, education, employment, social care and justice policies.

RCSLT RESPONSE

Introduction

- **Speech and language therapists assess, diagnose, and treat swallowing, voice and communication difficulties arising as a result of cancer.**
- **In accordance with National Institute for Clinical Excellence (NICE) guidelines, the speech and language therapist is a named core member of the multidisciplinary team for head and neck cancer, neuro-oncology, critical care and paediatrics and young adults.**
- **While head and neck cancers make up a significant proportion of the speech and language therapy caseload, it is not a homogenous group; people with various cancers including, but not exclusive to, lung, brain, oesophageal, haematological and patients with metastatic disease are also referred. There is emerging evidence demonstrating the need for more frequent speech and language therapy screening and intervention of patients with lung and oesophageal cancer.**

Question 1: Which of these area(s) would you like to see prioritised over the next decade? Please explain why.

1, Raising awareness of the causes of cancer and how it can be prevented

2, Raising awareness of the signs and symptoms of cancer

3, Getting more people diagnosed quicker

4**,** Improving access to cancer treatment and experiences of treatment

5, Improving after-care and support services for people and their families

All of these are essential for improving care and outcomes for people with cancer.

To support the Government's ambition of increasing diagnostic capacity and treatment, and to recognise the increased survivorship from advances in treatment, we would welcome increased focus on *Improving access to cancer treatment and experiences of treatment* and *After care treatment and support*.

Providing speech, voice and swallowing support for people with advanced or later stage tumours during treatment as well as supporting people for longer post-treatment is putting additional pressure on speech and language therapy services. Without action, there is a risk of poorer outcomes. We would the government to prioritise this area to ensure that high quality and responsive services are available to meet the needs of people with acute, fluctuating, persisting and late onset symptoms post-treatment.

With the introduction of advanced surgery, radiotherapy and targeted treatments, people are living longer after cancer often with the consequences of their treatment. Speech and language therapy services are reporting an increase in numbers of people with post-treatment side effects, requiring longer term rehabilitation. Macmillan data also reports the long-term consequences of cancer and its treatment (Macmillan, 2013). The management of the consequences of treatment receives little attention.

Later identification and diagnosis during the pandemic resulted in people presented with more complex needs and more advanced cancer. This complexity has resulted in

- >longer recovery times post-treatment
- >More people requiring laryngectomy surgeries, contributing to longer recovery times
- >greater numbers of people required emergency admission for pre-treatment tracheostomy; making timely recovery with tracheostomy weaning shortens hospital stay, enables more effective swallowing rehabilitation and decreases risk of hospital-acquired infections
- >more people being admitted with aspiration-related chest infections pre-treatment and post-treatment with affects their treatment, survival and recovery times

It is common for people to experience swallowing and/or speech and voice problems from the point of diagnosis, for the duration of, and beyond the completion of oncological

treatments. This can include vocal hoarseness following radiotherapy, to significant speech or swallowing problems associated with extensive surgery (Radford et al, 2004).

It is estimated that half of head and neck and oesophago-gastric cancer patients will experience speech difficulties, dysphagia or other upper gastrointestinal problems (HJN Andreyev HJN et al, 2012) and (García-Peris P et al, 2007).

SLT 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.

Delivering these priorities

Question 2: Do you have any suggestions for how to raise awareness of the causes of cancer and how it can be prevented?

- Studies have implicated that alcohol and tobacco use are the main risk factors for head and neck cancer. However, 20% of head and neck cancer also occurs in people who do NOT smoke or drink (Ferlay et al, 2004).
- Health inequalities exist in head and neck cancer; social deprivation is identified as a specific risk that needs to be addressed.
- Of growing concern is the cohort of individuals who, with no obvious risk factors, who are developing head and neck cancer. These individuals are often young and have aggressive tumours with poor prognosis (RCSLT, 2021).
- Speech and language therapists are reporting seeing more younger people with fewer 'traditional' risk factors and presenting with HPV related head and neck cancer, which is of concern.

Recommendation: The RCSLT recommends national public awareness campaigns to increase awareness, with sensitive messages of the risks across specific population groups and communities.

Recommendation: The RCSLT recommends that all public campaigns must be communication accessible and inclusive, so they don't disadvantage people with communication needs or poor health literacy. The messages must be accessible and understandable to all the population.

Recommendation: The RCSLT recommends campaigns should continue to target smoking cessation and alcohol reduction, with measurable targets to increase the prevention of cancer across these areas.

Recommendation: The RCSLT recommends efforts to continue to increase uptake of HPV vaccination.

- Healthcare is highly dependent on good communication and a high level of health literacy.
- People with communication difficulties – those with learning difficulties, mental health difficulties, dementia for example - often struggle to access services and understand information about their health.
- Information requires high levels of health literacy to fully understand and process. Complex information is difficult for those with poor health literacy to access. In one study 61% of adults struggled to understand health information that included both text and numbers. Poor health literacy leads to poorer health outcomes.
- Accessible information and resources should be complimented by an awareness training among 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.

Recommendation: The RCSLT recommends that the Cancer Strategy must make an explicit commitment to supporting people with communication needs, and their families, to better access and understand information about risks, symptoms and how to seek help.

Recommendation: The RCSLT recommends that the Cancer Strategy commit to communication accessible information and resources.

Recommendation: The RCSLT recommends that training, on better understanding people with communication needs, must be rolled out across all NHS settings.

Question 3: Do you have any suggestions for how to raise awareness of the signs and symptoms of cancer?
During the pandemic, people reported later with cancer, due to a combination of factors including shielding, hesitancy about accessing health services, and a lack of face-to-face GP appointments. Speech and language therapists have reported that the lack of face-to-face appointments has missed early identification of the more subtle symptoms patients can present with. More people have been diagnosed at a later stage and their outcomes consequently have been negatively impacted. Healthcare professionals • We need to learn from this experience during the pandemic and 'make every contact count'. AHPs and speech and language therapists in services outside of oncology can assist by being aware of the signs of cancer for prompt referral. • Swallowing difficulties, for example, can be a sign of head and neck cancer. Speech and language therapists could contribute to GP education sessions to enhance awareness and recognition of early presenting symptoms in "head and neck" cancers. Recommendation: The RCSLT recommends that all healthcare professionals are trained in, and aware of, the signs of early cancer for prompt referral. Recommendation: The RCSLT recommends that widespread GP training and upskilling on the underlying symptoms of head and neck, and other cancers should be rolled out. National campaigns • People from lower socio-economic groups often have lower recognition of signs and symptoms of cancer. This is also the case for people with learning disabilities. People with low health literacy are significantly more likely than individuals with adequate health literacy to delay or forgo seeking care and support (Geukes, C, et al, 2019). • Awareness raising campaigns about risks, signs and symptoms must specifically tailored to be more easily understood for all people. They must be communication accessible and avoid complex information and numbers and be complemented by photos or infographics. • These should use traditional channels such as TV advertising, or trusted web sites, and consider ways of reaching at risk groups and people who do not use

technology. Public health messaging should include identification of risk factors and preventative strategies and education for the public on healthy lifestyles and preventative changes.

Recommendation: The RCSLT recommends that the Government develop appropriate, and communication accessible, information and resources for all people communication difficulties.

Recommendation: The RCSLT recommends that the expertise of speech and language therapists, as experts in accessible communication, is used to develop resources and campaigns.

Question 4: Do you have any suggestions for how to get more people diagnosed quicker?

- During the pandemic, people were diagnosed at a later stage and their outcomes were negatively impacted (RCSLT, 2021). Early diagnosis enables better treatment outcomes (including survival and reduced need for multi-modality treatment) and improved quality of life.
- The Government's ambition of increasing the diagnosis rate can be met through a combination of factors, discussed below.
- Early diagnosis can be complex, however recognising the early symptoms is critical.
- Increased face-to-face GP appointments would ensure that the more subtle symptoms are not overlooked via telephone consultations. Primary care needs to be made more accessible for all.

Recommendation: The RCSLT recommends that GPs need more education sessions to enhance awareness and recognition of early presenting symptoms in cancers, such as swallowing problems.

Recommendation: The RCSLT recommends that all healthcare professionals should be trained to recognise the signs of early cancer and how to refer.

- For people with learning difficulties and other communication issues including dementia, it may be the family or carer who notices changes that require investigation.

Recommendation: The RCSLT recommends action to upskill the wider support network to be aware of the signs and symptoms of cancer.

Recommendation: The RCSLT recommends that all information and resources about diagnosis must be easily understood and communication accessible.

- The Government must invest in the workforce along the cancer care pathway if it is serious about achieving its early diagnosis ambition. In particular, this includes availability of specialists such as ENT, Maxillofacial specialists and speech and language therapists.
- Alternative options for self-referral route, for example drop-in/walk-in clinics rather than traditional GP appointments, should be further explored.
- Investment in AHP advanced practitioner roles such as SLT diagnostic scoping would relieve pressure elsewhere such as ENT consultants. Using the workforce should be a focus on the Strategy as we move forward.

Recommendation: The RCSLT recommends that the cancer workforce is reviewed, and access ensured for all people who have speech and language therapy needs.

Question 5: Do you have any suggestions for how to improve access to cancer treatment; and improve people's experiences of cancer treatment?

1., ACCESS TO TREATMENT

- Timely access to cancer treatment is essential to ensure the best outcomes and minimise number of treatments required. This will in turn, improve the person's experiences of treatment.
- People benefit from prompt access to healthcare professionals who can help manage symptoms, prevent hospital admissions and complications such as pneumonia, prolonged gastrostomy tube duration post-treatment with increased infection risk or malnutrition, which all impact on survival outcomes.
- Once diagnosed, every person should have equal access to the best treatment. However, at present there are wide variations in access to cancer speech and language therapy provision across the country. Staffing numbers are not in line with the incidence of cancer in a region. Gaps in community services places pressure on

acute cancer services, with services being increasingly provided further away from home.

- People with cancer should be seen by specialist multi-disciplinary teams, including allied health professionals, to ensure they have access to the best clinical services and rehabilitation.
- In order to clear the backlog and meet future demand, investment in the MDT workforce at all stages of the pathway is critical. Staffing makes a critical difference to patient flow through the pathway, to patient experience, management of treatment effects, positive quality of life outcomes and survival rates.

Recommendation: The RCSLT recommends that the Government needs to invest in training the current workforce to the highest standard and investing in the capacity of the future workforce.

- People with head and neck cancer often follow a combined pathway of treatments and prehabilitation needs are distinct for differing treatments and are also time sensitive. Access to targeted and specialist allied health professional (AHP) led prehabilitation programmes results in lower symptom burden, reduction in length of stay and hospital readmissions, therefore aiding flow through the hospital. However, there is not equal access to prehabilitation across the country.

Recommendation: The RCSLT recommends that the Government investment in prehabilitation for all people with cancer to improve the success rate of their treatment.

2., PEOPLE EXPERIENCE OF TREATMENT

- Personalised care is not fully embedded into the pathway and not recognised as “everybody’s business”. Ensuring people have personalised care is important, alongside access to the relevant services that can provide specialist assessment and advice.
- To improve care, ask the people affected and their families their experience so this can be constantly improved.
- Speech and language therapists were involved in the MDT NHS England patient collaborative project for laryngectomy patients and families. This found people would prefer information to be provided in more accessible digital ways such as via apps/ online videos. This raised that people would like easy ways to find contact information to ask health professionals about their concerns.

- People with communication difficulties report less positive experience when contacting health services. By supporting communication, we can reduce the barriers and make a big difference in the lives of many people and families.

Recommendation: The RCSLT recommends the Strategy commits to supporting people with communication problems to share their experiences and feedback.

Recommendation: The RCSLT recommends all patient feedback is providing in a range of easily understood ways.

Recommendation: The RCSLT recommends all information and resources are communication accessible.

Workforce

- Care, and people's experience, can be improved through a knowledgeable and skills workforce delivering the best, evidence based, care.

Recommendation: The RCSLT recommends that the Government needs to invest in, not only the current workforce, but plan for the future cancer workforce.

Question 6: Do you have any suggestions for how to improve after-care and support services for people and their families?

- With the introduction of advanced surgery, treatment and techniques people are living longer with the consequences of their treatment.
- The latest Macmillan data shows that across the allied health professions, speech and language therapists are seeing the largest percentage of patients seen once initial treatment is complete (due to patient living with long term effects of cancer treatment). This relates to a need for longer term intervention, rehabilitation and follow up.
- Providing speech, voice and swallowing support for people with advanced or later stage tumours during treatment as well as supporting people for longer post-treatment is putting additional pressure on speech and language therapy services. Without action, there is a risk of poorer outcomes.
- A skilled and knowledgeable workforce will provide tailored care across the pathway, from pre-, during and post-treatment

Recommendation: The RCSLT recommends that the Government must invest in the cancer workforce if it is serious about achieving its early diagnosis ambition and increasing patient's outcomes. Investing in speech and language therapists, across the pathway, will provide more timely support and rehabilitation.

- Speech and language therapy services are reporting an increase in numbers of people with post-treatment side effects, requiring longer term rehabilitation. Speech and language therapists anticipate an increase in longer-term rehabilitation needs of these patients, due to delayed treatment and increased complications during the pandemic, for years to come.
- Cancer services need to be provided closer to home. There is variation in following the NICE guideline on access to SLT. Access is important for people with head and neck cancer as treatment plans can last a sustained period of time.

Recommendation: The RCSLT recommends that action is taken to ensure access to speech and language therapy for all people with cancer. Investment in community rehabilitation services will provide longer term support post-treatment.

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Investment in speech and language therapy is needed for 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 and return-to-work outcomes.

Improving data and translating research into practice
Question 7: Do you have any suggestions for how to maximise the impact of research and data regarding cancer and cancer services in England, including how we can translate research and data into practice sooner?

First:

- Trusts need to be adequately and fully resourced to enable robust and systematic data collection of patient data, including outcome measures and diagnostic coding systems.
- IT software and EPR systems should be standardised across NHS services enabling full data aggregation across Trusts and local services.
- In addition, clinicians should be provided with job plans that adequately accommodate administrative time for data entry and collation, and research time for analysis and dissemination, or additional funding/resource should be provided to outsource this work where necessary.
- Where national databases and datasets do exist (such as the RCSLT Online outcome tool collecting therapy outcome measures of patients with head and neck cancers), investment and support should be in place for clinicians to fully engage and contribute to these.
- Audits and service evaluations offer a quick way for evidence about clinical practice to inform change and quality improvement.
- A streamlined and systematic approach to data collection across England, accompanied by adequate time and training given to practitioners for its analysis will enable greater real-world evidence to be generated and thus improve cancer patient care.
- Real world data of this kind creates evidence that can be of direct translation to clinical practice.

Second:

- Much greater investment should be made for clinical research, across the research pipeline, and specifically dedicated for allied health professions and rehabilitation research.
- This should therefore include targeted funding for device development and evaluation, intervention development, scoping research and pilot/feasibility testing, scaled-up trials and importantly, implementation studies.
- Implementation science frameworks and barrier/facilitator modelling should be used at the onset of research exploring new interventions, and throughout development.
- Research funding should also be made available to allow collaborative working to become central to the research process, enabling engagement with key stakeholders including patient advisory groups/PPI groups at every stage of research.
- Funds should be targeted at priority areas, for example the RCSLT research priorities for dysphagia which found that research exploring expiratory muscle strength training for the alleviation of swallowing difficulties in head and neck cancer patients is a top priority area.
- Such investment will enable the priority research areas to be focused on and the implementation into practice easier given the demands for research in this area.
- On a related note, innovation and acceleration funding will enable the take up of evidence-based approach in to practice more easily, ie. Investing in access to specialist swallowing assessments (such as FEES and videofluoroscopy) to be able to inform post-treatment therapy exercises and recommendations.

Last:

- More broadly speaking, the establishment of multi-disciplinary multi- centre collaborative cancer research units and groups with strong links with higher education institutions would maximise participation in research as well as meaningful data collection and support for maximising the impact of research.
- These should be linked into specialist clinical groups of national importance, such as the RCSLT Head and Neck CEN, to promote research findings as well as be a platform for site recruitment and building research culture and capacity in the profession and among clinicians working in this area.
- Ideally, to accelerate research translation even faster, investment in specific clinical-academic roles and training opportunities should be funded and designed which allow backpay for allocated time for research and/or research-related professional development.

- Encourage AHP participation in clinical trials (and leadership of these) though schemes such as the NIHR Associate Principal Investigator scheme would also be beneficial and will both maximise the impact of research directly via clinicians, but also ensure the research is clinically appropriate and thus support transfer to practice.