Stroke Strategy 2020-2025

Consultation Feedback Form

To assist us in reviewing your feedback, please let us know (where applicable) where in the document your feedback relates to. Please add additional rows if required.

Space is provided below for general feedback also.

General feedback on the document
The draft Stroke Strategy focuses on 4 pillars important for stroke prevention, treatment, rehabilitation and restoration to life and education and research. These are clear and we welcome the reference to **complementary Irish health policy documents** such as Sláintecare and the Neurorehabilitation strategy. We have identified several areas that we believe will strengthen the Strategy and further aligns with health policies around supporting people with chronic conditions to live well in the long-term. This too is per the strategy and vision of the Irish Association of Speech and Language Therapists. We observe that no **Speech and Language Therapist (SLT)** inputted into the development of the draft Strategy content. This is reflected in a lack of attention around best practice support for the 64% of people with stroke (and families) affected by communication impairment including motor speech disorders and aphasia. It is additionally reflected in under-specification of SLT WTE resources with respect to international best practice levels. SLTs are the only profession qualified to assess, diagnose and treat the highly prevalent range of communication and swallowing impairments which occur post-stroke. In addition to providing evidence-based, complex biopsychosocial intervention at all stages of recovery, SLTs play a unique role in stroke liaison, advocacy and navigating and connecting people with relevant support across various stages of recovery. We further observe that **people with lived experience of stroke** (including those with communication and swallow impairments) were not included in developing the draft Strategy pillars. We believe that there is an opportunity to explicitly commit to (1) including the views of experts-by-experience in implementing the Strategy across all 4 pillars and (2) meaningful Public and Patient Involvement in the Education and Research pillar. Such inclusion is paramount for

designing quality and relevant support across the continuum of care (including pre-acute and acute stroke care) that is integrated across professional and care boundaries.

We additionally recommend explicit commitment to implementing **enhanced data collection and management** to increase equity and transparency in accessing stroke care 'at the right time, right place' etc. We suggest the following specific areas for consideration:

- Need extension of the INAS to capture data relating to post-stroke communication status, access to (or reasons for lack of access to) stroke units, ESD, rehabilitation and post-acute support (including SLT, mental health support) for each individual.
- INAS extension to incorporate a **parallel post-acute audit**, like the Post-Acute Sentinel Stroke National Audit Programme (SSNAP) commenced in the UK in 2015.
- Need **national unique health identifiers**, in line with Sláintecare, which would enable integrated data collection, monitoring and intervention design to better address health inequities in stroke care.

We provide further detail for consideration in the relevant sections below. **We welcome further discussion and opportunity to input** and to develop and implement evidence-based, person-centred interventions (across all 4 pillars) that address current documented short-comings in the transparency and equity of accessing quality stroke care in Ireland, particularly for people with post-Stroke communication and swallow impairments.

Sincerely, on behalf of IASLT:

Aoife Carolan, Senior SLT (aoife.carolan@hse.ie),

Dr Molly Manning, Lecturer, UL (molly.manning@ul.ie).

SECTION	Feedback
Stroke Prevention **P4-5**	We welcome the focus on Stroke Prevention. As documented (p4), "risk of Stroke is highest in those that have already had a Stroke" and there are barriers to effective secondary prevention in an Irish context. About 64% of people with Stroke have communication impairment. About one third have aphasia. Post-stroke aphasia affects understanding spoken and written language and expressing oneself verbally and via gesture and written language. Consequently, people with these communication difficulties experience more challenges when trying to access effective healthcare in all healthcare settings (acute, rehabilitation, primary care, general practice etc.). There is empirical evidence that information and training about working with people with post-Stroke communication impairment is not routinely available to healthcare workers across the stroke care continuum. This additionally includes General Practitioners. There is further evidence that people with post-Stroke communication impairment in Ireland have reduced access to digital technology and evidence-based self-management support. **As such, people with post-Stroke communication impairment have restricted access to the proposed secondary prevention interventions, unless communicative access barriers are addressed. This will additionally have implications for access to timely stroke diagnostics and acute interventions. This is an important safety and quality issue that we believe should be considered.** Linked with this is a need to address documented shortcomings in access to Speech and Language Therapy (see below).
Acute care and cure	PATHWAYS OF CARE

P5-8	We welcome the emphasis on developing organised pathways of acute (and pre-acute) stroke care. It's important to consider the needs of people with post-stroke communication impairment, who are at significantly higher risk of experiencing adverse events in acute care and reduced access to healthcare. This is directly linked with known lack of consistent/structured training and knowledge amongst healthcare workers and issues around communicative accessibility in healthcare settings. The following steps are imperative as part of remediating this issue (in addition to addressing SLT resourcing issues per below): 1. Per international best practice, all people with stroke require **prompt communication screening and assessment of functional communication abilities after stroke.** Early access to communication screening and/or Speech and Language Therapist support is essential to ensure early identification of aphasia status and access to communication and advocacy support in hospital settings. **It is essential that the NCPS guidelines are updated to include prompt communication screening and assessment of ability to communicate healthcare needs.** This is currently not the case in any NCPS stroke care bundle and/or the Stroke Unit care bundle. 2. **A national guideline around acute management of communication impairment and post-stroke communication impairment in acute settings will formalise early recognition of aphasia and assignment of a named team member to provide advocacy and communication support, and to ensure prompt referral to SLT.** 3. It is crucial that people with post-stroke communication impairment are **recognised as potentially vulnerable in healthcare settings**. This would firstly involve early (documented) **identification of aphasia-status at pre-acute and/or at the point of Emergency Department review** and hospital admission, with **standardised communication of communication-status to all relevant staff** and beyond to rehabilitation and primary care. Ideally, this would be monitored via the INAS as described above and again supported by the introduction of a unique health identifier. 4. **Support with transitions of care** for people with post-stroke communication and swallow impairment has been previously recommended. This type of support would **need to be formalised by the NCPS** to ensure that the function was **delivered regardless**

of availability of, and access to, Stroke Units. If this role was limited to Stroke Unit Nurses, it would exacerbate the inequity and vulnerability experienced by those who are not admitted to Stroke Units.

STROKE UNIT / "**ORGANISED INPATIENT CARE"**

We welcome the focus on increasing consistency of access to acute Stroke Units for all patients with stroke across Ireland. There is additional evidence that people with communication and swallow impairment in Ireland value access to Stroke Units over general wards as they are perceived as being more communicatively accessible, restful and with better coordination and access to therapy across the multidisciplinary team.

The evidence supporting effectiveness of Stroke Units in the recently published Langhorne et al (2020) Cochrane meta-analysis (the 2013 version is referenced on p5 in support of Stroke Units) examines and emphasises the important element of "**co-ordinated multi-disciplinary care using standard approaches to manage common post-stroke problems**." Therefore, **we recommend that this emphasis is referenced explicitly in this section, and that shortcomings in relation to SLT referral (per care bundles above) and staffing (see below) are addressed.**

SLT RESOURCING

We must recognise the importance of HSCP staffing at different skill levels for stroke care as recognised in national stroke audit (2015: 47). 'A mix of therapy grades is required to deliver optimum care to the person who has had a stroke, and this includes basic, senior and clinical specialist posts (Guideline A)'. A commitment to investing in SLT/HSCP posts across these levels is required..

Stroke Units

	We observe with concern that the Speech and Language Therapy staffing recommendations of 0.4 WTE for a 5-bed Unit are at odds both with clinical need and international best practice. As above, SLTs are the only profession qualified to work with a range of common post-stroke sequalae including communication and swallowing impairment. Shortcomings in access to SLT in Ireland are documented across a number of recent reports; and this is further exacerbated by the dual role of Speech and Language Therapists in managing dysphagia and communication impairment, which has resulted in reduced resourcing for supporting people with communication impairment in recent decades (in Ireland and internationally). SLTs are instrumental in delivering complex interventions for people with post-stroke speech, language, cognitive-linguistic and swallowing impairments; at all stages of recovery. In addition to direct intervention, the role involves psychosocial treatment, education, training, advocacy and liaison support to increase communicative access and informed decision-making for patients with swallow and communication impairment. The latter is of safety concern given the documented lack of communication training for other healthcare workers involved in stroke care (outlined above). **Acute - general** Similar shortcomings in SLT resourcing have been documented in the past 5 years in general acute settings. Acute stroke care SLT staffing levels are 30.9% below minimum international standards and community staffing deficits are likely to be significantly higher (although please see point below about the need for effective data system to improve transparency and equity of access and integration of stroke care across settings and professionals). **We therefore call for the following:** 1) SLT staffing to be in line with PT and OT colleagues in terms of WTE and allocation of financing.

	2) In the context of Stroke Units, we query the validity of allocating 45 minutes of SLT input only for patients with multiple (non-overlapping) impairments requiring SLT input for communication and swallowing. 3) We observe that just €1m of €7.5m HSCP Stroke Unit budget is for SLT. **This is insufficient for providing a quality, safe service.** 4) Best practice community resourcing. Although the Strategy document (p18) suggests that most patients (83.5%) seen by SLT in acute Stroke Units in 2018 required onward post-acute SLT follow up, there are documented access barriers to community SLT in Ireland. Additionally, there is evidence that SLT, when available, is generally of insufficient dosage for effectiveness. There is a real need to increase SLT WTE resourcing to international best practice levels. As above, this is particularly salient considering the increased (dual) remit of SLTs in dysphagia management, which has at times reduced capacity for supporting people with communication impairment. Additionally, **increasing community SLT capacity is especially important in primary care regions which will continue to be unsupported by an ESD service.**
Restoration to Living **P8-10**	We welcome the emphasis and focus given to Restoration to Living. We have identified several key **omissions in the scope of this pillar based on the relevant evidence-base. A high-level summary is below.** - Given the documented shortcomings in Stroke care, particularly relating to **fragmentation, variable access and front-loading of post-acute stroke care**, the Stroke Strategy would be strengthened by explicitly aiming to provide a responsive, quality pathway of care, integrated across care settings, sectors and professionals **to support people to live well in the long-term post-stroke**. - The scope and focus of the 'rehabilitation and restoration to life' pillar must be broadened and refined. As it stands, it remains under-specified with respect to the long-term support and social participation needs of people living with the consequences of Stroke, including people with communication impairment and their families.

- As such, the Strategy is not sufficiently aligned with national and international health policy emphasising person-centred approaches to supporting people affected by chronic conditions to live well and to achieve personally meaningful goals across the life-course, including the stated 2020 Strategy of the Irish Association of Speech and Language Therapists.
- Related to this, the concept of Restoration to Living is not explicated in scope or timeframe. It would benefit from explicitly aligning with concepts and goals in related policy documents to support people with stroke to 'live well' across the life course.
- This is particularly salient in the context of increasing incidence of stroke in working-aged adults who will have unique needs (for a longer number of years) around social participation, vocational training and education, return to work, parenting and supporting young families. This too has implications in the context of international research demonstrating *inconsistent access to post-acute stroke care for working-aged adults* with stroke.
- The Strategy should explicitly reference and address the complex psychosocial support needs people affected by post-stroke communication impairment (occurring in about 64% of people with stroke). People with communication impairment post-Stroke additionally experience poorer outcomes compared to those without communication impairment on a range of measures including hospital length of stay, health-related quality of life, return to employment, social networks and participation and depression.
- The Strategy should address healthcare access barriers for people with communication impairment through training for other healthcare professionals involved in stroke care and joint-working, for example between SLTs and psychologists and GPs.

EMOTIONAL SUPPORT NEEDS

- There is evidence that **communication impairment is a barrier to accessing appropriate psychological support in Ireland** and elsewhere. The Strategy needs to critically address the general exclusion of people with post-stroke communication impairment from stroke research examining psychological support – due to the nature of their acquired impairments. **There are several steps that will need to be taken which will ensure that mental healthcare professionals are equipped to support communicative access to emotional support that is *communicatively accessible* and in line with best practice with this population**. This would

take the form of a whole-systems approach including peer-support, self-management support and stepped psychological care (jointly with SLT and psychological professionals).

SELF-MANAGEMENT AND ACCESSIBLE INFORMATION:

The Strategy needs to address a need to develop and implement effective, inclusive self-management support and accessible information formats (including a comprehensive, maintained, accessible database of relevant community support) to support people to self-advocate and navigate the healthcare system.

KEYWORKERS

- Whilst we broadly welcome the concept of Key-Worker support in the community, it is important that the Strategy explicitly includes the following components of the role: **informational, emotional, liaison and advocacy support. Additionally, all Keyworkers / Stroke Liaison Workers must have appropriate communication impairment competencies.** This role should be **formally integrated across acute / community settings to ensure that people with aphasia are not lost to support and tracked via the updated INAS and unique health identifier** as discussed above. Finally, the boundaries of this role in relation to other similarly planned roles (e.g. case management role in the National Strategy & Policy for the Provision of Neuro-Rehabilitation Services in Ireland). The evidence around clinical and cost-effectiveness of Stroke Liaison support is equivocal and will require a collaborative, participatory approach to its implementation. People with communication impairment are generally not included in research studies examining Stroke Liaison interventions. The same can also be said of a Stroke Passport intervention, which would need further participatory implementation and evaluation.

EARLY SUPPORTED DISCHARGE

	We welcome the commitment to increase access to ESD. Increased supports to allow therapy in patients' homes as soon as possible post Stroke is positive. However, **this draft Strategy does not sufficiently address variation and shortcomings in access to regional ESD teams around Ireland.** For example, a patient discharged home from Midland Regional Hospital Mullingar to Co. Offaly will not have access to ESD under proposed model. **We strongly recommend, at minimum, increasing HSCP community staffing in areas not supported by ESD.**
Research and Education p. 10-13	We welcome the inclusion of a Research and Education pillar, essential for designing, implementing and evaluating quality, evidence-based, person-centred stroke care. This represents an important opportunity to address the following shortcomings in the stroke evidence-base, essential for delivering quality, accessible and inclusive support. 1) Addressing a lack of inclusion of people with post-stroke communication impairment in research studies examining interventions for post-stroke depression, stroke liaison support, stroke passports and self-management support. Further participatory implementation science approaches required to address evidence-practice gaps extensively documented. 2) Meaningful inclusion of people with lived experience of stroke (including those with communication impairment and aphasia) in setting the research, policy and service improvement agenda. 3) Training to increase communication competence of healthcare workers for post-stroke communication impairment (per above). 4) Targeted information campaigns around common sequalae of stroke including communication and swallowing impairments. Increased awareness would help support inclusion and access in the community and to commercial and public organisations. Such campaigns would be underpinned by interdisciplinary knowledge from marketing, health promotion and communication research, and co-developed with PWA, families and healthcare professionals. 5) Implementation science approach to developing and evaluating new data collection and management system as above. 6) **Investment in clinical specialist and clinical academic posts for SLT/ HSCPs.**

Thank you for participating in this consultation. Please return feedback forms to edina.odriscoll@hse.ie by **5pm on Wednesday 18th November**