DEMENTIA RESEARCH NETWORK IRELAND

Prevention, Cure & Care for Neurodegenerative Diseases

Proceedings of the DRNI Policy and Practice Forum: Referral of People with Dementia to Speech and Language Therapy Services

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Contents

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1.0 Introduction

The aim of DRNI Policy and Practice Fora is to implement new or influence existing policy in the dementia / neurodegeneration field. The aim of this Policy and Practice Forum was to explore issues relating to the referral of people living with dementia to Speech and Language Therapy (SLT) services in Ireland, and to identify barriers and facilitators to early referral.

2.0 Background

According to a survey by Dooley and Walshe (2020) of Speech and Language Therapy practice in Ireland, people living with dementia are not routinely referred to SLT services for communication intervention[1]. The clinical trend is for later referral of people living with dementia to SLT services for the management of dysphagia and not communication difficulties.

A Position Paper issued by the Irish Association of Speech and Language Therapists (IASLT) in 2016[2] on the provision of SLT services to people living with dementia, reiterates that early referral of people with dementia for communication assessment ensures that people living with dementia can avail of interventions at the earliest possible opportunity, resulting in maximum effect. Early referral for communication evaluation, intervention and support ensures a holistic approach to care from an early stage and will improve everyday communication function, communication independence, and psychosocial wellbeing. The identification of a person's communication profile can facilitate integrated multidisciplinary team (MDT) working, support decision-making and improve care planning. However, early referral to SLT services of people living with dementia for management of communication difficulties is not standard practice.

The DRNI Policy and Practice Forum aimed to explore these issues in more detail with SLTs, clinicians and people with experience of accessing SLT services for dementia.

3.0 Forum Format and Participants

The Forum took the form of a two-hour online meeting. Forum participants included a Clinical Specialist SLT (Dementia), a SLT Manager, six senior SLTs, a Consultant Geriatrician and a person with experience of accessing SLT services for her husband. In relation to the SLTs and Geriatrician, people with dementia are a large part of their caseload. The participants were mostly employed in hospital-based services, supporting people with dementia as in-patients on acute hospital wards and/or out-patients of memory clinic and day hospital services. One SLT was a member of a Psychiatry of Later Life (POLL) team's memory assessment service. The majority of participants were based in Dublin, but included one SLT based in Westmeath and one based in Portlaoise in a service covering the counties of Laois and Offaly. One SLT had previous experience of working in a primary care setting. The wife of a person living with Primary Progressive Aphasia (PPA) joined the meeting to share her experience of and

[1] Dooley and Walshe (2020) Management of Cognitive Communication Difficulties in Dementia: A Cross-sectional Survey of Speech and Language Therapists in Ireland. http://dementianetwork.ie/management-cognitive-communication-difficulties-dementia-cross-sectional-survey-speech-language

[2] IASLT (2016) Position Statement: Speech and Language Therapy Provision for People with Dementia, https://www.iaslt.ie/documents/public-information/Adult%20Speech%20and%20Language/IASLT%20Position%20Statement%20SLTServiceProvisionDementia2016.pdf

perspective on early referral to SLT services for her husband. See Appendix I for list of participants.

A topic schedule was used to guide the discussion. It included the following four questions:

1. How common is early referral to SLT services for people diagnosed with dementia in Ireland?
2. What are the benefits of early as opposed to late referral to SLT services for people diagnosed with dementia?
3. What are the barriers and facilitators to early as opposed to late referral to SLT services for people diagnosed with dementia?
4. Are there any recommended actions around the referral of SLT services for people diagnosed with dementia in Ireland?

4.0 Summary of Discussion

The Forum was chaired by Dr. Suzanna Dooley, Clinical Specialist Speech and Language Therapist (Dementia), HSE. The chair thanked DRNI for organising the Forum and for providing SLTs with the space and time to discuss this important topic, and shining a light on it**.** The four questions in the topic guide have been used to present the points raised and discussed at the Forum.

Q.1 How common is early referral to SLT services for people diagnosed with dementia in Ireland?

The discussion as to how common it is for people diagnosed with dementia in Ireland to get an early referral to SLT services revealed that experiences are very different depending on the clinical care setting.

Primary care

Participants reported that when people diagnosed with dementia were referred to primary care-based SLT services, referrals were mostly from public health nurses (PHNs) for dysphagia among people at the later stages of dementia. Referrals to primary care-based SLTs for cognitive communication difficulties in dementia are rare to non-existent. Referrals of people with dementia for cognitive communication difficulties mainly come from day hospitals and memory clinics, and in some community care areas can be as low as two to three referrals per year. Factors identified as contributing to low referrals of people with dementia to primary care-based SLT services included: (i) limited SLT staff in primary care; (ii) lack of knowledge about the role of SLTs in dementia care especially in relation to cognitive communication difficulties; and (iii) the prioritisation in dementia care of dysphagia over cognitive communication difficulties. It was reported that in one North Dublin area, a group therapy service was established for people with dementia experiencing cognitive communication difficulties, but despite an awareness raising campaign targeted at general practitioners (GPs) and PHNs, the number of referrals was so low that the group intervention could not go ahead. Participants report that SLT colleagues in primary care were much more likely to receive referrals to assess cognitive communication difficulties among people with neurological conditions such as Parkinson's disease, Motor Neurone Disease and Multiple Sclerosis than for people with dementia.

Referrals of people with dementia experiencing cognitive communication difficulties from GPs and other primary care professionals to hospital-based SLT services tend to be low, attributed to poor levels of knowledge about cognitive communication difficulties and the role of SLTs. St Columcille's Hospital (SCH) has developed initiatives aimed at increasing referrals of people with dementia and cognitive communication difficulties from primary care to its hospital-based SLT services. It found that referrals increased when PHNs and other primary care professionals were provided with training about the benefits of making a referral to the SLT service. Improved communication between staff in hospital-based SLT services and primary care professionals also helped. Despite these initiatives, referrals from primary care remain low.

Memory services

Participants discussed their links with dementia assessment and diagnostic services as well as day hospitals and the role these services play in referring people with dementia and cognitive communication difficulties to SLTs.

Tallaght University Hospital (TUH) has a well-developed memory service. The Senior SLT on the hospital's age-related service is linked into the memory service and is frequently involved, often early on, in the diagnostic process. As they work through the diagnostic process, advanced nurse practitioners, the medical team and other members of the memory service multidisciplinary team pay attention for any signs of cognitive communication difficulties, and, where a need is identified, this is followed up with an early referral to the SLT. At times, a person with dementia may be referred to the SLT for dysphagia, and this provides an opportunity to assess for cognitive communication difficulties as well. A well-developed pathway supports the referral process from memory service staff to the SLT. Staff in the memory services have seen the benefits of SLT involvement.

In St James's Hospital, the Senior SLT works across the acute wards, rehabilitation wards, day hospital and long-stay care setting. Although not directly linked into the hospital's memory clinic, referrals from the memory clinic are sometimes made to the SLT through the day hospital. The SLT is mostly asked to get involved in cases where a diagnostic work-up is still ongoing, but a formal sub-type diagnosis has not been made. The SLT may also get involved where a person needs support with communication.

In Portlaoise, the senior SLT has been a member of the Psychiatry of Later Life multidisciplinary team since 2015. The team, which includes an old age psychiatrist (OAP) and an advanced nurse practitioner (ANP), covers counties Laois and Offaly and operates a cognitive assessment service. Patients attending the service are initially seen by the OAP and ANP, who make a referral to the SLT where needed (e.g., where a person reports word finding difficulties) for assessment and treatment of cognitive communication difficulties. Most of the referrals to the SLT are made by the ANP. The number of referrals has increased over time as the ANP has become more knowledgeable about the role of the SLT and the contribution that SLT can make, and has seen the positive outcomes for people with dementia who receive SLT input. The SLT no longer has to seek referrals.

A SLT pathway for people with dementia attending the memory service in SCH has been established and referrals of people with early dementia (attending the memory clinic) to SLT has grown significantly over the past 5 years, particularly those with MCI or for differential

diagnosis. There is a dedicated Clinical Specialist SLT that links with the memory service to facilitate timely access for communication assessment and intervention as well as dysphagia management. A concern was expressed that memory clinic staff may believe that once a person has been referred to an Occupational Therapist (OT) for cognitive assessment, all aspects of cognition will be covered. However, this is often not the case meaning that cognitive communication difficulties may be missed. In the day hospital in SCH, there is a SLT on the team who is able to advocate for early referral of people with dementia experiencing cognitive communication difficulties.

In the Mater University Hospital, SLT services are not linked into memory services and therefore do not receive referrals from memory services. In Mullingar Regional Hospital, people presenting with memory problems tend to be referred elsewhere for memory assessment and dementia diagnosis due to lack of MRI scanning equipment and limited memory services in the area. The hospital also lacks a day hospital and specialist geriatric ward. As a consequence, SLTs in the regional hospital do not receive referrals of people with dementia experiencing cognitive communication difficulties.

Acute hospital in-patients

SLTs working with in-patients in acute hospitals reported that there are differences between hospitals. However, they mostly see people with dementia for dysphagia, and referrals of people with dementia for cognitive communication difficulties tend to be less common. Referrals for communication difficulties tend to be of people with dementia towards the more advanced stages and SLTs are usually needed to provide support to staff who are having difficulty communicating with the person, support with decision-making capacity assessments and to get involved when there are problems with discharge. Referrals may also be made to SLTs when an in-patient has a diagnosis of Primary Progressive Aphasia (PPA), or when a sub-type of dementia has been misdiagnosed, but this is rare. When a person with dementia is referred with dysphagia, SLTs use this opportunity to carry out a holistic assessment, which provides an opportunity to assess for communication as well as dysphagia.

With respect to in-patients in acute hospitals, participants noted a difference between general medical wards and care of older people's wards. On the care of older people's wards, people with dementia tended to be referred earlier to SLTs, and while these referrals are not always for communication difficulties, there is good acknowledgement of addressing communication needs among staff working on these wards. In contrast, it is extremely rare to receive a referral from the general medical ward of a person with dementia for communication assessment.

In-patients with dementia experiencing communication difficulties can be referred to SLTs by any staff, but the majority tend to be from the medical team, followed by nursing staff, and referrals are also sometimes made by occupational therapists (OTs) and physiotherapists. In St James's Hospital, there is good OT staffing in the age-related service, but on the general medical team OTs are short staffed. This means that referrals to OTs may be picked up first by the SLT who will include a cognitive communication assessment.

The presence of speech and language therapy does appear to increase early referrals to speech and language therapy for cognitive communication difficulties. For example, in SCH, an audit conducted in 2016 of in-patients on acute hospital wards referred to SLT, revealed

that 60% of people referred had unidentified communication difficulties associated with dementia or speech problems related to Parkinson's disease. However, the presence of a SLT with the knowledge and skills to advocate for the service led to an increase in referrals of people with dementia for communication difficulties by 52% over the time period of the audit and an increase by 82% in referrals for support with decision-making for future care planning.

Long-stay residential care

In St James's Hospital, participants reported that the majority of residents in long-term care settings attached to acute hospitals were people with mid- to late-stage dementia who had cognitive communication difficulties to different extents. Prior to the Covid -19 pandemic, staff were actively running group interventions such as the Sonas or reminiscence programmes, which helped with communication, and there was also some capacity for SLTs to provide one-to-one support with communication. However, this was only possible because SLTs had protected time and such interventions are not available to in-patients on the acute medicine of the elderly or rehabilitation wards.

Self-referral

Self-referral of people with dementia experiencing cognitive communication difficulties is rare.

Q.2 What are the benefits of early as opposed to late referral to SLT services for people diagnosed with dementia?

Participants identified a wide range of benefits of early as opposed to late referral to SLT services for people with dementia including aiding the diagnostic process. Acknowledging and explaining cognitive communication difficulties and providing timely and accurate information were identified as benefits for people with dementia and their family carers. The benefits from assessment of cognitive communication difficulties in dementia for therapeutic intervention and social prescribing were discussed, as well as the further benefits to which they lead. Other benefits discussed included support with decision-making and support to family carers. Benefits of early referral within the acute hospital setting were also identified. Each of these benefits is discussed in more detail below.

Aiding the diagnostic process

Participants spoke about the benefits of involving SLTs in the diagnostic process. They highlighted the valuable role that SLTs can play in assessing cognitive communication to aid differential diagnosis. They stressed that this role was valuable not just for memory services, but also for other out-patient clinics where medical doctors and other health professionals are involved in memory assessment and making a dementia diagnosis.

It was pointed out that SLT input when a dementia diagnosis is made late has its limitations, and in this context, the importance of early and timely diagnosis for ensuring that SLT involvement was beneficial was emphasised, especially for atypical types of dementia. Assessment of verbal fluency and semantic skills by a SLT, for example, can help with diagnostic decisions when undertaken at an early stage of disease progression. However, as dementia progresses, linguistic ability diminishes and it becomes more difficult to use speech and language assessments to aid differential diagnosis, even at a moderate stage of dementia.

Making a dementia diagnosis is difficult. The benefits were stressed of having the perspective of SLTs alongside those of medical doctors and other health professionals at diagnostic consensus meetings, for making a more informed and accurate diagnosis.

Acknowledging and explaining cognitive communication difficulties

Many people, including people with dementia and their family carers, associate dementia with memory loss, but less is known about the cognitive communication difficulties that people with dementia experience and the impacts that this has on the person and their family members. Participants believed that knowing about the existence of SLT and getting a referral to a SLT early on can be an important indication to people with dementia and their family members that cognitive communication difficulties exist and are real. SLT play an important role in validating their experience: 'if you [SLT] exist, then obviously my communication problems exist'.

Providing accurate and timely information to person with dementia and family carers

It was argued that access to a SLT with an understanding of cognitive communication difficulties and who can provide timely and accurate information, advice and education will have a significant impact for the person with dementia and their family carers. It gives people with dementia and their family carers an opportunity to ask questions about cognitive communication difficulties. With a better understanding of dementia from the perspective of speech and language, the person may be able to better come to terms with the diagnosis and any associated changes in communication. The SLT can also play a role in explaining progression of cognitive communication difficulties and communicate a positive but realistic message that there are things that a person can do to lessen some of the difficulties. Late referrals were seen as a missed opportunity to provide accurate information and advice about cognitive communication difficulties in dementia.

It was felt that people with dementia and their family carers are better able to take in and process information when dementia is at an earlier stage when the person still retains many of their cognitive and communication skills and abilities, but that this is much harder when dementia has progressed and the person and their family may be dealing with much more complex issues and problems. Experience of the Forum participants is that late referrals to SLTs often happen at a time of crisis and the crisis tends to overshadow everything. The crisis takes the focus off the person and can mean that a person with dementia may not or is less likely to have their voices heard or their wishes and preferences considered.

Participants explained that what information is given (or not given) to people with dementia and their family carers about cognitive communication difficulties, and how that information is communicated, has implications for what happens next. There was concern that without input early on from a SLT, people with dementia might rely on or be influenced by others, for example, family members who themselves may have little knowledge about and poor understanding of cognitive communication difficulties and what interventions may be needed. In this context, participants felt that SLTs have an important, influential and beneficial role to play in helping to place the person with dementia on the right path following or soon after diagnosis.

Mary, the wife of a person living with PPA, supported this view and provided a personal perspective on the benefits of early referral of a person with cognitive communication difficulties to SLT:

> "*The early stage [after a dementia diagnosis has been made] is when you are making sense of this new life development, where you are trying to create a new picture of what this means for you with very little to go on. There is no point telling people 'Don't google it', which is the best advice, but that is what everyone is going to do and seeing You Tube videos with advanced PPA [primary progressive aphasia] is not a good idea when you have had a diagnosis. And I think we got that access early on [to SLT] and it shaped so much in terms of an orientation towards being positive, a focus on strengths. A reminder of all the communication strategies still available was really influential in calming us down and instead of this very amplified environment in which the diagnosis is in the foreground looming large and consuming enormous proportions, I think contact with SLT allowed it to take its place alongside other things in life. It is transformative. You start to fix your idea of what dementia means for you quite quickly and those early influences are very important.*"

The importance of advanced care planning and starting conversations about future care early on when a person can be involved as much as possible, was stressed by participants. It was felt that SLTs can play an important role in advocating for the person at that stage, ensuring that such conversations and care planning are done sensitively, and helping the person to document their care plans.

Assessing cognitive communication difficulties for therapeutic intervention

A benefit of early referral to SLT is that a good baseline of cognitive communication can be established for a person with dementia. This can be used to identify cognitive communication difficulties at an early stage and to monitor progression over time. Participants stressed the value of a person-centre, holistic approach to care. Importantly, information from assessments can be used to determine the need for therapeutic interventions early on, identify appropriate therapeutic interventions that are available and assess the person's suitability for these. Signposting to therapeutic interventions that are available locally to support a person with dementia experiencing communication difficulties was seen as an important and beneficial role of SLTs. This type of assessment and signposting is not a once-off event but can be used to link people with dementia with most appropriate support as dementia progresses.

Social prescribing to build confidence, maintain skills and promote social inclusion

Participants stressed the importance of involvement in group-based activities and interventions early after diagnosis and on an ongoing basis for helping the person to maintain communication skills, build confidence, and keep them socially involved and engaged. Such involvement could help to prevent social isolation and social exclusion that can come with cognitive communication difficulties in dementia and would contribute to a better experience of dementia over a longer period of time. Assessments of people with dementia by SLTs includes assessing the person's capacity and suitability for potential involvement in groups, especially those with a strong conversational element. The SLT, using information gleaned from assessments, help people with dementia and their family carers to navigate services and support and link people with dementia who have cognitive communication difficulties with appropriate services, as well as helping them to get involved in local support groups. Having

an opportunity to be in conversations with other people, especially those in a similar situation, to build and maintain relationships with other people and derive benefits from peer support was seen to be really important for people with dementia. However, SLTs find that when people with dementia are referred late to SLTs, the assessment is often too late as the person may have already lost confidence, have become withdrawn, and it becomes harder to get people linked back into groups and to maintain skills.

Early assessment and intervention by an SLT were also seen as an enabler for other services in that the SLT could play a facilitative role in helping the person with dementia and the staff offering supports and services to engage with each other.

Supporting involvement in decision-making
Early referral was seen as important for helping the person to be involved in decision-making, whether the person is living in the community or in hospital.

Providing support to family carers
The participants acknowledged that caring for a person with dementia is challenging and that cognitive communication difficulties in dementia can make caring even more difficult. At the same time, family carers play an important supportive role for people with dementia such as reminding the person about the strategies that they can use to support communication and prompting them when to use them. Working with families to support them in their supportive role, and to help alleviate caregiver stress when communication is challenging, could pay benefits in terms of promoting good relationships between people with dementia and family carers and helping these to last longer.

Benefits of early involvement of SLT in hospital settings
It was felt that the above roles could be played by SLTs in all care settings including hospital settings. For example, getting SLTs in acute hospital settings involved early on, for both in-patients and out-patients, could help to ensure that appropriate referrals are made to suitable primary and community care supports and interventions.

The benefits of early referral to SLTs when a person with cognitive communication problems is admitted to hospital in particular were stressed. It can lead to finding a missed dementia diagnosis or to a SLT advocating for involvement of a geriatrician. It gives the SLT an opportunity to introduce a therapeutic intervention, that may not be available elsewhere, early enough before the person transitions to another setting. If the therapeutic intervention is shown to be beneficial, the SLT may potentially be able to influence what happens next and what supports the person gets with cognitive communication difficulties when they transition to another care setting, whether the transition is home or to a nursing home.

Participants reported that SLTs are mostly involved with in-patients when issues arise, especially around care planning and discharge. A key role played by the SLT in this regard is ensuring that the person is involved in decision-making and their wishes and preferences are communicated, as well as liaising with the family This provides another example of how involvement of SLT can impact on what happens next.

Q.3 What are the barriers and facilitators to early as opposed to late referral to SLT services for people diagnosed with dementia?

Participants identified and discussed a range of barriers and facilitators to early referral to SLT services for people diagnosed with dementia. In the sense that barriers and facilitators are often two sides of the same coin, the barriers and facilitators discussed are presented under thematic headings.

Prioritisation of dysphagia and acute medical issues over cognitive communication difficulties in dementia

One of the barriers to early referral to SLTs of people with dementia experiencing cognitive communication difficulties is the prioritisation of dysphagia in dementia and the acute medical issues that this presents. While this was an issue for most SLTs, it is a particular issue for SLTs working with in-patients in the acute hospital setting, where SLTs reported getting few referrals of in-patients for cognitive communication difficulties. Moreover, when they did get referrals of people with dementia experiencing cognitive communication difficulties, they found that they had to prioritise patients with dysphagia and acute medical issues as these were most pressing at the time. Referrals for cognitive communication difficulties tend to get pushed to the bottom of the pile.

The prioritisation of dysphagia over cognitive communication difficulties was also attributed to attitudes and the perception that communication is 'a soft area' and less important than medical issues that have a physical manifestation, and hence services focusing on such medical issues are prioritised. A person asked what their priority is may identify communication difficulties as a priority issue, but often the response is 'that's fine, but it is not a core service issue'. It is seen as an add-on or an extra rather than core to what the service responds to.

While it was accepted that dysphagia and other acute medical issues are always going to take priority, the importance of making space for communication was stressed. The way in which SLT has evolved historically was referred to – from a time when SLTs were regarded as experts in communication to a time when SLTs began to embrace dysphagia which had been up to then overlooked, to the present time when dysphagia has become the core of SLT's work and predominates over cognitive communication difficulties. Given that change has happened in the past, there is potential for change to happen again in the future, which can be regarded as a positive. Seeking to redress the low prioritisation of cognitive communication difficulties in dementia was seen to be a joint responsibility of SLTs and their SLT manager.

A model that appears to work well in terms of redressing the imbalance between dysphagia and cognitive communication issues is having a dedicated SLT attached to a memory service, as illustrated by the POLL cognitive assessment service in Portlaoise. Timely referrals are made to the SLT after a dementia diagnosis is made, meaning that most referrals are of people early in the progression of dementia and, accordingly, are mainly referred for assessment and treatment for cognitive communication difficulties and rarely for dysphagia.

Awareness and knowledge of cognitive communication difficulties in dementia and SLT's role

Poor awareness of and lack of knowledge about cognitive communication difficulties in dementia was identified as a major barrier to early referral. A related barrier is a general lack

of awareness and knowledge of the role that SLTs play in the assessment and treatment of cognitive communication difficulties in dementia. Lack of awareness and knowledge were seen to exist at a number of levels:

At the health professional level

Participants reported that understanding about cognitive communication difficulties in dementia and the role that SLTs play is generally poor among medical and health professionals. The perception among many professionals is that the SLT role in dementia care relates solely to dysphagia. This perception is most pronounced in the acute setting where dysphagia is a large part of the SLT caseload and is likely to be reinforced where professionals only ever see SLTs working with patients with dementia who are experiencing difficulties associated with dysphagia.

Lack of understanding of cognitive communication difficulties in dementia is likely to be a barrier to early referral, as clinicians are unlikely to recognise that a referral is needed or should be made. Without an understanding of the SLT's role in assessment and treatment, clinicians are unlikely to know what happens when a person with dementia experiencing cognitive communication difficulties is referred to an SLT, what supports, interventions or treatment they might get and what the benefits would be. Without this knowledge, there are unlikely to make a referral.

The lack of a clear pathway for referral was also identified as a barrier facing other health professionals. It was felt that having a clear pathway for referral of cognitive communication difficulties in dementia would be important for letting other health professionals know not only what SLT supports are available but also when to refer to SLTs to access these supports.

The time it takes to make a referral was identified as a barrier especially for GPs. It was felt that medical and health professionals are less likely to take the time to make a referral when they lack knowledge of the potential positive impact of such as referral, especially when the person has a range of issues to be addressed and clinicians are making decisions about which issues to prioritise.

Better awareness and understanding among health professionals of cognitive communication difficulties in dementia and good knowledge of the role that SLTs play in this regard were identified as facilitators of early referral. The consensus among participants was that SLTs, as a profession, have an important role to play in raising awareness, and indeed have a responsibility for providing education about cognitive communication difficulties to colleagues and staff in services more likely to see people with dementia. They also have a responsibility for educating colleagues about the role that SLT can play in assessment and treatment, and about the benefits of SLT intervention.

Participants identified different approaches to education and training that can be taken by SLTs to raise awareness and knowledge among other health professionals. A first step is to improve staff awareness within the SLTs' own team and clinical care setting. Examples given were awareness-raising and training for staff on the multidisciplinary team or making presentations at journal clubs within the acute hospital setting. The presence of the SLT at clinics and MDT meetings is also valuable as it may come to the attention of the SLT during case discussions that a person who may not have been referred to SLT is experiencing

cognitive communication difficulties. Another approach is to improve staff awareness and knowledge in other settings. For example, SLTs in SCH gave the example of training provided to PHNs and Primary Care Teams (PCTs) to improve knowledge of what triggers to look out for, when to make a referral, and what are the benefits of early referral. They found that such training led to improved rates of referral. However, unless training is provided regularly, improvement is short-lived, which is attributed to staff turnover, the requirement for staff to be reminded of the need for early referral and the need to develop habits of referring early. Maintaining connections with PHNs and other members of PCTs and ongoing communication such as reporting back on the positive outcomes of referrals helped to overcome these challenges.

At person with dementia and family carer level

In addition to health professionals, among people with dementia and their family carers there is a poor awareness and lack of knowledge about cognitive communication difficulties and about the role the SLTs play in this regard. This barrier was outlined by Mary, the wife of a person with PPA participating in the forum, who stated:

> "*As a general observation, I would say the client [with dementia] is lost. The client has never navigated this before. Everything about it [dementia] is new at every point in the system and I think what I would have experienced is that it is really difficult to find pathways or find signposting where I would have expected to find them*."

Mary's experience is unusual in that she is a trained SLT and understood the role. However, she pointed out that SLT is not widely understood and one of the barriers is lack of understanding of potential referrers. She noted that there are points in the system where people could be alerted to the potential value of SLT and directed towards that but that doesn't happen:

> *"I kept thinking if you weren't as bolshy as me and weren't as determined as me and as assertive and able to exploit the knowledge that I have about the value of SLT and the knowledge of where to go, how on earth would you do this? How would you do it outside of Dublin where there is a density of services? If I am finding this difficult, and I have an awful lot of resources in terms of knowledge and resources and connections, how would you do it if you had no idea what you are dealing with and gain access?"*

Participants agreed that a person with dementia or their family carer is never going to ask for a cognitive communication assessment when they don't know what the benefits of such an assessment are in the first place.

At societal level

Poor understanding of cognitive communication difficulties in dementia at the societal level was also identified as a barrier. The focus of dementia awareness raising campaigns is mainly on promoting an understanding of memory loss and memory problems. These campaigns had not yet sought to address societal understanding of communication difficulties associated with dementia. People with dementia who are experiencing communication difficulties are not usually portrayed in the media.

Role of SLTs in advocating for change

There was a consensus that SLTs and SLT managers have a role to play in advocating for change, both individually and collectively, both at service / care setting level and at a national level. However, SLTs participating pointed out that they are facing a Catch-22 situation when advocating for early referral. Promoting the role that speech & language therapy can play, the support SLTs can offer to the person and their family carer and associated benefits, may result in an increase in referrals. However, the reality is that, because of resource constraints, the SLT is not then able to either meet the increased demand or provide support to the person at an optimal level. Advocating for change needs to be accompanied with increased resources. As one SLT stated: "*We can all say what we want in an ideal world but it is being able to match it in reality*".

It was felt that government policy is an important facilitator for change. In particular, the change that SLTs are advocating is well aligned with the aspirations of Sláintecare.

The onus on SLTs to show policymakers and the HSE the value of early referral to SLT of people with dementia experiencing cognitive communication difficulties was discussed. It was pointed out that the metrics to measure impact typically used by the Department of Health and the HSE such as reduced length of stay, reduced waiting lists, hospital avoidance are not necessarily metrics that are well suited to showing the value of SLT input. Evidence to demonstrate the quality of SLT service and perceived impact on psychosocial wellbeing would be much more useful. This evidence could be used to demonstrate the value of the SLT input and the difference it makes to people's lives, and could form part of a business case to the HSE. The role of clinical leaders in articulating the necessity of the SLT role and consistency across services and the country, and advocating for urgent change was also raised. It was argued that policymakers and organisations involved in dementia care have a duty to guide services and allocate funding to develop adequately resourced services, and if unmet need is highlighted, will have to respond.

Framing and valuing communication as a human right just as nutrition and hydration are regarded as human rights was seen to have potential when advocating for change.

SLT skills and confidence

Lack of confidence on the part of SLTs was identified as a barrier. SLTs are much more experienced with dysphagia, but, due to the low rate of referrals may not have much experience with cognitive communication difficulties in dementia. When such a referral is received, SLTs often feel that they need specialist training, experience and dementia-specific tools. However, it was argued that, consistent with research evidence, SLTs often forget that communication is a core skill when faced with a referral for cognitive communication difficulties in dementia. They may not realise that they already have the skills, resources and tools needed to conduct an assessment, and, furthermore, lack the confidence to use and apply their core skills. Consequently, SLTs may not have the confidence to address a referral for cognitive communication difficulties, and a delayed response may be seen to be contributing to a delayed discharge. Despite these challenges, participants reported that basic grade SLTs showed great interest in developing their skills and confidence, which is a positive.

Participants identified a range of ways to build SLT skills and confidence. They highlighted the importance of support from senior SLTs. Experiential learning was also seen to be important.

One participant gave the example of SLTs who had spent time during their rotation on age-related wards in an acute setting learning about cognitive communication difficulties in dementia and then bringing their knowledge and experience to bear when they rotated to a general medical ward where they became advocates for early referral. This was echoed by other participants who believed that exposure and experiential learning were key. For example, if undergraduate students on placements in primary care, memory clinics or acute hospital settings get exposure to the work that SLTs do in relation to cognitive communication difficulties, then the awareness, knowledge and skills of SLTs will build over time. They get to see that addressing cognitive communication difficulties in dementia is routine practice.

SLT staff capacity

Staff capacity was identified as a major barrier. The relatively low number of SLTs was highlighted. As one SLT explained:

> "*We are 0.5 SLT in a 50-bedded acute geriatric ward and we are really short-staffed so I have to draw the line between proactively seeking referrals for cognitive communication difficulties in case it interferes with my role of looking after patients in my 0.5 role. So capacity is an issue*."

In SCH, there are 2.0 WTE SLTs working across acute care and out-patient care to meet the needs of people with dementia. The hospital has developed the first Clinical Specialist SLT (Dementia) role in the country. While a lot of services have been developed, communicating the message about cognitive communication difficulties in dementia across the hospital, across community and nationally is still challenging.

Some participants believed that lack of SLTs dedicated to cognitive communication difficulties was the key barrier. However, participants held very different views as to whether capacity issues should be addressed through generalist SLT posts or through specialist SLT posts. On the one hand, it was argued that communication is a core skill of all SLTs including newly qualified SLTs. It is the responsibility of all SLTs, including generalist SLTs, to meet the needs of clients in a holistic manner. That includes people with dementia. Therefore, when a SLT meets a client with dementia who is experiencing cognitive communication difficulties, s/he needs to respond to that need, regardless of the SLT's setting or staff level. On the other hand, it was argued that SLTs may have communication as a core skill set, but unless they have dedicated time to respond to cognitive communication issues in dementia, they will find it difficult to respond to individual client needs in a timely way. For example, a person with dementia who is aspirating will always be prioritised over a person who is experiencing profound difficulties with communication. Unless there is a SLT post dedicated to cognitive communication issues, people with dementia experiencing cognitive communication issues will receive sub-optimal care. This was put forward as an argument in favour of specialist as opposed to generalist SLT posts.

The dilemmas facing SLTs and their management of caseloads was also brought to the fore in discussions on capacity. Questions raised included: 'Is it better for a SLT to offer a lot of people a limited amount of service/ intervention or a few people intense supports / intervention?' Some participants pointed to innovation as a facilitator and explained how innovation can help to address such dilemmas. For example, an approach taken in the Mater University Hospital was to establish a group CST intervention, successfully used to reach a

greater number of people with dementia experiencing cognitive communication difficulties. This required working closely and innovatively with MDT colleagues. Another innovative element of the group intervention was the recruitment of a therapy assistant, who was found to be a very good group facilitator, and this helped to address capacity issues. Improvements have been demonstrated through the use of this innovative approach.

It was argued that having more people with the required clinical skills was important but that SLTs with special interest in driving innovation and service change within hospital and community settings was required.

Underdevelopment of community-based SLT, limits of hospital-based SLT and integration across care settings

A recurring issue raised throughout the discussion was the underdevelopment of community-based SLT services, the limits of hospital-based SLT and the importance of integration for continuity of care between hospital- and community-based SLT services.

Participants reported that early referrals of people with cognitive communication difficulties to community-based SLTs are often not followed up, which may be due to inadequate staffing in the community but also the fact that dysphagia in dementia is prioritised over cognitive communication difficulties. There are long waiting lists and delays in community-based services, which have been exacerbated by Covid-19.

The large amount of discrepancy in SLT services that exists between different community care areas complicates the referral process. Participants reported difficulties trying to navigate community-based SLT services, which vary depending on the catchment area in which the person they are referring lives. It is not always clear to SLTs where to refer a person being discharged from hospital-based services. They did not always know the SLT in a particular community care area. Getting to know community-based SLTs and building up a relationship with them takes time, but staff turnover and staff transfer in the community tends to be high and SLT positions are often left unfilled.

In any case, hospital-based SLTs reported that they are meeting people whom they had previously referred to community-based SLTs coming back in through the day hospital or admitted as an in-patient without having been seen. One SLT described this as a vicious cycle. She questioned the usefulness of making a referral in the first place and the impact that this has on future decisions for referrals to the community: 'Well I referred last time and nothing happened, so what is the point of making referrals?' Lack of integration between hospital and community was regarded as a key barrier by participants, who saw little point in starting a therapeutic intervention in a hospital setting without a guarantee of continuity in the community when the person is discharged home.

The limits of SLT intervention for cognitive communication difficulties for both in-patients with dementia and those attending the day hospital were highlighted. A short-stay in hospital can mean that the patient is discharged before being seen by the SLT. Hospital-based SLTs questioned the usefulness of starting an intervention for in-patients in the acute hospital setting, especially when it is known that a referral cannot be made for the treatment to continue when the person is discharged home from hospital. It was felt that starting an intervention was

unfair to the person as it gets their hopes up that treatment is available, only for hopes to be dashed when the person learns that the treatment is not available in the community.

In the day hospital setting, a SLT may have more capacity for one-to-one intervention with a person with dementia experiencing cognitive communication difficulties than on an in-patient hospital ward. However, it is only a matter of time before the person will be discharged back to the community. This raises uncertainty for SLTs, who are trying to gauge how many sessions they can offer before the person is discharged back to the community. In this context, and aware of the efforts that it takes for people to attend the day hospital, hospital-based SLTs are trying to pack in as much intervention as possible to make it worthwhile. However, they are also aware that, when discharged from the day hospital, the person will likely be placed on a waitlist, possibly a lengthy waitlist, for community-based SLT. Hospital-based SLTs shared their concern that any benefits of SLT intervention are lost when the person is discharged to the community to sit on a waitlist rather than continue with treatment. Some hospital-based SLTs reported that finding themselves in this position can be really challenging. This again highlights the importance of integration across care settings.

Integration of SLT services across settings was identified as a facilitator of early referral. The integrated service being developed between the hospital-based memory service and the community in one area was offered as an example of an integrated approach. In the memory service in TUH, there is a SLT and two ANPs. To integrate memory services with community services, an ANP in Dementia has been appointed to the community service. A SLT will also be appointed to the integrated care service. The role of this SLT will be to facilitate and ensure continuity across the hospital and community settings through close working with the hospital-based SLT and to identify and network with community-based SLTs. It is expected that this will help to address the problem of trying to find a community-based SLT who can continue with treatment started in the hospital.

The under-development of community and primary-based SLT services was less of a problem for one service model in Portlaoise, where there is a dedicated SLT to whom people with dementia are referred shortly after diagnosis. The SLT is able to see people referred in a timely manner and provide support based on assessed need. In addition, the person remains with memory services over a long time.

Dementia underdiagnosis and disclosure issues

Dementia underdiagnosis was identified as a barrier to early referral of people experiencing cognitive communication difficulties. One hospital-based SLT reported that there are in-patients in hospital who very likely have dementia, but where dementia has not been formally diagnosed. Sometimes, a formal diagnosis has been made, but is not documented in the patient records or notes. Even if a dementia diagnosis has been made and documented, it is not always clear if the diagnosis has been disclosed to the patient. This presents challenges for SLTs who may be the first person to discuss cognitive problems or a dementia diagnosis with the person and the issue has to be approached in an extremely careful and sensitive manner.

One of the challenges is the length of time it takes to make a diagnosis, which can often be protracted. Before a diagnosis is made, people may already be presenting with cognitive communication difficulties. However, because of stigma associated with dementia, medical

and other health professionals may be reluctant to discuss a potential dementia diagnosis as it means calling and naming it with the person. They may also be reluctant to make a referral to a SLT out of concern that the person may feel stigmatised being linked into dementia-focused services. However, SLTs believe that people have a right to have their communication needs met and their experience is that this is what people want.

Lack of a standardised approach for SLTs

A challenge facing SLTs is the lack of a standardised approach to cognitive communication difficulties in dementia. Participants noted that, following the National Clinical Programme (NCP) on Stroke, a lot of emphasis was placed on stroke rehabilitation. Energy was put into stroke rehabilitation and a standardised approach for SLTs was developed, so that when a SLT sees a person with a stroke, s/he knows what the expectation is and what process to follow. However, there is no NCP on Dementia, and SLTs had not seen the same knock-on effect following the publication of the National Dementia Strategy. Although they felt that there were pockets of excellent SLT practice in the area of dementia care, they were of the view that there was no standard in relation to SLT services and that practice across the profession and across the country also lacked standardisation. SLT managers find it hard to develop SLT services for dementia care when they are being pulled in many directions to develop SLT services across acute hospital care.

Q.4 Are there any recommended actions around the referral to SLT services for people diagnosed with dementia in Ireland?

A number of actions were recommended by participants, as follows:

- Build a network of SLTs (and others) with an interest in cognitive communication difficulties in dementia, to include SLTs at all levels, in all care settings and from across the country

- Increase awareness and knowledge of cognitive communication difficulties in dementia and the role that SLTs play in this area

- Increase awareness and understanding of the importance of an early referral to SLT of people with dementia experiencing cognitive communication difficulties

- Collate and communicate information on the valuable work that SLTs do in the area of cognitive communication in dementia

- Provide and share evidence of unmet need and the positive outcomes of early SLT input for people with dementia and their family carers, using evidence from both qualitative and quantitative research studies and single case studies, which can be disseminated widely, e.g. Irish Gerontological Society events

- Increase SLT capacity to respond to cognitive communication difficulties in dementia, with a particular focus on community-based SLT services and dedicated SLT in memory services

- Upskill SLT undergraduates and new SLT graduates in the area of cognitive communication

- Encourage and support SLTs and SLT managers to take ownership of their SLT role in communication

- Disseminate the IASLT Position paper

- Reach out and involve stakeholders beyond SLT to collectively develop and make a case to the National Dementia Office

- Develop a standardised and clear process for early referral to SLT of people with dementia experiencing cognitive communication difficulties

- Develop guidelines for SLT in the area of cognitive communication in dementia

Appendix I: List of participants

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Dr Suzanna Dooley, Clinical Specialist SLT (Dementia), HSE

Emma Finch, Senior SLT, Mater University Hospital, Dublin.

Deirdre Fitzgerald, SLT Manager, St Columcille's Hospital, Loughlinstown, Co. Dublin.

Sophie Furey, Senior SLT, Enablement Team, St Columcille's Hospital, Dublin

Professor Sean Kennelly, Consultant Geriatrician and Director of the Memory Assessment & Support Service, Tallaght Hospital, Dublin

Grainne O'Shea, Senior SLT, Psychiatry of Later Life, Portlaoise, Co. Laois.

Mary Rafferty, wife of a person living with Primary Progressive Aphasia (PPA)

Lisa Sheridan, Senior SLT, Memory Assessment & Support Service, Tallaght Hospital, Dublin

Katie Walsh, Senior SLT, St James's Hospital, Dublin

List of Abbreviations

ANP	Advanced Nurse Practitioner
CST	Cognitive stimulation therapy
DRNI	Dementia Research Network Ireland
GPs	General practitioners
HSE	Health Service Executive
IASLT	Irish Association of Speech and Language Therapists
MDT	Multidisciplinary team
NCP	National Clinical Programme
NDO	National Dementia Office
OT	Occupational therapist
PCT	Primary Care Team
PHN	Public Health Nurse
POLL	Psychiatry of Later Life
PPA	Primary Progressive Aphasia
SLT	Speech and language therapist
TUH	Tallaght University Hospital