An evaluation of speech and language therapy services for people with long COVID in the UK: a call for integrated care

Journal:	*Journal of Integrated Care*
Manuscript ID	JICA-07-2022-0038.R2
Manuscript Type:	Article
Keywords:	speech and language therapy, long COVID, post-COVID syndrome, Integrated care, Multi-disciplinary teamwork, dysphagia

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Introduction

Long COVID is estimated to currently affect 2.7% of the UK population. [1] Its presentation is highly heterogeneous, and the evidence proposes over 50 symptoms may be included. [2] The findings from systematic reviews appear to vary with regard to the reported 'most common' symptoms, however fatigue, dyspnea and attention difficulties consistently appear to be central characteristics of the syndrome. [2–5] The wider impacts of long COVID are associated with poor quality of life and mental health issues. [6] Varied care models for long COVID are being implemented globally, and recommendations suggest that central to their success is an integrated approach. [7]

In this article, we use the term *long COVID* in line with the definition given by the National Institute for Health and Social Care Excellence (NICE). This takes an inclusive approach, stating that long COVID describes symptoms that are experienced as part of: "ongoing symptomatic COVID-19 (from 4 to 12 weeks) *and* post-COVID-19 syndrome (12 weeks or more)". [8] Long COVID is also more widely used by patient advocacy groups and those experiencing the condition.

Several papers have highlighted that an integrated approach to care for long COVID must be adopted [9 10] and evidence indicates positive effects on the quality of health services. [11] "Integrated care" has been variably defined [12], and can be considered through the values commonly ascribed to it. A 2018 systematic review identified values of integrated care health services which include: collaborative, co-ordinated, transparent, empowering and comprehensive care, among many others. [13] Building on Kaehne's [14] call for consideration of integration to be understood as a paradigm with

clear theory and implications for policy and practice, Van Kemenade and van der Vlegel-Brouwer extend the definition of integrated care to comprise four unique but interplaying paradigms that relate to 'care quality', which culminate in defining integrated care as: "… process of help, care and service, managed and coordinated by interconnected highly competent professionals… with the patient and ..family" who "find solutions and create impact" [12] (p. 364). Such conceptualisations resonate with the role of speech and language therapists (SLTs), who use "specialist skills" to work "directly with clients and their carers and provide them with tailored support" and "life-improving treatment"[15], which integrates patient perspective. Indeed, integrated care models for speech and language therapy have been studied and shown to be positive in areas including head and neck cancer and stroke. [16,17] Given the breadth and unique presentation of combinations of symptoms in people with long COVID, it is easy to see why integrated approaches are recommended and why 'a one-size-fits-all' approach is likely to fail. Furthermore, the typical approach to care and expertise of SLTs within (and beyond) long COVID are a strong fit for models of integrated care.

Policy frameworks for the public health services now mandate integrated care in England. In July 2022, National Health Service (NHS) England adopted 'Integrated care systems' (ICS) as its approach to service delivery across the nation, which provide services through *collaboratives*. There are 42 ICSs across England, arranged regionally. Each comprise an integrated care partnership (between NHS trusts and local authorities) and an integrated care board (for planning and commissioning) and include an allied health professions (AHP) council who co-ordinate the AHP workforce. ICSs are "partnerships of organisations that come together to plan and deliver joined up health and care services" which have a goal to "improve the lives of people who live and work in their area". [18]. As AHPs, SLTs will be represented in the AHP council, thus they are a

key target for influencing the organisation and management of speech and language therapy services. This is especially pertinent when considering long COVID, the care pathways for which are currently mixed (some which routinely involve SLTs and others not) and their need to be further understood. For clarity, in this article we refer to integrated care to describe a model of care that is coproduced, responsive, adaptable, and personalised to individuals, and has interconnected and joined up working of services at its core, drawing on both the scholarly and practical definitions.

The World Health Organization (WHO) attempted to provide a clinical case definition of what they term 'post-COVID condition' in late 2021, however this avoided the listing of symptoms. Nevertheless, a body of research is emerging which demonstrates individuals with long COVID can experience difficulties that are best supported by SLTs. In one cohort study looking at 96 patients who were reported persistent symptoms following COVID-19, 'difficulties finding words' was one of the most common symptom – reported by 32.3% of patients at 12 months post-infection. [19]. In another cohort study utilising an online survey with 3762 respondents, almost 50% of participants with persisting symptoms following COVID-19 cited speech and language needs as symptoms, including 'difficulty finding the right words' (47%) and 'difficulty communicating verbally' (28%). Additionally, 'sore throat' was identified to be impacting over 60% of participants, another 35% reported a 'lump in throat/difficulty swallowing' and just under a third reported 'changes in the voice'. [20] 'Brain fog' may affect as much as 80% of individuals with post-COVID syndrome [21] and severe fatigue is also common, a predominant symptom of which has been found to be 'difficulties finding words'. [22] In one otolaryngology retrospective case series of 81 patients, at an average of 5 months post-infection, muscle tension dysphonia (difficulties in using the muscles to create voice) and laryngopharyngeal reflux were more frequently identified

in non-intubated COVID-19 patients (in 38.0% and 36.0% of the sample, respectively) when compared to post-intubation COVID-19 patients. [23] A recent meta-analysis presents a pooled prevalence of 'sore throat/difficulty swallowing' at 2% at one year follow-up from acute COVID-19 infection, and 5% for cough, both of which implicate speech and language therapy. [24,25]

The evidence in the literature is consistent with what is reported in practice by SLTs. Findings from a survey of SLTs in the UK undertaken by the Royal College of Speech and Language Therapists (RCSLT) – the professional body for SLTs in the UK- exploring long COVID in an earlier stage of the pandemic (May 2021) [26] highlighted the most common SLT symptoms as dysphagia (difficulties with swallowing related to eating and drinking), dysphonia (difficulties with creating voice) and cognitive communication disorder (difficulties with the cognitive aspects of communication such as attention or processing speed). This also indicated varied referral patterns into speech and language therapy services for individuals with long COVID across the UK. This is consistent with the mixed picture of the availability of 'dedicated' or specially-funded long COVID services, care models and professionals involved. [27–29] Given the prevalence of speech and language therapy needs described in published research and the increasing number of people contracting COVID-19 and thus long COVID, it is reasonable to assume that there is a substantial number of individuals in the UK living with long COVID who would benefit from SLTs input.

Despite the strong indicative evidence, no study to date has exclusively focused on the speech and language therapy needs arising in long COVID nor the current care pathways in which support is being provided. The aim of this article is to address this gap. This service evaluation, which looked at broad findings from the whole of the

pandemic so far, aimed to identify:

1. How individuals with long COVID are accessing and being referred to speech and language therapy services
2. The type and level of need these individuals are presenting with
3. The organisation of clinical services in which SLTs are providing support to them
4. The perceptions of SLTs regarding enablers and barriers to the delivery of quality care for individuals with long COVID.

Methods

Ethical considerations

This study comprised a service evaluation[30] , which is defined as a project that "seeks to assess how well a service is achieving its intended aims", which aims to "benefit the people using a particular healthcare service", and is "designed and conducted with the sole purpose of defining or judging the current service" (pg. 1). [31] Service evaluation "involves analysis of existing data but may include administration of interview or questionnaire". [32] As it is not a piece of formal research, the study did not require formal ethical approval according to the Health Research Authority guidelines. [30] However, ethical principles of research involving humans were adhered to [33] as SLTs participating in the evaluation were provided with information about the aims and purpose of the survey they were asked to complete, and were made aware of their right to withdraw at any time, including the removal of any given data upon request. Implicit consent was provided through completion of survey. No identifiable information was collected, except for respondents optionally providing their email address if they wanted to be contacted about project updates. These were stored only in the SurveyMonkey password protected online account and were not included in the offline dataset used for

analysis. Stored email addresses were deleted upon completion of the project.

Survey development

This service evaluation made use of an online survey. The survey formed part of a larger questionnaire designed for RCSLT members which had additional questions exploring the impact of COVID-19 on the profession more generally. For coherence, 'the survey' we report forthwith refers only to the part exploring long COVID.

The survey comprised 33 questions overall. Some questions were taken from an earlier RCSLT survey exploring long COVID and speech and language therapy needs, which collected data from February 2021. [26] Other questions were developed by the researcher group which comprised SLTs working with people with long COVID and were designed to reflect the latest evidence and intelligence from clinicians. The survey included 27 closed questions, 17 of which were accompanied by a space to collate further comments. There were 6 open questions. The questions encompassed the following six categories: respondent background information; organisational arrangements in which respondents were working; referrals they received; speech and language therapy needs identified; speech and language therapy support given; and experiences of SLTs. The survey questions aimed to collect data pertaining to experiences from *all time*, that is, all experiences of long COVID since the onset of COVID-19 in the UK in February 2020.

Survey dissemination

The survey was disseminated to the membership of the RCSLT via e-communications, social media, and professional networks, inviting qualified and practising SLTs to take part. There were approximately 18,000 RCSLT members at the time of the study went

live, with 15, 443 practising SLTs, who were the target audience for this survey. Seventeen thousand, six hundred and eighty-nine members were signed up to e-communications thus sent the survey (though not all were practising SLTs). The sampling method used was voluntary response sampling. As the number of SLTs receiving referrals for individuals with long COVID was unknown, and we were not testing set hypothesis or performing inferential statistics, a power calculation was not completed. A previous survey conducted by the RCSLT on this topic received 43 respondents, therefore it was hoped the response rate could be improved by 100% in this survey (aiming for 86 respondents). The survey was open for the duration of October 2021.

Data analysis

For quantitative survey data, descriptive statistics were produced using Microsoft Excel. For the qualitative data, principles of reflexive thematic analysis were used to identify key themes inductively and deductively (based on the researchers' clinical experiences), at a semantic level. [34] All qualitative data was coded and analysed by two independent raters, with discrepancies discussed and reviewed according to consensus between authors. The study as described here aligns with the reporting guidelines provided in the 'Consensus-Based Checklist for Reporting of Survey Studies (CROSS) [35] and the 'Improving the quality of Web surveys: the Checklist for Reporting Results of Internet E-Surveys (CHERRIES). [36]

Results

Survey respondents

One hundred and eleven SLTs from 111 unique IP addresses responded to the survey exploring long COVID and SLT needs. Completion of a minimum of 2 questions was set which was done by with 94.6% (105) of respondents.

The respondents represented mostly individual SLTs (65.8%, n=73), with 32.4% (n=36) responding on behalf of their team/service, and an unknown 1.8% (n=2). A range of regions, clinical settings and areas, and types of services were represented (Table I).

[[TABLE I ROUGHLY HERE]]

Demand for speech and language therapy services for long COVID

Respondents reported a range of referral numbers, and this varied with the type of service arrangements (Figure 1). Respondents working in dedicated services (ie. services that have specially commissioned, or posts funded, for meeting the needs of people with long COVID exclusively) most frequently reported referral numbers from the onset of COVID-19 in the UK in February 2020 to the time at which they were completing the survey, as being within the range of 50-100; those in non-dedicated services were more likely to report having fewer than 50 referrals. Referrals sources identified as the most common were medical consultants (22.3%, n=59) and GPs (19.2%, 54) although were varied and included post-COVID hubs/clinics, other allied health professions and nurses, among others.

[[FIGURE 1 ROUGHLY HERE]]

Needs of individuals with long COVID

The individuals referred to SLTs were largely of working age (defined as 18-69 years), comprising 69.8% (n= 191) of responses. Dysphagia and dysphonia were the most common symptoms, as identified by 34.7 % (n=46) and 33.3% (n=25) of respondents, respectively. (Figure 2)

[[FIGURE 2 ROUGHLY HERE]]

Over a third of respondents indicated that they felt the speech and language therapy needs associated with long COVID had a negative impact on the individuals' wellbeing and ability to carry out activities of daily living (35.9%, n=28 and 35.8%, n=24 respectively). Individuals' ability to carry out their life roles, stay in, return to, or fully engage in work or education, were also commonly considered to be impacted. Respondents identified that individuals with long COVID were accessing a range of additional services including support for their mental health, and financial difficulties. The most common speech and language therapy approach for these individuals was focused on being *rehabilitative* (35.5%, n=22) as defined by the Care AIMS framework. [37]

Organisation of services in which SLTs are supporting individuals with long COVID

A minority (13.8%, n= 15) were working within a specially 'dedicated', commissioned or funded long COVID service or resources. Those who were in 'dedicated' services operated as fully multi-disciplinary services and employed by the NHS. Most respondents were not working in dedicated services (86.2%, n=94) suggesting that individuals with long COVID were absorbed within usual speech and language therapy working caseloads and service infrastructure. These 'non-dedicated' SLTs were sometimes working in a multi-disciplinary team (44.7%, n=42) but were often working in a uni-professional setting (48.4%, n=45).

Speech and language therapists' experiences

Thematic analysis of the open text questions (pertaining to 'challenges in management' and factors which 'facilitated successful management') was based on the deductive assumption that the questions represented the overall themes, with the coded responses describing sub-themes. The analysis identified nine overall sub-themes, five related to the *challenges*, and four described *enablers*. Table II provides an overview of the thematic analysis and illustrative quotations.

Challenges of providing quality care

1. 'The patient with COVID.' Respondents identified the complex co-occurrence and longevity of symptoms that individuals present with. Their competing life demands which implicated the patients' ability and motivation to commit to speech and language therapy were challenging (e.g, they were typically working age with family responsibilities). SLTs needed to perform a therapeutic 'balancing act' to support individuals' needs, as well as be sensitive to the range of priorities for them, beyond speech, language, or swallowing.
2. 'COVID as an unknown.' Respondents described the difficulty in managing patients without having a clear trajectory of the illness and recovery. This meant that they needed to constantly review what they were doing to meet the changing needs, whilst also explaining this uncertainty to the patients' themselves.
3. 'Infrastructure and resourcing.' Respondents highlighted a severe lack of resource for supporting individuals with long COVID. This was often associated with other implications of the pandemic such as the battling the 'backlog'. Related to this were issues regarding limited staffing and the skill-mix of SLTs required to support this clinical population. Many respondents reported

struggling to meet the needs of both patients with long COVID and others on their caseload.

4. 'The multi-disciplinary team (MDT).' The absence of *and* existence of an MDT was frequently referred to as a challenge. The former was articulated through the lack of joined approaches and poor communication between teams. The latter was discussed in relation to the challenges of having multiple professionals involved in a singular individual's care. Thus, some respondents were fighting for greater integration, whereas for others, a poorly established MDT or integrated approach caused frustration.
5. 'The therapist experience.' Respondents commented on the personal and professional impact of supporting individuals with long COVID, including compassion fatigue and burnout, and challenges around needing to allow for time for supporting non-speech and language therapy symptoms of individuals. This meant that respondents – while 'doing their best' – often felt overwhelmed and isolated.

Enablers to providing quality care

6. 'Therapeutic skills, knowledge, and strategies.' As many symptoms of long COVID were familiar to SLTs in other contexts, respondents could draw on their existing knowledge. Additionally, their refined therapeutic and professional skills were considered valuable. Thus, respondents could draw on their already established skill-set, even though there was a degree of the unknown with long COVID.
7. 'Communication and resourcing.' Funding for additional or specialist resource was a key enabler, ensuring better care due to greater communication and collaboration between teams, shorter wait lists, centralised oversight, and access

to specialists. Seamless referral processes to consultants or tertiary services were also acknowledged.

8. 'Support networks and research.' Respondents reported that where they were supported by a broader MDT, it helped to develop confidence in managing patients. Making connections with other SLTs working in long COVID was also helpful, allowing for exchange of experience and peer-supported learning.
9. 'Person-centred care.' Respondents described employing person-centred care for individuals with long COVID, including jointly formulating realistic goals, and working with individuals' families. Respondents acknowledged that having sufficient time for this was a key enabler for quality, person-centred care.

[[TABLE II ROUGHLY HERE]]

Discussion

This service evaluation provides a broad overview of the services and care models in the UK for individuals with long COVID and speech, language, communication, swallowing and voice needs, as well as an account of what those needs are, and approaches to their management. Whilst only a relatively small number of SLTs identified that they were receiving referrals for individuals with long COVID, those who did respond constituted a reasonable spread from all UK nations, employment sectors and clinical settings (except for Northern Ireland where just one respondent engaged). The findings reported here can therefore be cautiously used as a guide to the state of service provision and symptom presentation for individuals with long COVID presenting to speech and language therapy across the UK, but within the acknowledged limitations. The results support arguments put forth in the literature that an integrated approach to care for long COVID is required, and the SLTs should always be

considered as key members in these pathways.

The key contribution of this service evaluation is that it presents the first focused account of speech and language therapy and long COVID, from the perspective of the profession. It has highlighted the variability in speech and language therapy needs, the care pathways, the demands placed on services, the arrangements of services in which they are received, and the type of rehabilitation provided. Crucially, the findings raise important considerations for the models of care in which individuals with long COVID are supported.

In terms of the speech and language therapy needs, the study has highlighted the volume and variety related symptoms in this clinical population – predominantly dysphagia and dysphonia- which corroborates the burgeoning evidence base. However, much of the current research has reported long COVID symptoms using terminologies that may be substitutes for a clinical diagnosis as made SLTs e.g. “sore throat” or “hoarseness” [38] or “voice change” [3] instead of laryngeal sensitivity issues or dysphonia. These ‘lay’ descriptions of symptoms could be overshadowing specific SLT needs, which can benefit from input from SLTs. The carry-over of evidence to practice therefore may be limited. Thus, future research on long COVID should endeavour to ascertain the precise nature of symptoms and potential clinical need and discuss them in the context of their management by SLTs. This will support a more comprehensive understanding of the volume and degree of speech and language therapy needs in long COVID, as well as increase the awareness of the role and employment of SLTs in long COVID management in practice.

Although focused on speech and language therapy needs, many other needs were often referred to. Importantly, the findings emphasise the interplay between speech

and language symptoms and other needs, which is especially supported by the qualitative data. An individual with fatigue, for example, may find it challenging to engage in swallowing exercises recommended by SLTs. Similarly, an individual with a cognitive-communication difficulty may be less able to participate in talking therapies for their wellbeing. Furthermore, we find that these needs were most likely to be affecting individuals of working age, reflecting that of some other studies, [39] and thus activities of daily living, including vocational or family-role related goals must be considered in rehabilitation. Thus, it is not just the range of needs that is of note, but the *interconnectedness* of them. This echoes 'multi-morbidity' more generally, thus elements of familiar care pathways for those with complex or multi-morbid conditions could be useful in long COVID. A common element of integrated care referred to in the literature for multi-morbidity is being "person-centred" [40] – a value that also emerged as a key enabler to quality care in this study. In fact, respondents often articulated many values of integrated care described in the literature [13] as key enablers. For example: "the *patient* being *heard* and *understood*"; "[An] *holistic* and *compassionate* approach", "*clear* pathways and a *M[ulti] D[isciplinary] T[eam]"* were identified. . Indeed, this also echoes the aims of NHS England's ICS models.[18] Together, these findings strongly support the need for cohesive and integrated care approach to long COVID. [41]

For most of the UK, directives for NHS services are set by clinical guidance produced by NICE.[42] In their guidance for the long-term effects of COVID-19, integrated multidisciplinary rehabilitation services are recommended and include a list of core professionals required. [8] However, at present, SLTs are not listed as core members of this team, despite symptoms which can be supported by SLTs being listed as common (for example, 'cough', 'brain fog' and 'sore throat'). This again echoes the earlier point regarding the need for more precise definition and clinical relevance of

symptoms described in the literature. This paper therefore further makes a case for the inclusion of SLTs as core members within the integrated/multi-disciplinary teams and pathways supporting individuals with long COVID.

Limitations

This study is a service evaluation therefore should be interpreted within the scope of this methodology. The findings are based on 111 respondents which limits generalisability. However, this substantially builds on the response rate of an earlier profession-wide survey (which had 43 respondents). [26] As a method, surveys have well-documented limitations including inevitable self-selected sample biases. [43] However, surveys can be valuable in monitoring change in practices, if recruitment is successful and response rates are high. If this evaluation exercise was to be repeated, more considered recruitment activities could be employed to increase this. It would be helpful especially to consider approaches for recruiting in the devolved nations especially, which were less represented in this survey. More research may be warranted on effective strategies. Nevertheless, the findings outlined here do concur with what has been reported previously, as well as through the anecdotal evidence gathered by the professional body during conversations with SLTs, and the emerging evidence base.

The analysis did lack some rigour. Due to the nature of the methods, the quantitative analysis was limited to descriptive evaluation only. Therefore, it is not possible to use this to make any observations that refer to differences between groups in a statistically robust way. It does, however, offer some useful insights. A limitation of the qualitative data related to the relevance of the answers given dependent on how the question had been interpreted. This posed some challenges to analysis, but its impact was mitigated using two independent data coders, and discussion to achieve consensus.

While limitations of this study are acknowledged, the results provide some useful insights into the current experiences of the speech and language therapy profession in the UK and may have value in guiding future policy and practice both in the UK and internationally.

Conclusion

This nationwide service evaluation has offered a unique insight into the arrangements of services and clinical needs of individuals with long COVID in relation to speech and language therapy. It has provided further insight into how individuals with long COVID are accessing speech and language therapy, the type and level of need these individuals are presenting with and the organisation of the services in which SLTs are supporting them. Furthermore, it has provided the voices from on the ground clinicians regarding the current delivery of care for individuals with long COVID. These insights further support the need for well-resourced multi-disciplinary and integrated care services for individuals with long COVID, and that SLTs should be a part of this. Individuals experience a range of speech and language therapy needs, which may impact their mental wellbeing and ability to engage with work and other important elements of their daily lives, including other therapies. Greater awareness and recognition of symptoms by health professionals, researchers and patients may lead to greater access to speech and language therapy through being identified as a core member of the integrated long COVID team.

Acknowledgements

We would like to thank all survey respondents for their time dedicated to completing the survey, and to members of the RCSLT COVID Advisory Board for their input into the initial version of a survey in which the one utilised here was adapted from.

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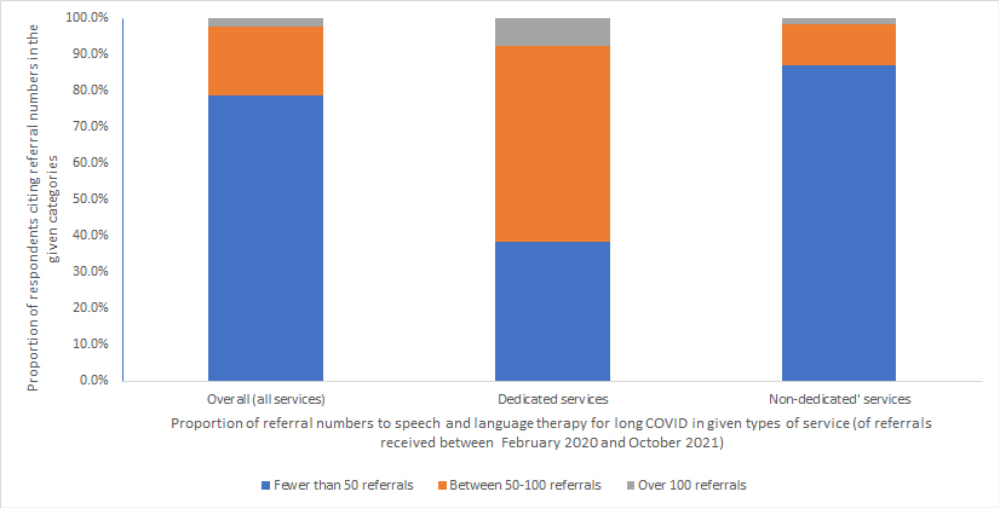
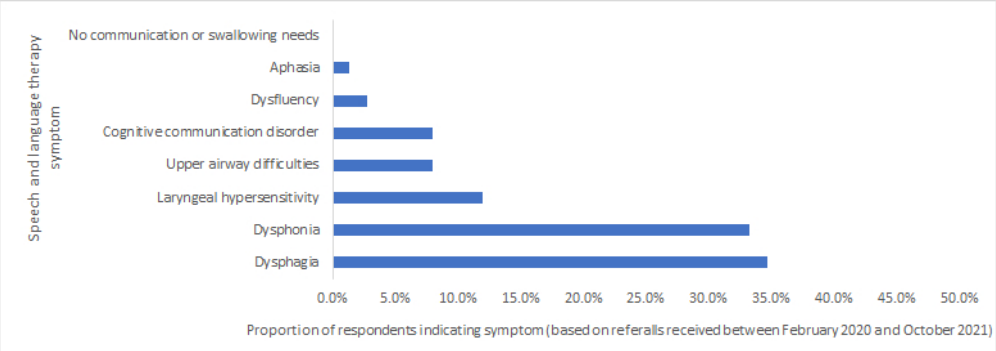


Overview of the ranges of long COVID referrals to speech and language therapy between February 2020 and October 2021.

552x281mm (38 x 38 DPI)



Most common speech and language therapy symptoms of Long COVID seen in speech and language therapy services between February 2020 and October 2021.

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Table I. Survey respondent information, presented from 'All services', 'Dedicated' services and 'Non-dedicated' services.

Descriptor	From All services		From 'Dedicated' services		From 'Non-dedicated' services	
Employer	**n**	**%**	**n**	**%**	**n**	**%**
National Health Service (NHS)	95	74.80%	13	81.3%	82	73.90%
Non- NHS	32	25.2	3	1270.0 %	29	26.1
TOTAL	127	100.00 %	16	100.0%	111	100.00 %
Clinical area						
Acquired speech difficulties	62	7.10%	8	6.3%	54	7.20%
Aphasia	54	6.20%	8	6.3%	46	6.10%
Dysphagia (adults)	72	8.20%	10	7.8%	62	8.30%
Progressive neurological disorders	57	6.50%	9	7.0%	48	6.40%
Voice	55	6.30%	10	7.8%	45	6.00%
Other (all communication and swallowing disorders)	558	63.60%	84	64.8%	495	66.00%
TOTAL	878	100.00 %	128	100.0%	750	100.00 %
Region						
Northern Ireland	8	7.30%	1	6.7%	7	7.40%
Scotland	6	5.00%	0	0.0%	6	6.40%
Wales	6	5.50%	2	13.3%	4	4.30%
England	89	82.20%	13	80.0%	77	81.90%
TOTAL	109	100.00 %	16	100.0%	94	100.00 %
Age of referrals						
Under 18	63	24.40%	5	15.7%	58	25.60%
18-24 years	100	38.60%	14	43.8%	86	37.90%
25 years +	96	37.10%	13	40.6%	83	36.60%
TOTAL	259	100.00 %	32	100.0%	227	100.00 %

*Respondents could select as many answers as appropriate, hence the total number does not reflect that number of survey respondents.

Table II. Illustrative quotations from respondent answers for themes and subthemes pertaining to challenges and enablers for delivering quality speech and language therapy care for individuals with long COVID.

Theme	Sub-theme	Verbatim quote	Respondent's work setting
Challenges	Patient with COVID	"Patients are often deteriorating over time due to complex health needs rather than improving.	'non-dedicated' service
	COVID as an unknown	"The newness of the diagnosis and not being able to predict outcome."	'non-dedicated' service
	Infrastructure and resourcing	"Time constraints and demands of the other SLT services. Reduced resource and staffing levels as not appropriately funded"	'non-dedicated' service
	The multi-disciplinary team	"Not managing the patients as part of an MDT or seamless pathway"	'non-dedicated' service
	Therapist experience	"[I am] feeling clinically isolated … [I am] feeling professionally isolated"	'dedicated' service
Enablers	Therapeutic skills, knowledge and strategies	"Listening – [the patient] story being heard and understood by a group of professionals"	'dedicated' service
	Communication and resourcing	The establishment of long covid clinic with clear pathways [and] interaction with MDT.	'non-dedicated' service
	Supporting networks and research	"SLT peer support group for SLTs working in LC [Long COVID]. Better Group supervision. More SLT led research in this area to know what works, what presentations we are seeing."	'dedicated' service
	Person-centred care	"[An] holistic and compassionate approach"	'dedicated' service