

# Improving clinical terminology for SLTs using electronic patient records

## CONSULTATION

November 2024

The information in this document is currently in development and has been shared as part of a consultation. If you are seeking guidance or information on this topic, please ensure you refer to final published content which can be found on rcslt.org.

This project aims to develop a list of terms that will be most useful to speech and language therapists (SLTs) when completing electronic patient records, to provide a clear diagnosis or description of the reason for speech and language therapy input.

Please read the information in this document carefully, to ensure you understand the context and rationale for this work, then <u>complete this short survey</u> to provide feedback.

It is important that we hear from as many SLTs as possible, to help us understand the requirements across the profession. Please complete the survey, even if you agree completely with the proposal. The closing date for feedback is **Friday 24 January 2025**.

If you have further questions, please contact us on professional development@rcslt.org

Thank you for your support with this project.



# **Background information**

#### Why is the RCSLT carrying out this work?

Across the UK, commitments have been made to adopt the UK version of an international structured clinical vocabulary called SNOMED CT in electronic patient record systems. There is more information about this <u>on the RCSLT website</u>.

Some SLTs working in the NHS are now being asked to enter a diagnosis for every clinical contact and are finding that the system does not have appropriate terms. Having the right terms available is not only important for the individual person's record and care, but services are able to use collated data about the people they work with to inform service planning, monitoring and commissioning.

The RCSLT is able to request changes and additions to SNOMED CT via the SNOMED UK National Release Centre and has previously done this on an ad hoc basis, but is now taking a whole profession approach.

Clinical information from electronic health records has huge potential to expand the available evidence-base. The COVID-19 pandemic highlighted the benefits of being able to quickly coordinate different sources of data to provide 'real-world evidence', as well as the challenges where data is inconsistent or incomplete. By encouraging a standardised approach to data collected about speech and language therapy input, the RCSLT hopes to maximise its potential for research and advocacy.

#### Why should I be interested in terminology and SNOMED CT?

The RCSLT needs your support to make sure the terms are suitable for your needs, before SNOMED CT is implemented more widely. Although members working in non-NHS settings may be less likely to be *required* to use SNOMED CT in future, we still want your views.

If we can use a consistent approach across the whole profession, this will allow for the collection of data that can be a powerful tool for advocacy and research. In particular, the intention is to use SNOMED CT codes in place of ICD-10 codes on the <u>RCSLT Online Outcome Tool (ROOT)</u>.

#### What is the scope of this list?

This list is intended to provide SLTs with the diagnostic terms they need when carrying out care with an individual, to describe the reason that person is receiving input from speech and language therapy (recognising that some people will have more than one diagnosis).

Based on advice from terminology specialists at the SNOMED UK National Release Centre, the RCSLT is focusing on developing individual terms that are acceptable for the profession, rather than on a complete hierarchy or categorisation system.

SNOMED CT also allows for the recording of more detailed observations about a person's strengths and challenges, as well as assessment procedures and interventions: these will be considered in future stages of this project.



#### What about diagnoses made by a medical professional or multi-disciplinary team (MDT)?

The majority of terms in this list refer to specific difficulties with communication or eating, drinking and swallowing, which are almost always diagnosed by a speech and language therapist. These may occur in association with a broader medical condition. For example, a person may have a medical diagnosis of 'cerebrovascular accident', but their speech and language therapy diagnosis is 'aphasia'.

A small number of conditions have been included in this list, which may not be diagnosed solely by an SLT. This is because SLTs provide intervention focussed specifically on that condition, without an 'additional' speech and language therapy diagnosis, for example, primary progressive aphasia.

#### How has this list been developed?

Members with an interest in this work have generated an initial list of terms, which have been refined through:

- Liaison with experts in specific clinical areas (including acknowledging where consensus activities have already taken place)
- Discussions with terminology specialists at NHS England about existing SNOMED CT terms and requirements
- Further review and input from members with an interest in clinical terminology

#### What is the aim of this consultation?

The RCSLT wants to gather the views of members from across the profession on the list of terms that is being proposed. It may not be possible to achieve complete consensus and we need to be realistic about the limitations of SNOMED CT and consider that some compromises may be necessary. The aim is to develop a set of terms which provide SLTs with the diagnostic terms that they typically need in their day-to-day clinical practice.

The outcomes of this consultation will be shared with members and used to inform the requests for changes to be made to SNOMED CT.

#### Will the agreed terms be mandated by RCSLT?

No, but the terms will be put forward into the SNOMED CT 'speech and language therapy reference set' and SLTs will be strongly encouraged to use this list in their local patient record system (whether or not it is yet enabled with SNOMED CT).

It is envisaged that, once these terms have been finalised, they will replace ICD-10 codes on the RCSLT Online Outcome Tool (ROOT), for SLTs who contribute data to that system.

There will be situations where SLTs want to use different terminology, but the intention is that these terms will be recommended for consistent recording in clinical systems, for the purposes of data collection.



#### Is it possible to start using these SNOMED CT terms in my clinical system now?

Some of the terms in this list are already in SNOMED CT and others require adding or adapting. Recommendations for changes that arise from this consultation will be passed to the SNOMED UK National Release Centre for their consideration. If you are implementing SNOMED CT locally, please contact the RCSLT for more details and support via <a href="mailto:professional-development@rcslt.org">professional-development@rcslt.org</a>

#### What if I strive to take a positive approach to disability and avoid terms like 'disorder'?

The RCSLT recognises that SNOMED CT has developed from a medical context and that assigning diagnostic labels and classifying groups of people, risks a negative focus on 'deficits' and stereotypes. However, there are also benefits to using recognised diagnostic terms for both individuals and people working with them.<sup>1</sup>

The fact that SLTs increasingly need to enter broad diagnoses using SNOMED CT has necessitated an initial focus on these terms, but it is important to recognise their limitations. Alongside any diagnosis, SLTs must develop a clear understanding of the specific strengths, needs and context of the individual person they are working with.<sup>2</sup> SNOMED CT also contains more descriptive terminology and RCSLT will explore this potential for capturing communication and eating, drinking and swallowing observations in a future stage of this project.

It is also important to be clear that, where a diagnosis identifies that a person has difficulties or differences in a particular area, it does not follow that the focus of intervention will be to 'fix' this in the individual. Many SLT interventions will be focussed on supporting people around the individual to make adaptations for them and remove barriers to effective communication and safe and enjoyable eating and drinking.<sup>3</sup> SNOMED CT is also capable of providing terms to describe different types of intervention and, again, these will be considered as a future project.

#### What about gathering the views of the people we work with?

The clinical nature and scope of SNOMED CT, along with the breadth of terms involved, means that the RCSLT has focussed this initial consultation on contributions from SLTs. However, we know that SLTs want to use terminology which is meaningful and acceptable to the people they work with. Wherever possible, existing evidence about patient views on terminology has and will be incorporated in the recommended terms. This consultation may highlight specific areas where more detailed consensus work is required, which would involve people with lived experience. One of the benefits of SNOMED CT is that it is a dynamic system with the potential for terms to be updated, as terminology develops.

Individuals or groups who are not SLTs but want to contact us about this project are welcome to do so via <a href="mailto:professional\_development@rcslt.org">professional\_development@rcslt.org</a>.

<sup>&</sup>lt;sup>1</sup> There is further discussion of these issues, especially in relation to neurodiversity, in the <u>RCSLT Autism</u> <u>guidance</u>. Autism itself has not been included in this list of terms because, although SLTs are often part of the diagnostic process, this is typically seen as a medical diagnosis, with SLT input linked to a specific aspect of the person's communication or eating and drinking.

<sup>&</sup>lt;sup>2</sup> This is discussed across RCSLT clinical guidance, but see particularly <u>Autism</u> and <u>Learning Disabilities</u>.

<sup>&</sup>lt;sup>3</sup> Again, see all RCSLT clinical guidance, but particularly <u>Autism</u> and <u>Position Paper on Learning Disabilities</u>



# Once the terms are agreed, what if I am working with a person who prefers a different term?

The RCSLT would suggest that, wherever possible, the recognised diagnostic term should be explained to the person and recorded in their record, for the purposes of clinical accuracy and data collection. However, the person's preferred way to refer to their condition should also be noted and used in any communication with them and their carers.

#### What if a clinical group I work with is not represented by the terms on this list?

We are aware that there are some potential gaps: in particular we are working with specialist colleagues to explore terminology relating to gender-affirming care and functional neurological disorders. Please use the survey to let us know about any terms that you feel are missing, relating to these or any other clinical areas.

#### What about when it is not possible to make a speech and language therapy diagnosis?

SNOMED CT also contains the terms 'diagnosis not made' and 'problem resolved' which may be required in some situations, though it would be advisable to only use these when there is no alternative.



# Draft list of terms for consultation

### Eating, Drinking and Swallowing

Suggested terms	Comments
Dysphagia	Recommended for use with adults and children.
	Children with dysphagia would be expected to also
<ul><li>Oral phase dysphagia</li><li>Pharyngeal dysphagia</li></ul>	have a diagnosis of paediatric feeding disorder.
<ul> <li>Oesophageal dysphagia<sup>4</sup></li> </ul>	Stage(s) to be identified, where appropriate.
Paediatric feeding disorder	Recommended as a unifying diagnosis for children with a range of activity and behaviours relating to eating, drinking and feeding, that may or may not include problems with swallowing. Where the child does have a swallowing difficulty, they may also have a diagnosis of dysphagia. <sup>5</sup>

# Speech, Language and Communication

Suggested terms	Comments
Aphasia     Expressive aphasia     Fluent aphasia     Global aphasia     Jargon aphasia     Non-fluent aphasia     Receptive aphasia	Subtypes to be used, where appropriate.
Aphonia	

<sup>&</sup>lt;sup>4</sup> Comments are welcome on whether oesophageal dysphagia should be included, as is it is not typically an SLT diagnosis.

Reference: Goday, P.S., Huh, S.Y., Silverman, A., Lukens, C.T., Dodrill, P., Cohen, S.S., Delaney, A.L., Feuling, M.B., Noel, R.J., Gisel, E., Kenzer, A., Kessler, D.B., Kraus de Camargo, O., Browne, J. and Phalen, J.A. (2019), Pediatric Feeding Disorder. *Journal of Pediatric Gastroenterology and Nutrition*, 68: 124-129. https://doi.org/10.1097/MPG.00000000000002188

<sup>&</sup>lt;sup>5</sup> This term has been developed via international consensus (Goday et al, 2019). Paediatric feeding disorder does not include avoidant restrictive food intake disorder (ARFID). There is a growing awareness of the role for the SLT with children who have a diagnosis of ARFID, but as this can often relate more to supporting co-occuring communication needs, it has not been included in this list, but comments are welcome on this. RCSLT is currently updating eating, drinking and swallowing guidance to also reflect changes in terminology.



Acquired apraxia of speech	Use of 'acquired' is suggested, to distinguish from 'childhood apraxia of speech'.
Cluttering	
Cognitive communication disorder	
Developmental language disorder	
Dysarthria  • Ataxic dysarthria  • Flaccid dysarthria  • Hyperkinetic dysarthria  • Hypokinetic dysarthria  • Mixed dysarthria  • Spastic dysarthria  Also Childhood dysarthria	Subtypes to be used, where appropriate.  It is suggested that 'childhood dysarthria' is used to identify a dysarthria that occurs whilst the speech system and the brain are developing.
Dyscalculia  Dysgraphia	It is expected that these would be used by SLTs working with acquired difficulties. Although SLTs may
Dyslexia	<ul><li>work with children who have these diagnoses, these</li><li>are not usually made by SLTs or the specific reason for SLT input.</li></ul>
Dysphonia	
Language disorder	<ul> <li>This term may be dependent on the presence of other diagnoses on the child's record:</li> <li>If the child has a diagnosis of biomedical condition 'X', this term should be interpreted as 'language disorder in association with X'.</li> <li>If there is no differentiating biomedical condition, this would indicate that differential diagnosis is ongoing (and the diagnosis should be updated to 'developmental language disorder' if this becomes appropriate).<sup>6</sup></li> </ul>

<sup>&</sup>lt;sup>6</sup> See RCSLT guidance on developmental language disorder and differential diagnosis: https://www.rcslt.org/speech-and-language-therapy/clinical-information/developmental-language-disorder/dld-diagnosis-and-support/



<ul> <li>Primary progressive aphasia</li> <li>Logopenic primary progressive aphasia</li> <li>Nonfluent primary progressive aphasia</li> <li>Semantic primary progressive aphasia</li> </ul>	Variants to be used, where appropriate. <sup>7</sup>
Primary progressive apraxia of speech	
Progressive aphasia	This would be used where the aphasia is a secondary symptom of a memory or behaviour led dementia.
Selective mutism	Some individuals have expressed other preferences, but this is currently the recognised diagnostic term. <sup>8</sup>
Social communication differences	
Speech, language and communication needs	It has been suggested that this term is needed in some scenarios, where it is not possible to use one of the other terms in this list. These might include:  • Young children where assessment is ongoing and particularly when it is not yet possible to identify how persistent any speech, language and communication difficulties might be.  • People who may have transient communication difficulties, for example in association with a mental health disorder.  A more specific diagnosis should always be used where possible.

<sup>&</sup>lt;sup>7</sup> See RCSLT guidance on dementia: <a href="https://www.rcslt.org/members/clinical-guidance/dementia/">https://www.rcslt.org/members/clinical-guidance/dementia/</a>

 $<sup>^8</sup>$  See statement from SMiRA regarding use of 'situational mutism'  $\frac{https://www.selectivemutism.org.uk/wp-content/uploads/2024/01/Situational-Statement.pdf}$ 

<sup>&</sup>lt;sup>9</sup> The CATALISE consortium (Bishop et al, 2017) rejected use of the term 'language delay'. The term 'SLCN' was proposed as useful, although primarily as a superordinate category, not helpful for explaining a child's specific difficulties or determining intervention.

Reference: Bishop, D.V.M., Snowling, M.J., Thompson, P.A., Greenhalgh, T. and (2017), Phase 2 of CATALISE: a multinational and multidisciplinary Delphi consensus study of problems with language development: Terminology. *Journal of Child Psychology and Psychiatry*, 58: 1068-1080. <a href="https://doi.org/10.1111/jcpp.12721">https://doi.org/10.1111/jcpp.12721</a>



Speech sound disorder  • Articulation disorder	Subtypes to be used, where appropriate. 10
<ul> <li>Childhood apraxia of speech</li> <li>Consistent phonological disorder</li> <li>Inconsistent phonological disorder</li> <li>Phonological delay</li> </ul>	See also 'childhood dysarthria'.
Stammering	

# Other

Suggested terms	Comments
Chronic cough	
Inducible laryngeal obstruction	
Sialorrhea	
Velopharyngeal dysfunction	Some individuals with velopharyngeal dysfunction will also have an articulation disorder or speech sound disorder.
Xerostomia	

<sup>&</sup>lt;sup>10</sup> See RCLST guidance on speech sound disorder, especially regarding the importance of differential diagnosis of subtypes: <a href="https://www.rcslt.org/members/clinical-guidance/speech-sound-disorders/">https://www.rcslt.org/members/clinical-guidance/speech-sound-disorders/</a>