

# **COVID-19 data collection**

18 May 2020

# CONTEXT

The RCSLT has developed a dataset to support the speech and language therapy profession with capturing data on the management of patients with **confirmed and suspected COVID-19**. This data will help us to understand the impact on patients and those that care for them, be that in an acute, clinic or community setting.

The dataset includes fields to collect information about patient outcomes, and the impact of interventions and on service delivery. In the longer term, the RCSLT would be interested in collating the data gathered by teams/services across the UK, to clarify lessons learned and inform preparations for future events.

Speech and language therapy teams/services interested in using this dataset may do so by using one of the following two options:

- 1. **Spreadsheet**: A spreadsheet is available for you to download and begin collecting data on individuals with confirmed and suspected COVID-19. Click here to download the spreadsheet.
- RCSLT Online Outcome Tool: If your team/service already uses the ROOT, you can record the COVID-19 status of each patient there with each rating. It is also possible to collect the additional fields included in the dataset on the ROOT. For more information, please contact root@rcslt.org.

This document contains some guidance for using each of the two data collection methods, along with a detailed set of definitions that accompany the dataset (Annex 1). It is recognised that this is an extensive dataset, and it is not necessary to collect all of the suggested data fields contained in this dataset. Locally, you may wish to identify which are most relevant to your local needs.

**Please note:** this document refers to the version of the template published on 15 May 2020. Where possible, <u>please discontinue use of any previous templates and start using this</u> <u>version</u>. Please be reassured that data collected on earlier versions of the template can still be submitted to the RCSLT COVID 19 Data Collection Tool and you will <u>not</u> need to transfer the data into this new template.

#### 1. Using the spreadsheet

The COVID-19 speech and language therapy dataset is available to download here. In view of the need to develop something at pace, it was not possible to widely pilot the dataset before it was released. As a result, the dataset has undergone two iterations since its initial release, to make improvements in response to feedback from speech and language therapists who have been collecting data. The changes that have been made include amendments to the columns and improvements to aid usability.

#### Do I need to collect all of this information?

We recognise that the spreadsheet contains a large number of fields and **it is not necessary to collect all of the suggested data fields contained in this dataset.** The mandatory columns are shaded in dark blue in the template and indicated by two asterisks (\*\*). You will need to complete these for every patient if you wish to submit data to the RCSLT COVID-19 Data Collection Tool. Locally, you may wish to identify which of the remaining fields are most relevant to your local needs (the columns shaded in green with one asterisk (\*) are 'desirable' and those in white are 'optional').

Whilst we would encourage you to collect as much of the other data as you are able, please do not let this put you off from completing it. There will be benefits and learning made even from partial datasets.

# Is the dataset for patients receiving speech and language therapy in hospitals only?

The dataset has been developed to record information about individuals with confirmed and suspected COVID-19 at **any point in the pathway**. Services should record information about how individuals present at the point at which they are referred to and discharged from their service.

#### What should I do if a patient already on my caseload contracts COVID-19?

The purpose of the data collection is to evaluate the impact of COVID on our patients. Therefore, if you have an open episode of care with a patient who subsequently becomes COVID positive you should capture the 'initial assessment' data at the first contact with the patient after their COVID diagnosis.

#### How do I use the spreadsheet?

The way in which the spreadsheet is used by you and your colleagues at a local level will vary according to your local context. Before getting started, here are a few things to think about:

- Have you decided which of the 'desirable' and 'optional' fields you are going to collect? It may be helpful to 'hide' any columns you are not going to use. To do this, select the column, right-click and select 'hide'. <u>Please do not delete any columns in the template.</u>
- Are all colleagues clear on the set of the definitions provided (Annex 1) and clear about how to input data onto the spreadsheet? This is important to ensure that everyone is collecting the data in a consistent way.
- **Do you need more than one copy of the spreadsheet for your team/service?** This may be necessary for practical reasons, for example, where there are number of people that will need to have access to the spreadsheet at the same time.

Finally, when opening the spreadsheet it is important to **'enable macros'** or **'enable editing'**, when asked. This will allow you to use to use select multiple options for some fields. If your organisation prevents the enabling of macros the multi-select functions may not work. In this instance you should contact **root@rcslt.org** to request an alternative version of the spreadsheet.

# How do I submit the data we have collected to the RCSLT?

The RCSLT has been working in partnership with Different Class Solutions to develop an online system for teams and services to submit their data online for this to be collated at a national level.

To get involved in the project, please click here to:

- Download the **Information Governance Pack**, which contains details about what you will need to do at a local level to participate in the project
- **Register** to use the RCSLT COVID-19 Data Collection Tool

Once you have completed the information governance processes and have set up an account, you can log-in to the **RCSLT COVID-19 Data Collection Tool** to upload your spreadsheet. You will find more information about this on the tool.

If you plan to submit your data to the RCSLT, please do not make any changes to the structure or format of the spreadsheet template. This includes not changing the name or order of any of the columns.

- If you wish to remove any columns, please 'hide' these.
- If you wish to include additional columns for your local use, please add these at the end, after the 'comments' field (i.e. after column CB).

# 2. Using the RCSLT Online Outcome Tool (ROOT)

Speech and language therapy teams and services already using the ROOT will be given the option to record the COVID-19 status of each patient, if applicable, each time that a new rating is entered onto the ROOT. This is available as a drop-down box:

Additional Data Fields		
COVID-19 status:		~
Type of intervention:	Not applicable No COVID-19 Suspected COVID-19 - Confirmed COVID-19	

The ability to record other information contained in the COVID-19 dataset is also available. Please contact **root@rcslt.org**.

#### **FURTHER INFORMATION**

- For further information about this work and to download tools and resources, please visit the RCSLT COVID-19 Data Collection Tool.
- Please contact us with any questions and feedback on this work.

# **APPENDIX 1: COVID-19 speech and language therapy dataset definitions**

The table, below, details the fields contained in the COVID-19 speech and language therapy dataset. For each field, there is definition containing:

- A **description** of the field, to support a consistent understanding of what data should be recorded
- The format of the field, in terms of whether this, for example, a free text field or date field
- A recommendation about whether this is 'required', 'desirable' or 'optional':
  - **Required**: To participate in the national data collection, these fields are essential to collect for every patient. (If not applicable, please select N/A.)
  - **Desirable:** Where possible and if relevant to your service, we would encourage you to collect this data. NB at least one outcome measure (shaded in the table below) should be used per patient at initial assessment and discharge, as appropriate.
  - **Optional:** These fields are optional. You may wish to collect these additional data to gather a richer dataset, if relevant to your service.

Field	Description	Format	Recommendation (required/desirable/ optional)
Local patient identifier	This is a local patient identifier and can take any alpha-numeric form. This should not be the NHS number and any code used should not identify the individual outside of the organisation. If possible, it would be desirable for the same local patient identifier to be used throughout the pathway.	Free text	Required
Location	This is where the individual was seen for the episode of care.	Multi-select list	Required
Year Of Birth	The year of the patient's birth.	Number	Required
Gender	The patient's gender.	Single select list	Required

Field	Description	Format	Recommendation (required/desirable/ optional)
Hospital Admission Date	The date on which the individual was admitted to hospital.	Date (DD/MM/YY)	Optional
Primary medical diagnosis on admission/referral	The patient's primary medical diagnosis at the point of referral to speech and language therapy.	Single-select list	Required
Past Medical History	A summary of past medical history relevant to this referral to speech and language therapy.	Multi-select list	Required
Pre-existing Dysphagia (Fluids)	The dysphagia status of the individual prior to this admission to hospital (where known), using IDDSI descriptors.	Single-select list	Desirable
Pre-existing Dysphagia (Diet)	The dysphagia status of the individual prior to this admission to hospital (where known), using IDDSI descriptors.	Single-select list	Desirable
Date COVID +ve confirmed	The date that the patient was confirmed as testing positive for COVID- 19. This is the date that the swab was taken.	Date (DD/MM/YY)	Optional
Date COVID -ve confirmed	The date that the patient was confirmed as testing negative for COVID-19. This is the date that the swab was taken.	Date (DD/MM/YY)	Optional
Date(s) of intubation	The dates of any intubation or re-intubations during their ICU admission	Date (DD/MM/YY)	Optional
Date(s) of extubation	The dates of any extubations during their ICU admission	Date (DD/MM/YY)	Optional
Grade of intubation	The grading of the endotracheal tube (ETT) insertion (Grade I, II, III or IV). Grades IIa and IIb should be recorded as Grade II. This information should be recorded by the doctor who inserted the ETT and is a classification of the view of the larynx during ETT insertion.	Single-select list	Optional
Total Number of endotracheal tubes (ETT)	The total number of endotracheal tubes used across the duration of the episode of care.	Number	Desirable
Total no. of days intubated	The total number of days the individual was orally intubated across the duration of the episode of care.	Number	Desirable
Date of trache insertion	The date at which the first tracheostomy was inserted on this admission to hospital.	Date (DD/MM/YY)	Optional

Field	Description	Format	Recommendation (required/desirable/ optional)
Percutaneous or surgical	A description of whether the tracheostomy was inserted percutaneously or surgically.	Single-select list	Optional
Trache size (initial tube)	The size of the tracheostomy tube. Where multiple tubes are used, please record the size of the initial tracheostomy tube.	Single-select list	Optional
Trache downsized as part of the weaning process?	Whether the tracheostomy tube(s) used were down-sized as part of the weaning process.	Single-select list	Optional
Type of Trache	The type of tracheostomy inserted. Where multiple tubes are used, please record the type of the initial tracheostomy tube.	Single-select list	Optional
Date of decannulation	The date at which the patient was finally decannulated on this admission to hospital.	Date (DD/MM/YY)	Optional
Total number of days with tracheostomy	The total number of days the individual had a tracheostomy inserted across the duration of the hospital admission.	Number	Desirable
Date of Referral to SLT	The date on which the individual was referred to SLT.	Date (DD/MM/YY)	Optional
Response time	The time period between the individual being referred to SLT and receiving an initial SLT assessment.	Single-select list	Required
Reason for delay in SLT assessment	The reason for the delay in the initial assessment, where relevant.	Single-select list	Desirable
Reason for referral	The reason for the patient being referred to SLT.	Multi-select list	Required
SLT Diagnosis	The individual's communication/swallowing disorder(s).	Multi-select list	Required
Remote activity	The SLT input delivered prior to, or during, the initial assessment, delivered remotely.	Multi-select list	Optional
Face to face activity	The SLT input on initial assessment, delivered face-to-face.	Multi-select list	Optional

Field	Description	Format	Recommendation (required/desirable/ optional)
Date of initial SLT assessment	The date on which the initial SLT assessment was conducted.	Date (DD/MM/YY)	Required
COVID-19 status (at initial assessment)	The COVID-19 status on the date of the initial assessment (Positive, Negative, Suspected, Not known).	Single-select list	Required
Respiratory support at initial assessment	The level of respiratory support being provided to the patient during the initial assessment.	Single-select list	Desirable
Dysphonia TOM: impairment score (initial)	Numerical value for the TOMs score for the impairment domain, using the descriptors from the Therapy Outcome Measure User Guide which can be found on the second sheet of the spreadsheet titled "Scale Sheet" (Enderby and John 2019). <i>Values: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (where zero is the severe/profound end of the scale, five is the normal end of the scale).</i>	Single-select list	Please complete at least one per patient, as appropriate
GRBAS score(initial) - grade	Numerical value and description for the GRBAS (grade) score (Hirano 1981).	Single-select list	Please complete at least one per patient, as appropriate
GRBAS score(initial) - roughness	Numerical value and description for the GRBAS (roughness) score (Hirano 1981).	Single-select list	Please complete at least one per patient, as appropriate
GRBAS score (initial) - breathiness	Numerical value and description for the GRBAS (breathiness) score (Hirano 1981).	Single-select list	Please complete at least one per patient, as appropriate
GRBAS score(initial) - asthenia	Numerical value and description for the GRBAS (asthenia) score (Hirano 1981).	Single-select list	Please complete at least one per patient, as appropriate
GRBAS score (initial) – strain	Numerical value and description for the GRBAS (strain) score (Hirano 1981).	Single-select list	Please complete at least one per patient, as appropriate

Field	Description	Format	Recommendation (required/desirable/ optional)
Dysphagia TOM: impairment - initial score	Numerical value for the TOMs score for the impairment domain, using the descriptors from the Therapy Outcome Measure User Guide, which can be found on the second sheet of the spreadsheet titled "Scale Sheet" (Enderby and John 2019). Values: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (where zero is the severe/profound end of the scale, five is the normal end of the scale). NB The individual should be scored according to how they present at the point of referral, not after the assessment (i.e. before recommendations have been made).	Single-select list	Please complete at least one per patient, as appropriate
Functional Oral Intake Scale	The level of oral intake observed on initial assessment, using the Functional Oral Intake Scale (Crary et al, 2005).	Single-select list	Please complete at least one per patient, as appropriate
Communication AAC TOM: Activity - initial score	Numerical value for the TOMs score for the activity domain, using the descriptors from the Therapy Outcome Measure User Guide (Enderby and John 2019), which can be found on the second sheet of the spreadsheet titled "Scale Sheet". Values: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (where zero is the severe/profound end of the scale, five is the normal end of the scale).	Single-select list	Please complete at least one per patient, as appropriate
Trache TOM: impairment – initial score	Numerical value for the TOMs score for the impairment domain, using the descriptors from the Therapy Outcome Measure User Guide (Enderby and John 2019), which can be found on the second sheet of the spreadsheet titled "Scale Sheet". <i>Values: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (where zero is the</i> <i>severe/profound end of the scale, five is the normal end of the scale).</i>	Single-select list	Please complete at least one per patient, as appropriate

Oral hygiene TOM: impairment - initial score	Numerical value for the TOMs score for the impairment domain, using the descriptors from the Therapy Outcome Measure User Guide (Enderby and John 2019), which can be found on the second sheet of the spreadsheet titled "Scale Sheet". <i>Values: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (where zero is the</i> <i>severe/profound end of the scale, five is the normal end of the scale).</i>	Single-select list	Please complete at least one per patient, as appropriate
Fluid Recommendations (initial assessment)	The recommended level of fluid intake by the SLT following initial assessment.	Single-select list	Desirable
Food Recommendations (initial assessment)	The recommended level of food intake by the SLT following initial assessment.	Single-select list	Desirable
FEES indicated?	Whether a FEES examination is required.	Single-select list	Optional
FEES completed?	Whether a FEES examination was completed during this hospital admission.	Single-select list	Optional
Reason for being unable to complete FEES	The reason why it was not possible to undertake a FEES examination, where this was indicated.	Single-select list	Optional
Penetration Aspiration Scale (FEES)	The worst Penetration Aspiration Scale (Rosenbek et al, 1996) score recording during the FEES.	Single-select list	Optional
VFSS indicated?	Whether a videofluoroscopic swallowing study is required.	Single-select list	Optional
VFSS completed?	Whether a videofluoroscopic swallowing study has been undertaken during this hospital admission.	Single-select list	Optional
Reason for being unable to complete VFSS	The reason why it was not possible to undertake a videofluoroscopic swallowing study, where this was indicated.	Single-select list	Optional
Penetration Aspiration Scale (VFSS)	The worst Penetration Aspiration Scale (Rosenbek et al, 1996) score recording during the VFSS.	Single-select list	Optional

Care pathway (objective of intervention)	The objectives of the care pathway (improvement, sustain, managed decline).	Single-select list	Required
Therapy implemented	Whether therapy was implemented with a given individual during the course of the hospital admission.	Single-select list	Required
Type of Therapy	The type of therapy/intervention delivered by and/or on the advice of speech and language therapy during the hospital admission.	Multi-select list	Desirable
Other intervention – please state	The type of therapy/intervention delivered if not provided in the drop- down list of options.	Free text	Optional
Date of discharge from SLT	The date on which the patient is discharged from speech and language therapy.	Date (DD/MM/YY)	Required
Reason for discharge from SLT	The reason for the patient being discharged from SLT.	Single-select list	Required
COVID-19 status (on discharge)	The COVID-19 status on the date of discharge (Positive, Negative, Suspected, Not known)	Single-select list	Desirable
Respiratory support at discharge from SLT	The level of respiratory support being provided to the patient on discharge from SLT	Single-select list	Optional
Dysphonia TOM: impairment - final score	Numerical value for the TOMs score for the impairment domain, using the descriptors from the Therapy Outcome Measure User Guide (Enderby and John 2019), which can be found on the second sheet of the spreadsheet titled "Scale Sheet". Values: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (where zero is the severe/profound end of the scale, five is the normal end of the scale).	Single-select list	Please complete at least one per patient, as appropriate
GRBAS score (final) - grade	Numerical value and description for the GRBAS (grade) score (Hirano 1981).	Single-select list	Please complete at least one per patient, as appropriate

GRBAS score (final) - roughness	Numerical value and description for the GRBAS (roughness) score (Hirano 1981).	Single-select list	Please complete at least one per patient, as appropriate
GRBAS score(final) - breathiness	Numerical value and description for the GRBAS (breathiness) score (Hirano 1981).	Single-select list	Please complete at least one per patient, as appropriate
GRBAS score(final) - asthenia	Numerical value and description for the GRBAS (asthenia) score (Hirano 1981).	Single-select list	Please complete at least one per patient, as appropriate
GRBAS score(final) – strain	Numerical value and description for the GRBAS (strain) score (Hirano 1981).	Single-select list	Please complete at least one per patient, as appropriate
Dysphagia TOM: impairment - final score	Numerical value for the TOMs score for the impairment domain, using the descriptors from the Therapy Outcome Measure User Guide (Enderby and John 2019), which can be found on the second sheet of the spreadsheet titled "Scale Sheet". <i>Values: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (where zero is the</i> <i>severe/profound end of the scale, five is the normal end of the scale).</i>	Single-select list	Please complete at least one per patient, as appropriate
Functional Oral Intake Scale	The level of oral intake observed on discharge, using the Functional Oral Intake Scale (Crary et al, 2005).	Single-select list	Please complete at least one per patient, as appropriate
Communication AAC TOM: Activity - final score	Numerical value for the TOMs score for the activity domain, using the descriptors from the Therapy Outcome Measure User Guide (Enderby and John 2019), which can be found on the second sheet of the spreadsheet titled "Scale Sheet". Values: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (where zero is the severe/profound end of the scale, five is the normal end of the scale).	Single-select list	Please complete at least one per patient, as appropriate
Trache TOM: impairment – final score	Numerical value for the TOMs score for the impairment domain, using the descriptors from the Therapy Outcome Measure User Guide (Enderby and John 2019), which can be found on the second sheet of the spreadsheet titled "Scale Sheet". <i>Values: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (where zero is the</i> <i>severe/profound end of the scale, five is the normal end of the scale).</i>	Single-select list	Please complete at least one per patient, as appropriate

Oral hygiene TOM: impairment – final score	Numerical value for the TOMs score for the impairment domain, using the descriptors from the Therapy Outcome Measure User Guide (Enderby and John 2019), which can be found on the second sheet of the spreadsheet titled "Scale Sheet". Values: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (where zero is the severe/profound end of the scale, five is the normal end of the scale).	Single-select list	Please complete at least one per patient, as appropriate
Fluid Recommendations (discharge)	The recommended level of fluid intake by the SLT at discharge.	Single-select list	Desirable
Food Recommendations (discharge)	The recommended level of food intake by the SLT at discharge	Single-select list	Desirable
Time involved in activities related to this individual patient	The total amount of time involved in activities related to this individual patient (remote and face to face activities) delivered across the duration of the episode of care. <i>NB It is <u>not</u> necessary to complete this <u>and</u> 'total number of contacts'</i>	Single-select list	Optional
Total number of contacts	The total number of contacts related to this individual patient (remote and face to face activities) delivered across the duration of the episode of care. NB It is <u>not</u> necessary to complete this <u>and</u> 'time involved'	Number	Optional

#### References

Crary, M. A., Mann, G. D. C., & Groher, M. E. (2005). Initial psychometric assessment of a functional oral intake scale for dysphagia in stroke patients. *Archives of physical medicine and rehabilitation*, *86*(8), 1516-1520.

Enderby, P., John, A. (2019) Therapy Outcome Measure User Guide. Croydon: J & R Press Ltd.

Hirano, M. (1981) Clinical Examination of Voice. New York, NY: Springer-Verlag.

Rosenbek, J. C., Robbins, J. A., Roecker, E. B., Coyle, J. L., & Wood, J. L. (1996). A penetration-aspiration scale. *Dysphagia*, *11*(2), 93-98.

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