Long Covid speech and language therapy dataset

June 2023

Background

The professional body for speech and language therapists in the UK, the RCSLT, has developed a dataset to support the speech and language therapy profession with capturing data on the presentation, management and outcomes of patients with Long Covid.

This document contains information for speech and language therapy services and colleagues in their employing organisation to:

- Provide an overview of the dataset and rationale behind its development
- Outline the options available to services wishing to use the dataset
- Signpost to key resources, particularly for services who wish to upload the data that they collect to the **RCSLT Online Outcome Tool**
- Provide answers to frequently asked questions about the dataset and the project

Should you have any questions or feedback about this work, please contact root@rcslt.org

Long Covid speech and language therapy dataset

The Long Covid speech and language therapy dataset has been developed and piloted by a working group consisting of members of the profession with experience of supporting individuals with Long Covid who have speech and language therapy needs.

The dataset has been designed to facilitate data collection on the presentation, management and outcomes of patients with Long Covid in order to support:

- practising speech and language therapists with delivering high quality patient care (e.g. increasing reflective practice leading to improvements in patient care, professional development and informing clinical decision making)

- speech and language therapy services with:
    - demonstrating the impact of speech and language therapy
    - informing service change/quality improvement
    - informing resourcing decisions
    - benchmarking the effectiveness of speech and language therapy services
    - informing commissioning
    - ensuring services are of good quality for service users and sustainable for the future

- the wider speech and language therapy profession at a national (UK-wide) level with:
    - providing evidence to present to commissioning and funding bodies about the value of speech and language therapy
    - demonstrating how the speech and language therapy profession contributes to the delivery of policies and frameworks across the UK
    - influencing key decision makers
    - supporting research and development of the evidence base for speech and language therapy.

The dataset contains fields that will support the collection of data about patient demographics, presentation, management and outcomes, using Therapy Outcome Measures[1]. It is recognised that this is an extensive dataset, and it is not necessary to collect all of the fields contained in this dataset. Locally, you may choose to collect only the mandatory fields, or a subset of the optional fields in addition to the mandatory fields.

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[1] Enderby, P. and John, A. (2019) Therapy outcome measures user guide, Croydon: J&R Press Ltd

Collecting and using the data

The data collection template for the Long Covid speech and language therapy dataset can be downloaded from the RCSLT website.

Services may decide to collect and analyse the data at a local level only. Alternatively, speech and language therapy services can opt to submit their data online for this to be collated at a national level as part of a national project. More information about the latter option is provided, below.

Submitting data collected to the RCSLT Online Outcome Tool (ROOT)

Speech and language therapy services that opt to submit their data to the national database, the RCSLT Online Outcome Tool (ROOT), will need to complete information governance processes. This includes processes and procedures required by your employing organisation (e.g. data protection impact assessment) and, in addition, a data sharing agreement will need to be put in place between your employing organisation and the RCSLT. The **ROOT information governance pack** contains more information about this and the team at RCSLT will support you with these processes.

By submitting your data to the ROOT, your service will be able to access reports and analytics on your data. This will include the added benefit of enabling an easy comparison of the outcomes for your service with other services from across the UK that are submitting their data. In doing so, you will be contributing to a national database for the various scopes mentioned above, enabling the profession to obtain a nationwide picture using the contributions from local clinics and services. This will assist local services and the profession more widely with answering questions such as:
- What are the most common presenting symptoms for patients referred to speech and language therapy services?
- Which symptoms have shown the largest improvements through speech and language therapy?
- How many referrals are being received monthly?

- What is the balance of age, gender etc.?
- Are there differences between services?

Figure 1: Sample view of the ROOT dashboard, showing an at-a-glance view of the make-up of the Long Covid caseload at your service.
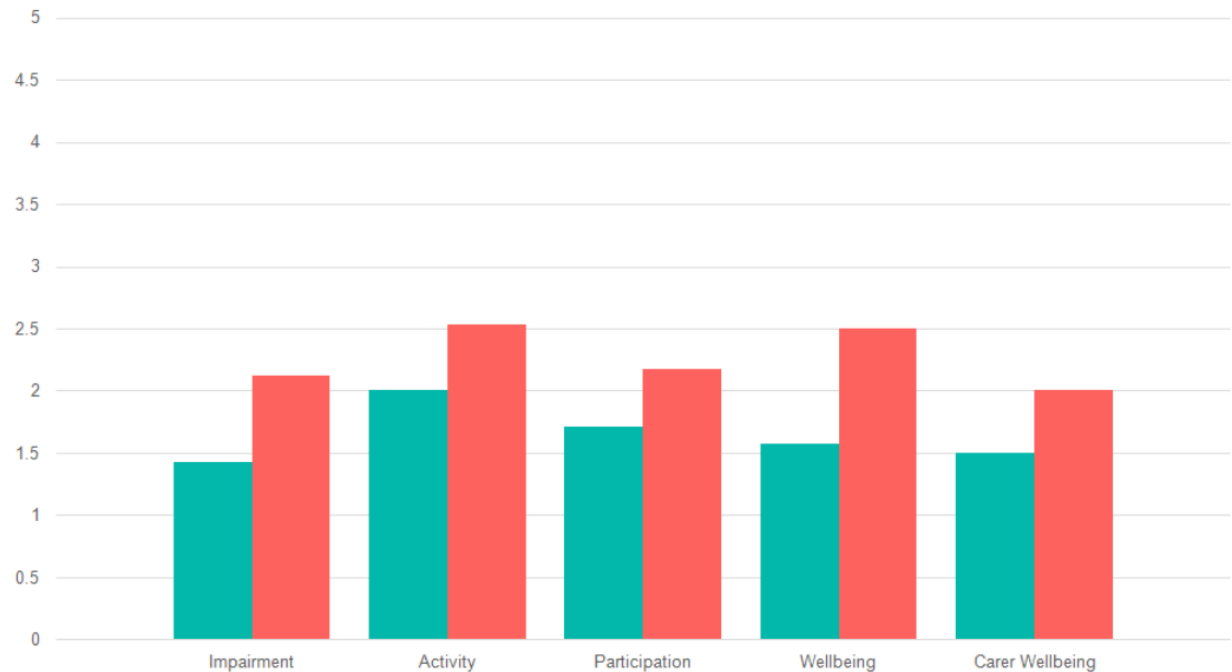
Figure 2: Sample report from the ROOT showing the Therapy Outcome Measures ratings for impairment, activity, participation, wellbeing and carer wellbeing at the beginning (green) and end (red) of speech and language therapy.

If you are interested in getting involved, please:
- **Register** to use the RCSLT Online Outcome Tool (if you do not already); and/or,
- Contact the team at RCSLT on **root@rcslt.org** to discuss next steps.

FREQUENTLY ASKED QUESTIONS

Which patients should be recorded on the spreadsheet?

The dataset has been developed to capture speech and language therapy involvement with all patients who present with symptoms that have developed following COVID-19.

NICE/SIGN guidance uses the term *Long Covid* to refer to "signs and symptoms that continue or develop after acute COVID-19. It includes both ongoing symptomatic COVID-19 (from 4 to 12 weeks) and post-COVID-19 syndrome (12 weeks or more)"[2].

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[2] https://www.nice.org.uk/guidance/ng188/resources/covid19-rapid-guideline-managing-the-longterm-effects-of-covid19-pdf-51035515742

Patients who fall within this Long Covid category can be recorded on the spreadsheet. Patients who are self-referred, referred by primary physicians or other members of the MDT, as well as those who fall under a Long Covid clinic, can all be included in the dataset.

Should I record all patients with Long Covid on the spreadsheet?

We encourage you to record data about all eligible patients on the spreadsheet. Recording only a sample will be less meaningful and could potentially skew the dataset.

Do we need to add data retrospectively to this spreadsheet?

There is no expectation that SLTs will add data to the spreadsheet retrospectively, but you are welcome to do so if you have the information readily available and would find this beneficial.

The working group recommend that you decide on a date from which you will start using the template, and then record data for all new referrals received after this date.

How long is the project?

The project will initially run for 12 months. In September 2024, the working group will conduct a review to decide whether the project will be extended. The ability for services to submit data to the RCSLT Online Outcome Tool will still be available.

I'm not currently using Therapy Outcome Measures. How do I get started?

In order to use the Long Covid speech and language therapy dataset, you should be familiar with the principles and scales of the TOM[3] (Enderby and John 2019) and have practised using this approach regularly. This can be achieved through a number of routes, including:
- Completing a formal TOM training course; or,
- Attending local training provided by colleagues who have completed a formal TOMs training course (or are qualified TOM trainers), and practising using the TOM with a minimum of 10 cases; and/or,

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[3] Enderby, P. and John, A. (2019) Therapy outcome measures user guide, Croydon: J&R Press Ltd

- Using the Therapy Outcome Measure User Guide and practising using the TOM with a minimum of 10 cases.

When practising, you should check your rating of cases with a colleague who is familiar.

For any questions about Therapy Outcome Measures, please contact root@rcslt.org

Things to consider before getting started

- **Your 'go live' date:** Have you decided when you'll start collecting the data? You may also want to think about whether you'll only enter data for new referrals, or whether to retrospectively enter data for all of the individuals on the caseload at that date.

- **Which of the optional fields you'll be collecting:** It is worth taking a few minutes to look at all of the optional fields in the dataset and considering which will be most valuable for your local service. There is no expectation that you should collect all of the fields marked 'optional' on the template, and you may wish to adapt the template to remove the unnecessary columns. If you decide to submit your data to the ROOT, you will need to decide on this prior to signing of the data sharing agreement.

- **Who will fill in the spreadsheet:** If more than one person will be filling in the spreadsheet, there are a few things you may wish to agree with your colleagues before you start to collect the data:

    - Where will the spreadsheet be saved?
    - Do you expect it to be kept up-to-date on a weekly basis, monthly basis etc.?