RCSLT

RCSLT Information Governance Pack

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RCSLT Online Outcome Tool (ROOT) & COVID-19 Data Collection Tool (CDCT)

Executive summary

The Royal College of Speech and Language Therapists (RCSLT) is working to support speech and language therapy services to improve the collection of data and to assist with demonstrating the impact of therapy for individuals with speech, language, communication and swallowing needs.

RCSLT Online Outcome Tool

The RCSLT Online Outcome Tool (ROOT) has been developed in collaboration with speech and language therapists, to collect and collate Therapy Outcome Measures (TOMs) (Enderby and John, 2015; Enderby and John, 2019) data and generate aggregated data reports. These reports can be utilised by speech and language therapists to inform clinical decision making and offer the potential to demonstrate the impact of speech and language therapy (SLT) interventions for individuals accessing services and cohorts of individuals. The reports could be used to assist with service evaluation and quality assurances purposes. The de-personalised datasets submitted by speech and language therapy services contribute to a national database, which supports the profession with benchmarking and exploring variation across the UK. It also provides evidence that can be used nationally to demonstrate the impact of the profession and to influence key decision makers.

COVID-19 data collection tool

The COVID-19 data collection tool (CDCT) is a module of the ROOT. It was developed in 2020 to support speech and language therapy services with capturing data on the management of patients with confirmed and suspected COVID-19. The CDCT also enables speech and language therapists to generate reports on the data submitted and contribute to a national database. Similarly, this is designed to support the profession with benchmarking, exploring variation across the UK and to shared lessons learned, as well as for use at a national level by the profession.

This document has been developed to support speech and language therapy services with understanding the legal requirements and local policy relevant to the use of the **ROOT and/or CDCT**, and with demonstrating due diligence with regards information governance and data security legislation. Local and national policies and procedures must always be followed.

Key points

- The information and resources provided in this pack are for guidance and support only and do not replace local documentation or national guidance. Local and national policies and procedures must always be followed.
- This document makes reference to "Data Protection Legislation", which means (i) the UK General Data Protection Regulation and (ii) the Data Protection Act 2018.
- The RCSLT has consulted with the Information Commissioner's Office (UK) and NHS Digital (England) during the course of these projects.
- The data collected via the ROOT and the CDCT is within the scope of Data Protection Legislation and, therefore, a Data Sharing Agreement will be required between the organisation providing the speech and language therapy service and the RCSLT, as joint data controllers. This can be completed electronically. Data Sharing Agreements will be routinely reviewed on 2-yearly basis.
- Individuals have the right to be informed about how data about them is used. Therefore, speech and language therapy services using the ROOT and/or CDCT should be transparent with service users about the ways in which data is used. This can be covered by an organisation's fair processing notice.
- Speech and language therapy services wishing to use the ROOT and/or CDCT will be required to confirm that they have satisfied all local policies and procedures related to information governance, including completion of all documentation required by their organisation, before access to the ROOT and/or CDCT will be granted.

Contents

1. Introduction

The RCSLT has developed two datasets and corresponding online tools to support a national approach to collecting information on outcomes related to speech and language therapy (SLT) intervention. This is to support speech and language therapists in clinical practice as well as service users, service managers and other key stakeholders. For practising clinicians, outcome measurement increases reflective practice leading to improvements in patient care, professional development and informing clinical decision making. At a service level, outcomes data can assist in informing service change, quality improvement, and resourcing decisions. In addition, outcomes-based commissioning in some parts of the UK requires services to evidence in a validated, robust and reliable way the outcomes for individuals receiving speech and language therapy.

Furthermore, a robust and validated demonstration of the impact of speech and language therapy has the potential to be useful evidence to present to commissioning bodies, to demonstrate how the profession contributes to the delivery of policies and frameworks across the UK and to influence key decision makers.

2. Overview of the RCSLT Online Outcome Tool (ROOT) and data collected

The RCSLT Online Outcome Tool (ROOT) facilitates the collection of Therapy Outcome Measures (TOMs) (Enderby and John, 2015; Enderby and John, 2019) data to support with monitoring, evaluating and reporting on outcomes for individuals receiving speech and language therapy. The ROOT has been developed by, and is hosted by, Different Class Solutions Ltd. It facilitates the collection of data about individuals' outcomes at different points in time, using TOMs. It is a stand-alone online tool that collects, collates and reports on outcomes data.

SLT services can enter TOMs data for service users directly into the ROOT, or, alternatively, data held in local electronic systems/databases can be uploaded in bulk to the ROOT (Figure 1).

Direct data entry	• Data about individual service users is entered directly into the ROOT
Data upload	• SLT services that are currently able to collect and collate TOMs data effectively within their local electronic system(s) can export data and uploaded in bulk to the ROOT

Figure 1: ROOT data collection methods

Speech and language therapists can access reports that show change over time for individuals in association with SLT interventions. The ROOT also aggregates data collected across an SLT service and generates reports on groups of service users. Filters can be applied to the reports to drill down to specific clinical groups at the required level for data analysis and reporting. SLT services using either method of data collection detailed in Figure 1 will have access to aggregated data reports about the outcomes delivered by their service.

Further information about the ROOT is available on the RCSLT webpages: [The RCSLT online outcome tool (ROOT)](#) The RCSLT has adopted a privacy-friendly approach in the development of the ROOT, with respect to the information collected about the individuals receiving speech and language therapy and the SLTs using the tool.

Data about individuals receiving speech and language therapy

The RCSLT has received advice from the Information Commissioner's Office about the data collected via the ROOT about the individuals receiving speech and language therapy. The data collected about service users are pseudonymised/de-personalised. In the majority of cases, individuals will not be identifiable from the data, nevertheless, the data should be treated as personal data. Annex 1 details the core information collected about individuals. This includes a unique patient identifier, which is required to enable outcomes to be monitored over time for individual service users. The unique patient identifier used to de-identify the data is at the discretion of the data controller, but this should be an identifier known only inside the organisation. Pseudonymised data falls within the scope of Data Protection Legislation. Please refer to section 8 for information about the data sharing agreements that will need to be put in place before any information can be submitted to the ROOT.

In addition to core data items outlined in Annex 1, the ROOT also has the capability to record additional data items, if required, locally; any additional data shared with the ROOT by users of the system must comply with local information governance policies and will be detailed in the data sharing agreement, which will be reviewed on a biennial basis.

Any data shared with the ROOT is a pseudonymised copy of the data recorded in the organisation's local speech and language therapy records; the ROOT is an addition to rather than a part of the organisation's case management system.

Data about speech and language therapists and other individuals using the ROOT

The ROOT collects personal data about the speech and language therapists and any other individuals who have to the ROOT. This is limited to key information, such as name, email address, employing organisation, RCSLT membership number (where applicable) and IP address. This information is provided by the employing organisation and the individual themselves on registration.

Each individual user is informed of how their personal data is used via a privacy notice prior to access to the ROOT being granted.

3. Overview of the COVID-19 data collection tool (CDCT) and data collected

The COVID-19 data collection tool is a module of the ROOT, which enables speech and language therapists to submit de-personalised datasets containing details of the presentation, management and outcomes of individuals with COVID-19. The data collection template was developed in collaboration with speech and language therapists working with COVID-19 patients during the early phase of the pandemic. The CDCT was developed by, and is hosted by, Different Class Solutions Ltd.

Data about individuals receiving speech and language therapy

It is not necessary for services to collect and submit all the fields provided in the data collection template. Services are encouraged to identify which fields are most relevant and useful locally.

The data collected about individuals receiving speech and language therapy is pseudonymised/de-personalised. Each individual should be allocated a unique patient identifier locally, which should be known only inside the organisation. Pseudonymised data falls within the scope of Data Protection Legislation. Please refer to section 8 for information about the data sharing agreements that will need to be put in place before any information can be submitted to the CDCT.

Data about individuals receiving speech and language therapy

As part of this project, data is collected about the speech and language therapists submitting the data. This is limited to key information, such as name, email address, employing organisation and RCSLT membership number. This information is collected on registration. Each individual user is informed of how their personal data is used prior to access being granted.

4. Purposes of processing

The ROOT has been developed to support the speech and language therapy profession to collect and report on outcomes data to improve the quality and provision of care.

The specific aims for this project are as follows:

Primary aims:

1. To support practising speech and language therapists to increase reflective practice leading to improvements in patient care, professional development and informed clinical decision making.

2. To support speech and language therapy services at a local level to:

   - demonstrate the impact of speech and language therapy
   - inform service change/quality improvement
   - inform resourcing decisions
   - benchmark the effectiveness of speech and language therapy services
   - inform commissioning

- ensure services are of good quality for those receiving speech and language therapy and sustainable for the future

Secondary aims:

3. To support the speech and language therapy profession at a national level by developing a national database which:

   - provides evidence to present to commissioning bodies and influence key decision makers
   - demonstrates the value of the profession, and its contribution to the delivery of policies and frameworks across the UK
   - support research and development of the evidence base for speech and language therapy.

Further information about the nature, scope, context and purpose of processing is summarised in the data protection impact assessment, available on request.

5. Roles and responsibilities

Organisational roles and responsibilities

The governance arrangements and roles and responsibilities of the RCSLT, the organisations submitting the data and Different Class (the data processors) are set out in Annex 3. In summary:

- The RCSLT is a joint data controller. It is responsible for validating requests to use ROOT and/or CDCT from organisations providing speech and language therapy to ensure that organisations using the system are legitimate and have a justified purpose for accessing the system.
- The organisation providing speech and language therapy services is a joint data controller. It controls the data shared with the ROOT and/or CDCT and is responsible for ensuring compliance with all legal requirements and local policies and procedures related to information governance. The organisation can assign user accounts to its staff and is responsible for allocating the correct level of access (Annex 4). This is to ensure that only persons with valid reasons can access the system, manage the administrative functions of the system and view the reports.
- The data processor (Different Class Solutions Ltd) hosts the ROOT and the CDCT and will process the data as instructed.

Individuals' roles and responsibilities

All users of the ROOT and CDCT are allocated a password-protected user account to protect access to the system and the data stored in the databases. All users, including contractors and temporary

staff, are required to agree to the Acceptable Use Agreement (Annex 5) to confirm their understanding and acceptance of what constitutes acceptable use of the ROOT and/or CDCT before being granted access. Users of the system must ensure that they use the systems in a way that complies with current local and national legislation, policies and frameworks related to information governance and information management and use it in an acceptable way. Any demonstrable misuse of the ROOT and/or CDCT will result in the suspension/revoking of system use.

6. System security overview

The software developer and data processor, Different Class Solutions Ltd, has put in place a number of security measures to ensure data shared with the ROOT is secure in transit and storage. Different Class Solutions Ltd is ISO 27001:2013 certified and has achieved Cyber Essentials Plus accreditation (Certificate no.: 5944466513017922).

Encryption

The ROOT and the CDCT are securely hosted web systems utilising SQL Server 2016 and ASP.net 4.6.1. The servers have SSL certification to ensure that all data flowing to and from the server is encrypted and could not be deciphered if intercepted in transit. The servers are protected by firewalls to protect the data and prevent unauthorised access by anyone else. The data is stored using an encryption algorithm so that if anyone physically removed a disk or the server itself, they would not be able to access the data.

Servers

The servers are located in UK data centres. The data centre is provided by Microsoft Azure, all meeting the security standards of ISO27001.

Audit

The specific content of any transactions and other system use is logged and monitored to look for unusual/unexpected use patterns that may be indicators of improper use. Regular audits of use will be undertaken by the data processor to monitor this and to ensure the Acceptable Use Agreement (Annex 5) is adhered to. The system provider, Different Class Solutions Ltd, maintains the right to monitor the volume of system use and navigation.

Further information about system security is provided in Annex 7.

The ROOT and CDCT have been developed to be compatible with all modern, secure web browsers. Please be aware that, if using an out of date or insecure web browser, you will not be able to access all of the content and functionality available. This is likely to be the case if you are using a version of Internet Explorer older than version 11, for example.

7. Privacy risks

Although the amount of personal data collected by the ROOT is minimal, a data protection impact assessment has been undertaken, which is available on request. This includes a summary of the privacy risks identified for the project and risk mitigation strategies.

8. Documentation

Data Sharing Agreements

Under the UK General Data Protection Regulation, pseudonymisation is a security measure and can reduce the risks to the data subjects, however, the UK GDPR classifies pseudonymised data as 'personal data' and so data collected via the ROOT and/or CDCT is within the scope of the UK GDPR.

It is a requirement under the UK GDPR (and DPA 2018) that joint controllers of personal data have transparent joint control arrangement, which sets out each parties' responsibilities. **It is essential, therefore, that a data sharing agreement (annex 6) is put in place between each organisation submitting data to the ROOT and/or CDCT and the RCSLT.**

A data sharing agreement:

- helps all the parties be clear about their roles;
- sets out the purpose of the data sharing;
- covers what happens to the data at each stage;
- sets standards;
- provides a framework to help all parties meet the requirements of the data protection principles.

A data sharing agreement will be sent to you once you have registered to use the ROOT and/or the CDCT. Alternatively, to request an electronic copy of a data sharing agreement, please contact ROOT@rcslt.org, confirming the name and address of your employing organisation and the contact details of your data protection officer (where relevant).

Other documentation

Speech and language therapy services may be required to complete local documentation to comply with local processes and procedures around information governance to receive authorisation from their organisation to use the ROOT and/or the CDCT. Examples of such documentation include Data Protection Impact Assessments, Data Mapping and Processing Forms, and Data Protection Notification Forms. These documents require details about how the information is being collected and shared, any risks to privacy and the precautions that have been undertaken to mitigate any risks.

Fair processing notice

Individuals have the right to be informed about how data about them is used. Therefore, speech and language therapy services using the ROOT and/or the CDCT should be transparent with

service users about the ways in which data is used. This can be covered by the organisation's (or service's) fair processing notice.

The ICO provides checklists to assist with developing fair processing notice in their [guidance on individual rights](#). To support with informing individuals about the ROOT specifically, the RCSLT has also developed some templates that could be adapted, including an easy-read version. Copies of these templates are available on request by contacting ROOT@rcslt.org.

9. Terms of use

Speech and language therapy services will be required to confirm that they agree to the terms of use when registering to use the ROOT and/or the CDCT. They will also need to confirm that they have satisfied all local policies and procedures related to information governance, including completion of all documentation required by their organisation, before access to the ROOT and/or CDCT will be granted.

10. Further information

Annex 7 contains a summary of frequently asked questions in relation to both projects. For further information about the ROOT and/or CDCT please contact ROOT@rcslt.org or visit the RCSLT webpages: [The RCSLT online outcome tool (ROOT)](#)

11. References

Enderby, P. & John, A. (2015). *Therapy outcome measures for rehabilitation professionals*, Third Edition. Guildford: J&R Press Ltd

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Information Commissioner's Office (2012). *Anonymisation: managing data protection risk code of practice*. [Online]. Available at: https://ico.org.uk/media/1061/anonymisation-code.pdf <Accessed 29 September 2021>.

NHS Digital (2019) *National Data Opt-out Operational Guidance Document.* [Online]. Available at: https://digital.nhs.uk/services/national-data-opt-out/operational-policy-guidance-document <Accessed 29 September 2021>.

World Health Organization (2001). *International Classification of Functioning, Disability and Health (ICF)*. Geneva: WHO Publishing

Annexes

Annex 1: Fields and data items collected and used by the RCSLT Online Outcome Tool (ROOT)

The following table details the fields and data items collected and used by the ROOT, according to the method of data collection used (e.g. direct data entry or data upload). This table indicates whether the data fields are required, desirable or optional. Services that opt to use the upload method would need to provide the required data fields to enable reports to be generated on the data. A document setting out the specification has been developed, which is available here. For more details about the different data structures for the data upload method (e.g. "Episode per row", "Rating per row", "Score per row"), please contact ROOT@rcslt.org.

Field	Description	Purpose	Direct data entry	Data upload		
				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
Local Patient Identifier	This is a local patient identifier and can take any alpha numeric form.	To link together records for a particular patient across episodes of care.	Required	Required	Required	Required
Year Of Birth	The year of the patient's birth	To enable outcomes data to be filtered by age for the purposes of analysis, which is helpful both locally and nationally	Desirable	Desirable	Desirable	Desirable
Gender	The patient's gender	To enable outcomes data to be filtered by gender for the purposes of analysis, which is helpful both locally and nationally	Desirable	Desirable	Desirable	Desirable
Episode of care Identifier	An episode of care identifier can take any alpha numeric form and delineates an episode of care. For the purposes of TOMs, an episode of care is a package of intervention(s) and will contain:	To link ratings for a given episode of care	Required (this is automatically assigned by the ROOT)	N/A	Required	Required

Field	Description	Purpose	Direct data entry	Data upload		
				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
	• Start of Episode ratings (S) • Interim(s) ratings (I) (Optional) • End of Episode ratings (E)					
Primary Communication and Swallowing Disorder Descriptor/Code	The descriptor and/or ICD10 code for the patient's primary communication/swallowing disorder	To enable outcomes data to be filtered by the services users' primary communication/swallowing disorder (e.g. dysphagia) for the purposes of analysis	Required	Desirable	Desirable	Desirable
Additional Communication and Swallowing Disorder Descriptor(s)/ Code(s)	The descriptor(s) and/or ICD10 code(s) for any additional communication/swallowing disorder(s)	To enable outcomes data to be analysed with reference to co-morbid conditions and complexity	Optional	Optional	Optional	Optional
Primary Medical Diagnosis Code/ Descriptor	The descriptor and/or ICD10 code for the patient's primary medical diagnosis	To enable outcomes data to be filtered by the services users' primary medical diagnosis (e.g. stroke) for the purposes of analysis	Desirable	Desirable	Desirable	Desirable
Additional Medical Diagnosis Descriptor(s)/ Code(s)	The descriptor(s) and ICD10 code(s) for any additional medical diagnoses	To enable outcomes data to be analysed with reference to multiple co-morbidities	Optional	Optional	Optional	Optional

Field	Description	Purpose	Direct data entry	Data upload		
				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
TOMs Scale Primary/ Secondary	The description of whether the TOMs Scale is for the 'primary' impairment or 'secondary' impairment	To indicate whether the TOMs scale is 'primary' or 'secondary' where more than one scale is used	N/A	N/A	N/A	Required
Primary TOMs Scale	The name of the TOMs scale that was used to rate the primary impairment (Enderby and John 2019)	To identify the TOMs scale used to rate the patient	Required	Desirable	Desirable	Desirable
Primary TOMs Scale ID	The identifying number of the TOMs scale that was used to rate the primary impairment (Enderby and John 2019). The Core Scale is coded as 0 (zero).	To verify the TOMs scale used to rate the patient	Required	Desirable	Desirable	Desirable
Secondary TOMs Scale	The name of the TOMs scale that was used to rate the secondary impairment (Enderby and John 2019)	To identify the secondary TOMs scale used to rate the patient, where applicable	Optional	Optional	Optional	Optional
Secondary TOMs Scale ID	The identifying number of the TOMs scale that was used to rate the primary impairment (Enderby and John 2019). The Core Scale is coded as 0 (zero).	To verify the secondary TOMs scale used to rate the patient, where applicable	Optional	Optional	Optional	

Field	Description	Purpose	Direct data entry	Data upload		
				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
Rating ID	A rating identifier can take any alpha numeric form. For the purposes of TOMs, a rating is a single set of scores collected across the domains of TOMs at a single point in time and will contain scores for: • Impairment (primary/secondary) • Activity (primary/secondary) • Participation • Wellbeing • Carer Wellbeing – optional	To link together scores into a rating (if this is not available, the date that the rating was made may serve the purpose)	N/A	N/A	N/A	Desirable
Rating Type	S = Admission/Initial Assessment/First Rating/Start of Episode I = Interim/On-Going (optional) F= End of Episode/Final Rating/Discharge	To determine the sequence of ratings in an episode of care	Required	N/A	Required	Required
Rating date	The date the TOMs rating took place	To enable outcomes over time to be tracked	N/A	N/A	Required	Required
Rating Date – start of episode	The date the first TOMs rating in the episode took place	To enable outcomes over time to be tracked	Required	Required	N/A	N/A

Field	Description	Purpose	Direct data entry	Data upload		
				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
Rating Date – interim	The date the interim TOMs rating(s) in the episode took place (where appropriate)	To enable outcomes over time to be tracked	Optional	N/A	N/A	N/A
Rating Date – end of episode	The date the final TOMs rating in the episode took place	To enable outcomes over time to be tracked	Required	Required	N/A	N/A
Impairment Score (Primary) – start of episode[1]	Numerical value for the TOMs score for the impairment domain: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (Zero is the severe / profound end of the scale, five is the normal end of the scale)	To record the level of impairment (primary)	Required	Required	Required	Required
Impairment Score (Primary) – end of episode	Any TOMs domains where a TOMs score is not applicable should be indicated accordingly.	To record the level of impairment (primary)	Required	Required	Required	Required
Impairment Score (Secondary) – start of episode	Numerical value for the TOMs score for the impairment domain: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5	To record the level of impairment (secondary)	Optional	Optional	Optional	Optional

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[1] For SLT services using the AAC adapted scale, the TOMs domains are: Impairment (physical), Impairment (cognitive), Impairment (sensory), Impairment (speech and language output) Impairment (comprehension), Activity, Participation, Wellbeing and Carer-wellbeing.

Field	Description	Purpose	Direct data entry	Data upload		
				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
Impairment Score (Secondary) – end of episode	(Zero is the severe / profound end of the scale, five is the normal end of the scale) Any TOMs domains where a TOMs score is not applicable should be left blank (null).	To record the level of impairment (secondary)	Optional	Optional	Optional	Optional
Activity Score (Primary) – start of episode	Numerical value for the TOMs score for the activity domain: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (Zero is the severe / profound end of the scale, five is the normal end of the scale) Any TOMs domains where a TOMs score is not applicable should be left blank (null).	To record the level of activity limitation (primary)	Required	Required	Required	Required
Activity Score (Primary) – end of episode		To record the level of activity limitation (primary)	Required	Required	Required	Required
Activity Score (Secondary) – start of episode	Numerical value for the TOMs score for the activity domain: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (Zero is the severe / profound end of the scale, five is the normal end of the scale) Any TOMs domains where a TOMs score is not applicable should be left blank (null).	To record the level of activity limitation (secondary)	Optional	Optional	Optional	Optional
Activity Score (Secondary) – end of episode		To record the level of activity limitation (secondary)	Optional	Optional	Optional	Optional

Field	Description	Purpose	Direct data entry	Data upload		
				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
Participation Score – start of episode	Numerical value for the TOMs score for the participation domain: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (Zero is the severe / profound end of the scale, five is the normal end of the scale) Any TOMs domains where a TOMs score is not applicable should be left blank (null).	To record the level of participation restriction	Required	Required	Required	Required
Participation Score – end of episode		To record the level of participation restriction	Required	Required	Required	Required
Wellbeing Score – start of episode	Numerical value for the TOMs score for the wellbeing domain: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (Zero is the severe / profound end of the scale, five is the normal end of the scale) Any TOMs domains where a TOMs score is not applicable should be left blank (null).	To record the impact on well-being	Required	Required	Required	Required
Wellbeing Rating Score – end of episode		To record the impact on well-being	Required	Required	Required	Required
Carer Wellbeing Score – start of episode	Numerical value for the TOMs score for the carer wellbeing domain: 0, 0.5, 1, 1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5 (Zero is the severe / profound end of the scale, five is the normal end of the scale)	To record the impact on carer well-being	Optional	Optional	Optional	Optional

Field	Description	Purpose	Direct data entry	Data upload		
				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
Carer Wellbeing Rating Score – end of episode	Any TOMs domains where a TOMs score is not applicable should be left blank (null).	To record the impact on carer well-being	Optional	Optional	Optional	Optional
End-of-episode/Discharge Code/Description	Free text description of the status at the end of the episode of care and/or reason for discharge (e.g. therapy complete, did not attend)	To record the status at the end of the episode of care and/or the reason for discharge	Optional	Optional	Optional	Optional
Local/user-defined fields	These are data items that are deemed useful, and created by participating services. Examples include the department/team, number of contacts etc. They are only available to the service that created them should the service opt for this functionality. As such these fields are under the control of the local service and their own organisation's information governance frameworks must be adhered to. These should be recorded in the data sharing agreement.	To increase the value of the data by ensuring the data better matches local structures, practices and reporting requirements.	Optional	Optional	Optional	Optional

Annex 2: Fields and data items collected and used by the Covid-19 Data Collection Tool

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
Hospital Admission Date	The date on which the individual was admitted to hospital.	Date (DD/MM/YY)	Optional

Field	Description	Format	Recommendation (required/desirable/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). *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(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". *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
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	Single-select list	Please complete at least one per patient, as appropriate

Field	Description	Format	Recommendation (required/desirable/optional)
	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)._		
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

Field	Description	Format	Recommendation (required/desirable/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

Field	Description	Format	Recommendation (required/desirable/optional)
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". *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
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	Single-select list	Please complete at least one per patient, as appropriate

Field	Description	Format	Recommendation (required/desirable/optional)
	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).*		
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". *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
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. *NB It is not necessary to complete this and 'total number of contacts'*	Single-select list	Optional

Field	Description	Format	Recommendation (required/desirable/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.

Annex 3: Governance Arrangements: Organisational Administrative Roles and Responsibilities

Organisation	Roles and Responsibilities
Royal College of Speech and Language Therapists (RCSLT)	• Joint data controller (with organisations submitting the data) • Provides data sharing agreement template, and routinely reviews signed data sharing agreements on a biennial basis • Provides oversight of the data processor and their activities on behalf of the data controllers • Ensures the required data processing agreement is in place • Ensures that organisations using the system are legitimate and have a justified purpose for accessing the system • Validates requests from organisations to use the system • Provides organisations with access to the ROOT
Different Class Solutions Ltd	• Data processor: processes information as instructed by the data controllers • Provides a regular quality report to RCSLT and organisations on user log-ins / activity • Monitors the volume of system use and navigation[2] • Complies with, and completes relevant documentation in accordance with, Data Protection Legislation • Registered with the Information Commissioner's Office (data protection registration number: Z2840119) • Has ISO 27001 and Cyber Essentials Plus certification/accreditation (Certificate no.: 5944466513017922)

Each organisation submitting data to the ROOT and/or CDCT	• Joint data controller (with the RCSLT)
	• Reviews data sharing agreement on a biennial basis
	• Manages user accounts linked to their organisation
	• Assigns roles and permissions to users linked to their organisation.
	• Appoints local administrative user(s) to manage users which will include:
	    o adding users to the ROOT
	    o changing user roles and privileges
	    o monitoring users
	    o removing/suspending users
	• Ensures that usernames are valid email addresses and all users have a legitimate reason for accessing the databases,
	• Ensures all organisation users agree to the Acceptable Use Agreement
	• Revokes /removes users
	    o when the user leaves the organisation

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[2] The specific content of any transactions and other system use is logged and monitored to look for unusual/unexpected use patterns that may be indicators of improper use.

	o when a user acts in way contrary to the Acceptable Use Agreement • Ensures that their organisation adheres to the principles of fair processing • Ensures that information security and records management standards are met (international, national and local)

Annex 4: Users of the ROOT and/or CDCT

ROOT/CDCT User Type	Description of access	Purpose
Local user *User can enter data directly into the ROOT. This might be a clinician or delegated to an administrator. Use of the system would mirror existing working practices.*	• Access to pseudonymised data for service users under their care • Access to reports for individual service users under their care • Access to aggregated data reports on outcomes at a team/service level and external benchmarking level[3] • Local users must comply with all policy, legislation and the local organisation's protocols, working in a way that mirrors existing working practices • Must also agree to the Acceptable Use Agreement (Annex 5)	• To evaluate the impact of interventions • To inform patient-centred care • To support clinical decision making
Local admin *User responsible for monitoring and validating access to the online tool for users within an organisation, in addition to "Local User" functions*	• Access to pseudonymised data for service users under their care • Access to reports for individual service users under their care • Access to aggregated data reports on outcomes at a team/service level and external benchmarking level[3] • Access to the data upload functions of the ROOT, where appropriate • Access to user administration functions • Access to reports monitoring appropriate use of the system and other audit reports • Local admins must comply with all policy, legislation and the local organisation's protocols, working in a way that mirrors existing working practices • Must agree to the Acceptable Use Agreement (Annex 5)	• To evaluate the impact of interventions • To inform patient-centred care • To support clinical decision making • To evidence the impact of SLT input to decision makers and commissioners • To support sharing of best practice and reflect on service outcomes • To inform changes to service delivery • To manage and validate user accounts for access to the ROOT • To monitor use of ROOT for auditing purposes

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[3] Benchmarking reports will not identify organisations without explicit consent

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RCSLT administrative users	• Access to user administration functions • Access to anonymised service-level and national-level reports (which do not contain data for fewer than 6 service users) • Access to the pseudonymised patient data for the purposes of providing help and support to users • Must agree to the Acceptable Use Agreement (Annex 5)	• To assist with technical and administrative enquiries • To support SLT services with service evaluation and service improvement • To support SLT services to benchmark the effectiveness of SLT services • To support development of the evidence base and identification of research priorities
Different Class Solutions Ltd administrative users	• This role has special access to all system features, functions, and data • The organisation is ISO 27001 certified, has achieved Cyber Essentials Plus accreditation and is registered with the Information Commissioner's Office	• To install, or upgrade computer components and software • To provide routine automation • To maintain security policies • To troubleshoot • To train or supervise staff; or offer technical support • To support the upkeep, configuration, and reliable operation of computer systems • To ensure that the uptime, performance, resources and security of the server and software meet the needs of the users

Annex 5: Acceptable Use Agreement

The ROOT and the CDCT have been developed to support speech and language therapy services with collecting, collating and analysing outcome data.

In using the ROOT/CDCT, users must ensure they do so in an acceptable way, and must not engage in any of the behaviours considered unacceptable.

It is the responsibility of the users of the ROOT/CDCT to use the system in a way that complies with existing standards and expectations about fair processing in accordance with Data Protection Legislation[4]. Use of the ROOT/CDCT is fully monitored and audited.

- ☐ I understand that it is my responsibility to use the ROOT/CDCT in a way that complies with existing standards and expectations about fair processing in accordance with Data Protection Legislation[5]
- ☐ I am aware that the use of the ROOT/CDCT is fully monitored and audited and that any demonstrable misuse of the ROOT/CDCT will result in the suspension/revoking of system use.
- ☐ I will not attempt to use someone else's login details to access the ROOT/CDCT
- ☐ I will not allow anyone else to use my login details. I am aware that passwords should be kept securely and I will not disclose my password to anyone else.
- ☐ I will not attempt to search for information on a service user that I am not authorised to access
- ☐ I will not download information to use in ways that run counter to the system's objectives
- ☐ I will not attempt to access unauthorised areas
- ☐ I will not introduce any spurious or non-existent cases into the system[5]
- ☐ I will not attempt to alter, deface, block, erase, destroy or conceal records with the intention of preventing disclosure under a request relating to the Freedom of Information Act 2000 or the Data Protection Legislation.
- ☐ I will not remain logged on to the ROOT/CDCT when unattended.

Any demonstrable misuse of the ROOT and/or CDCT will result in the suspension/revoking of system use.

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[4] "Data Protection Legislation" means (i) the Regulation (EU) 2016/279 General Data Protection Regulation (GDPR) and (ii) the Data Protection Act 2018
[5] Please note, there is test environment available to use with 'dummy data' for training purposes

Annex 6: Data Sharing Agreement

A data sharing agreement will be required between the organisation providing the speech and language therapy service and the RCSLT.

Sample data sharing agreements for both the ROOT and the CDCT can be downloaded from our website.

Once your organisation has registered to use the ROOT and/or CDCT, a data sharing agreement will be sent to you. This needs to be signed by the appropriate person within your organisation and returned to the RCSLT before access is granted to these online tools.

Alternatively, to request an electronic copy of the Data Sharing Agreement for the ROOT and/or CDCT, please contact ROOT@rcslt.org, confirming the name and address of your employing organisation and the contact details of your data protection officer (where relevant).

Annex 7: Frequently Asked Questions

1. Why is the information being shared?

Information is being shared with the ROOT and/or CDCT for the purposes of collating outcomes data to generate data reports. This will support SLT services to:

- demonstrate the impact of SLT
- inform commissioning
- demonstrate contribution of SLT services to national policy outcomes
- ensure services are of good quality for service users and sustainable for the future
- benchmark the effectiveness of their SLT service

Further details about the purposes of processing is provided in section 4 of this document.

2. What information is being shared?

The following information about the speech and language therapists (and any other individuals using the ROOT/CDCT) is shared:

- The user's name
- The user's email address
- Employing organisation
- RCSLT membership number
- The IP address that the user connects from

Annexes 1 and 2 provide a detailed summary of the information shared about individuals accessing speech and language therapy by organisations using the ROOT and the CDCT, respectively. This includes:

- A pseudonymised local patient identifier
- Gender
- Year of birth
- Medical diagnoses
- Communication and swallowing disorder descriptor(s)
- Outcomes data (e.g. Therapy Outcome Measure (TOMs) scales, scores, rating dates)

With respect to the ROOT only, additional fields may be added, if required. Additional data shared with the ROOT by users of the system must comply with local information governance policies and frameworks and is not the responsibility of the data processor or the RCSLT. Please contact ROOT@rcslt.org for further information.

3. Will the project involve the collection of new information about individuals or collection of information in a new way?

All data shared with the ROOT and/or CDCT is already collected by the organisations prior to their involvement with this project. These online tools provide services with an electronic method of data collection and analysis.

4. Will the project compel individuals to provide information about themselves or will information be collected without explicit consent?

The personal data about the speech and language therapists (and other individuals) accessing the ROOT/CDCT is provided by the individuals themselves and/or their employing organisation.

The data collected about service users are pseudonymised. In the majority of cases, individuals will not be identifiable from the data, nevertheless, the data should be treated as personal data. Pseudonymised data falls within the scope of Data Protection Legislation and data controllers should consider the lawful basis for processing. Consent is one of the available lawful bases for processing; nevertheless, the GDPR defines high standards for consent and if consent does not meet the criteria, it is not valid under GDPR. Furthermore, under GDPR, consent must offer the individuals genuine choice and control over the processing of their personal data. Therefore, consent may not be the most suitable basis and data controllers may wish to consider alternative options. Local processes around gaining consent should be followed.

Nevertheless, individuals have the right to be informed about how data about them is used, which can be covered by the organisation or service's fair processing notice.

5. Will using the ROOT/CDCT involve using information about individuals for a purpose it is not currently used for?

The use of the ROOT/CDCT involves the sharing of data that has been pseudonymised/de-personalised. The tools generate anonymised, aggregated reports at (i) a service level (ii) national level (iii) external benchmarking, which are additional uses of the data already collected by the organisations involved in the project. Individuals are not identifiable from these reports.

6. Is the information about individuals of a kind particularly likely to raise privacy concerns or expectations?

Information about the speech and language therapists (and other individuals) using the ROOT will only be used to in relation to their use of the system. Users are informed of how their information is used via a privacy notice.

Information about service users is pseudonymised. The aggregated reports generated by the ROOT do not contain data for fewer than 6 service users to minimise risk of service users being identifiable from the reports. Furthermore, organisations are not identifiable to other organisations from external benchmarking reports.

7. How will the information be stored?

The data is stored on a secure server. This means that encryption technology is used to ensure that all data flowing to and from the server is encrypted and could not be deciphered if intercepted in transit. The servers used are protected by firewalls to protect the data and prevent unauthorised access by anyone else. The data is stored using an encryption algorithm so that if anyone physically removed a disk or the server itself, then they would not be able to access the data. Thus all data is encrypted in the database and in transit.

The servers are located in UK data centres. The data centre is provided by Microsoft Azure, all meeting the security standards of ISO27001.

8. Are you transferring personal data to a country or territory outside of the EEA?

No, the servers are located in UK data centres.

9. Who will have access to the information?

As outlined in detail in Annex 4, there are four different types of user:

- 'Local users' are individuals with access the ROOT/CDCT, as authorised by their organisation. They will have access to pseudonymised data and reports for service users under their care. They will also have access to aggregated data reports on outcomes at a team/service level and anonymised external benchmarking reports (i.e. organisations are not identifiable to other organisations).

- 'Local admins' are individuals with access the ROOT/CDCT that have been appointed by their organisation to monitor and validate access to the ROOT/CDCT. They are responsible for ensuring that only persons within that organisation with valid reasons to access the system are issued a user log-in to view information stored there. 'Local

admins' will have access to the information about all 'local users' within the organisation in addition to the access described above.

- Employees of Different Class Solutions Ltd are able to access the pseudonymised data and reports for service users, but will only do so in order to support use of the system. This may be to correct or assess errors in system running or data itself. Moreover, checking the accuracy of screens and or reports will require tracking back to the individual records that are displayed or counted. Different Class Solutions Ltd comply with the standards of ISO 27001. They will also have access to aggregated data reports on outcomes at a team/service level and external benchmarking level.

- Administrative users at RCSLT are able to access the pseudonymised data and reports for service users to support use of the system. They are able to access anonymised service-level and national-level reports (which do not contain data for fewer than 6 service users) and user administration functions.

10. Under what circumstances will Different Class Solutions Ltd access the data?

Different Class Solutions Ltd, as the data processor, has access to the physical servers where data is held. All data is stored in encrypted tables so that maintenance and developments will not need to decrypt the data. Only in cases of suspected system defects/errors and new developments will Different Class employees need to look at the decrypted results, test the outputs from the system and respond to direct user queries.

11. Why would Different Class Solutions Ltd need to access the data?

Access to the data will be required where there is technical support requirement i.e. where software engineers and support staff will need to see the data to understand a reported issue. For example, to be able to either instruct the user as to what they are seeing and why or ask questions of the user to ascertain the behaviour of the system and if a defect is responsible. They will also have to see the resultant data after a fix has been applied to see if the system is now behaving as expected.

12. Who will handle the information?

Each organisation's administrative user(s) will be responsible for ensuring that only persons with valid reasons can access the system and view information stored and shared there.

13. Our organisation is required to comply with NHS England's national data opt out policy. Is there anything we also need to consider before we start using the ROOT or CDCT?

To be compliant with the national data opt out, you need to assess whether the sharing of data with the ROOT and/or CDCT is in scope of the national data opt-out policy. More information about the national data opt out is provided on the NHS Digital website.

Data that is anonymised in line with the ICO code of practise on anonymisation is not considered to be confidential patient information and the national data opt-out does not apply (NHS Digital 2019). It therefore recommended that organisations consult best practice guidelines on anonymisation techniques detailed in "Anonymisation: managing data protection risk code of practice" (ICO, 2012) to ensure that the information that they are sharing is not confidential.

The Royal College of Speech and Language Therapists (RCSLT) is the professional body for speech and language therapists in the UK. As well as providing leadership and setting professional standards, the RCSLT facilitates and promotes research into the field of speech and language therapy, promotes better education and training of speech and language therapists, and provides its members and the public with information about speech and language therapy.

rcslt.org | info@rcslt.org | @RCSLT

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