## Royal College of Speech and Language Therapists Information Governance Pack RCSLT Online Outcome Tool

#### **Executive summary**

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

The RCSLT has commissioned Different Class Solutions Ltd to develop the RCSLT Online Outcome Tool (ROOT) in collaboration with speech and language therapists. The ROOT has been developed to collect and collate Therapy Outcome Measures (TOMs) (Enderby and John, 2015) data and generate aggregated data reports (Annex 1). 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 individual service users and cohorts of service users. The reports could be used to assist with service evaluation and quality assurances purposes.

Following a proof-of-concept pilot (Annex 1) involving speech and language therapy services from across the UK, the RCSLT is rolling out the use of the ROOT to the profession using a phased approach.

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 with demonstrating due diligence with regards information governance and data security legislation. Local and national policies and procedures must always be followed in relation to the use of the ROOT.

This document contains:

- information about the ROOT, including data security, acceptable use and the data the system collects and uses
- guidance on completing information governance documentation related to the use of the ROOT
- an outline of the safeguards undertaken in relation to the project

## Key points

- The information and resources provided in this pack are for guidance and support only and do not replace local documentation. Local and national policies and procedures must always be followed when completing any information governance documentation in relation to the use of the ROOT.
- This document makes reference to "Data Protection Legislation", which means (i) the Regulation (EU) 2016/279 General Data Protection Regulation (GDPR) and (ii) the Data Protection Act 2018
- The RCSLT has consulted with the Information Commissioner's Office (UK) and NHS Digital (England) during the development of the ROOT.
- The data collected via the ROOT is within the scope of Data Protection Legislation and, therefore, a Data Processing Agreement will be required between the organisation providing the speech and language therapy service (the data controller) and Different Class Solutions Ltd (the data processor). This can be completed electronically.
- Individuals have the right to be informed about how data about them is used. Therefore, speech and language therapy services using the ROOT 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 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 will be granted.

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## 1. Introduction

Outcomes-based commissioning in some parts of the UK requires the speech and language therapy (SLT) profession to evidence in a validated, robust and reliable way the impact of SLT services and interventions on outcomes for patients.

The RCSLT has adopted a national approach to collecting information on outcomes related to speech and language therapy 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. 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)

The RCSLT Online Outcome Tool (ROOT) facilitates the collection of Therapy Outcome Measures (TOMs) (Enderby and John, 2015) data to support with monitoring, evaluating and reporting on outcomes for individuals receiving speech and language therapy. The ROOT has been developed by Different Class Solutions Ltd in collaboration with SLT services involved during a pilot (Annex 1). It facilitates the collection of data about individual service users' 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	<ul> <li>Data about individual service users is entered directly into</li></ul>
entry	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



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.

### 3. Data collected using the 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. In the majority of cases, individuals will not be identifiable from the data, nevertheless, the data should be treated as personal data. Annex 2 details the 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, and therefore, a GDPR-compliant contract will be required between the organisation providing the speech and language therapy service (the data controller) and Different Class Solutions Ltd (the data processor). Please refer to section 8.

In addition to data items outlined in Annex 2, the ROOT also has the capability to record additional data items, if required; any 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.

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.

Annex 3 contains schematic diagrams of the data flow mapping for the ROOT.

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

The ROOT collects personal data about the individuals using the ROOT. This is limited to key information, such as name, email address, employing organisation, RCSLT membership number (where applicable) and IP address (this is collected automatically – users are not

expected to know what their 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 and will be required to consent to their details being processed in relation to their use of the system prior to access to the ROOT being granted.

### 4. Purposes of processing

The ROOT has been developed to support SLT services to collect and report on outcomes data to improve the quality and provision of care. Outcomes data can assist in informing service change, quality improvement, and resourcing decisions. Furthermore, a robust and validated demonstration of 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.

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 data processors and the data controllers are set out in Annex 4. In summary:

- The RCSLT is responsible for validating requests to use ROOT 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 data controllers (i.e. organisations providing speech and language therapy services and control the data shared with the ROOT) are responsible for ensuring compliance with all legal requirements and local policies and procedures related to information governance. The organisation has control over the user accounts that it assigns 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) processes information under contract with data controllers and will only process data as instructed. The data processor will comply with any local requirements regarding documentation to permit the processing of data on the organisation's behalf. Different Class Solutions Ltd is

registered with the Information Commissioner's Office (data protection registration number: Z2840119).

#### Individuals' roles and responsibilities

All users of the ROOT are allocated a password-protected user account to protect access to the system and the data stored in the database. All users, including contractors and temporary staff, are required to agree to the Acceptable Use Agreement (Annex 6) to confirm their understanding and acceptance of what constitutes acceptable use of the ROOT before being granted access. Users of the system must ensure that they use the ROOT 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 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 is a securely hosted web system 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 a UK data centre, hosted by a third party supplier, Heart Internet, based in Derby, UK. The servers are hosted in an environment serviced by fail-safe mechanisms and data is synchronised to secure database servers every 30 minutes. The data centre is monitored by CCTV both externally and internally. All CCTV images are recorded and stored for 3 months. The building is surrounded by an 8ft perimeter fence. Gates are locked outside of normal business hours. There are two locking doors to go through for access to each of the separate data halls within the data centre. These are locked and can only be opened using secure fobs which are only held by named employees of Heart Internet.

#### 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 6) 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 9.

### 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 Processing Agreements

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

Where personal data is being processed, article 28 of the GDPR requires that a contract is in place between the data controller and the data processor. **To ensure that your organisation is not in breach of the Data Protection Legislation, it is essential that a GDPR-compliant contract is put into place between your organisation and the data processor, Different Class Solutions Ltd.** The data processor is under contract to the data controller and will only process data as instructed. Different Class Solutions Ltd has a GDPR-compliant data processing agreement that can be used (Annex 7), or you can use your organisation's own documentation.

To request an electronic copy of the Data Processing Agreement please contact <u>ROOT@rcslt.org</u>, 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. 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.

The data processor will comply with any local requirements.

#### 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 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.

### 9. Terms of use

Speech and language therapy services will be required to confirm that they agree to the terms of use (Annex 8) when registering to use the ROOT. 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 will be granted.

## **10. Further information**

Annex 9 contains a summary of frequently asked questions in relation to the project. For further information about the ROOT please contact <u>ROOT@rcslt.org</u> or visit the RCSLT webpages: <u>https://www.rcslt.org/speech-and-language-therapy/rcslt-online-outcome-tool-overview</u>

## 11. References

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

Enderby P, John A, & Petheram B. (2006). *Therapy outcome measures for rehabilitation professionals,* Second edition. London: Wiley

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 May 2019>.

NHS Digital (2019) *National Data Opt-out Operational Guidance Document*. [Online]. Available at: <u>https://digital.nhs.uk/binaries/content/assets/website-assets/services/national-data-opt-out-programme/guidance-for-health-and-care-staff/ndopnationaldataoptoutpolicy\_v3.0.pdf</u> <Accessed May 2019>.

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

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#### Annex 1: The RCSLT Outcomes Programme

The RCSLT commissioned a review of outcome measures to identify an existing reliable and valid outcome measure for use by the profession. Over 60 outcome measures, frameworks and systems commonly used by speech and language therapists (SLTs) were appraised against this set of criteria. *Therapy Outcome Measures for Rehabilitation Professionals* (Enderby, John and Petheram 2006)<sup>1</sup> was selected as the 'best fit'.

Therapy Outcome Measures (TOMs) is used by professionals working with adults and children with a range of clinical disorders to monitor change over time in response to interventions. TOMs addresses the dimensions of impairment, activity and participation in line with the International Classification of Functioning, Disability and Health (WHO, 2001). Additionally, TOMs looks at the individual's and/or carer's well-being, where appropriate. Each is rated by the therapist (preferably in consultation with the individual and /or family) on an 11-point ordinal scale with six defined descriptors, ranging from 0 (worst case scenario), to 5 (best possible presentation).

In 2015, the RCSLT Council approved the development of a proof of concept online tool to support collection of TOMs data. The RCSLT Online Outcome Tool was developed using feedback from RCSLT members using an approach known as Agile, in which the software is developed in stages gathering feedback from users in services and using it to shape the next iteration of the development.

Twelve SLT teams/services from across the UK working with a broad range of service users with speech, language, communication and/or swallowing needs in adult and paediatric settings with experience of using TOMs were invited to pilot the ROOT. Following an evaluation of the pilot, the RCSLT Board of Trustees approved a phased roll-out of the use of the ROOT more widely across the profession in July 2017.

Further information about the work is available on the RCSLT webpages: https://www.rcslt.org/speech-and-language-therapy/rcslt-online-outcome-tool-overview

<sup>&</sup>lt;sup>1</sup> Third edition now available: Enderby P, John A. *Therapy outcome measures for rehabilitation professionals*, Third Edition. Guildford: J&R Press Ltd, 2015.

## Annex 2: 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 <u>here</u>. 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 <u>ROOT@rcslt.org</u>.

	Description	Purpose		Data upload		
Field			Direct data entry	"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
Local Patient	This is a local patient identifier and can	To link together records for a particular	Required	Required	Required	Required
Identifier	take any alpha numeric form.	patient across episodes of care.				
Year Of Birth	The year of the patient's birth	To enable outcomes data to be filtered by age for the purposes of analysis	Desirable	Desirable	Desirable	Desirable
Gender	The patient's gender	To enable outcomes data to be filtered by gender for the purposes of analysis	Desirable	Desirable	Desirable	Desirable
Episode of care Identifier	<ul> <li>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: <ul> <li>Start of Episode ratings (S)</li> <li>Interim(s) ratings (I) (Optional)</li> <li>End of Episode ratings (E)</li> </ul> </li> </ul>	To link ratings for a given episode of care	Required (this is automatically assigned by the ROOT)	N/A	Required	Required

Local and national policies and procedures must always be adhered to in relation to the use of the RCSLT Online Outcome Tool

	Description	Purpose		Data upload		
Field			Direct data entry	"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
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
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

	Description	Purpose	Direct data entry	Data upload		
Field				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
Primary TOMs Scale	The name of the TOMs scale (adapted and core) that was used to rate the patient from the third edition of 'Therapy Outcome Measures for Rehabilitation Professionals' Pam Enderby and Alexandra John, 2015	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 used from the third edition of 'Therapy Outcome Measures for Rehabilitation Professionals' Pam Enderby and Alexandra John, 2015 (The Core Scale is coded as 0 (zero))	To identify the TOMs scale used to rate the patient	Required	Desirable	Desirable	Desirable
Secondary TOMs Scale	The name of the primary TOMs scale (adapted and core) that was used to rate the patient from the third edition of 'Therapy Outcome Measures for Rehabilitation Professionals' Pam Enderby and Alexandra John, 2015	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 used from the third edition of 'Therapy Outcome Measures for Rehabilitation Professionals' Pam Enderby and Alexandra John, 2015 (The Core Scale is coded as 0 (zero))	To identify the secondary TOMs scale used to rate the patient, where applicable	Optional	Optional	Optional	

	Description	Purpose	Direct data entry	Data upload		
Field				"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
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

	Description	Purpose	Direct data entry	Data upload		
Field				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
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 <sup>2</sup>	Numerical value for the TOMs score	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	for the impairment domain: 0, 0.5, 1, (9) (1.5, 2, 2.5, 3, 3.5, 4, 4.5, 5)	To record the level of impairment (secondary)	Optional	Optional	Optional	Optional
Impairment Score (Secondary) – end of episode	<ul> <li>(Zero is the severe / profound end of the scale, five is the normal end of the scale)</li> <li>Any TOMs domains where a TOMs score is not applicable should be left</li> </ul>	To record the level of impairment (secondary)	Optional	Optional	Optional	Optional

<sup>2</sup> 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.

Local and national policies and procedures must always be adhered to in relation to the use of the RCSLT Online Outcome Tool

	Description	Purpose	Direct data entry	Data upload		
Field				"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
	blank (null).					
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	To record the level of activity limitation (primary)	Required	Required	Required	Required
Activity Score (Primary) – end of episode	<ul> <li>(Zero is the severe / profound end of the scale, five is the normal end of the scale)</li> <li>Any TOMs domains where a TOMs score is not applicable should be left blank (null).</li> </ul>	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	To record the level of activity limitation (secondary)	Optional	Optional	Optional	Optional
Activity Score (Secondary) – end of episode	<ul> <li>(Zero is the severe / profound end of the scale, five is the normal end of the scale)</li> <li>Any TOMs domains where a TOMs score is not applicable should be left blank (null).</li> </ul>	To record the level of activity limitation (secondary)	Optional	Optional	Optional	Optional
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	To record the level of participation restriction	Required	Required	Required	Required
Participation Score – end of episode	(Zero is the severe / profound end of the scale, five is the normal end of the scale)	To record the level of participation restriction	Required	Required	Required	Required

		Purpose	Direct data entry	Data upload		
Field	Description			"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
	Any TOMs domains where a TOMs score is not applicable should be left blank (null).					
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	To record the impact on well-being	Required	Required	Required	Required
Wellbeing Rating Score – end of episode	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
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
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

	Description	Purpose		Data upload		
Field			Direct data entry	"Episode per row" file structure	"Rating per row" file structure	"Score per row" file structure
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.	To increase the value of the data by ensuring the data better matches local structures, practices and reporting requirements.	Optional	Optional	Optional	Optional

## Annex 3: Data flow mappings for ROOT



Figure 2: Data flow mapping for direct data entry



Figure 3: Data flow mapping for data upload

## Annex 4: Governance Arrangements: Organisational Administrative Roles and Responsibilities

Organisation	Roles and Responsibilities
Royal College of Speech and Language Therapists (RCSLT) Different Class Solutions Ltd (Data Processor)	<ul> <li>Provides governance and scrutiny of the data processor on behalf of the data controllers</li> <li>Ensures that organisations using the system are legitimate and have a justified purpose for accessing the system</li> <li>Validates requests from organisations to use the system</li> <li>Provides organisations with access to the ROOT</li> <li>Processes information from the user organisation</li> <li>Provides a regular quality report to RCSLT and organisations on user logins / activity</li> <li>Monitors the volume of system use and navigation<sup>3</sup></li> <li>Completes relevant documentation with user organisations (e.g. Data Processing Agreements)</li> <li>Complies with Data Protection Legislation</li> <li>Registered with the Information Commissioner's Office (data protection registration number: Z2840119)</li> <li>Has ISO 27001 and Cyber Essentials Plus certification/accreditation</li> </ul>
Each organisation engaged in the project (Data Controllers)	<ul> <li>(Certificate no.: 5944466513017922)</li> <li>Appoints a local administrative user to manage users which will include: <ul> <li>adding users to the ROOT</li> <li>changing user roles and privileges</li> <li>monitoring users</li> <li>removing/suspending users</li> </ul> </li> <li>Ensures that usernames are valid email addresses</li> <li>Manages user accounts linked to their organisation</li> <li>Assigns roles and permissions to users linked to their organisation</li> <li>Ensures all organisation users agree to the Acceptable Use Agreement</li> <li>Revokes /removes users <ul> <li>when the user leaves the organisation</li> <li>when a user acts in way contrary to the Acceptable Use Agreement</li> </ul> </li> <li>Ensures that their organisation adheres to the principles of fair processing</li> <li>Ensures that information security and records management standards are met (international, national and local)</li> </ul>

<sup>&</sup>lt;sup>3</sup> 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.

## Annex 5: Users of the RCSLT Online Outcome Tool

ROOT User	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.	<ul> <li>Access to pseudonymised data for service users under their care</li> <li>Access to reports for individual service users under their care</li> <li>Access to aggregated data reports on outcomes at a team/service level and external benchmarking level<sup>4</sup></li> <li>Local users must comply with all policy, legislation and the local organisation's protocols, working in a way that mirrors existing working practices</li> <li>Must also agree to the Acceptable Use Agreement (Annex 6)</li> </ul>	<ul> <li>To evaluate the impact of interventions</li> <li>To inform patient-centred care</li> <li>To support clinical decision making</li> </ul>
Local admin User responsible for monitoring and validating access to the online tool for users within an organisation, in addition to "Local User" functions	<ul> <li>Access to pseudonymised data for service users under their care</li> <li>Access to reports for individual service users under their care</li> <li>Access to aggregated data reports on outcomes at a team/service level and external benchmarking level<sup>3</sup></li> <li>Access to the data upload functions of the ROOT, where appropriate</li> <li>Access to user administration functions</li> <li>Access to reports monitoring appropriate use of the system and other audit reports</li> <li>Local admins must comply with all policy, legislation and the local organisation's protocols, working in a way that mirrors existing working practices</li> <li>Must agree to the Acceptable Use Agreement (Annex 6)</li> </ul>	<ul> <li>To evaluate the impact of interventions</li> <li>To inform patient-centred care</li> <li>To support clinical decision making</li> <li>To evidence the impact of SLT input to decision makers and commissioners</li> <li>To support sharing of best practice and reflect on service outcomes</li> <li>To inform changes to service delivery</li> <li>To manage and validate user accounts for access to the ROOT</li> <li>To monitor use of ROOT for auditing purposes</li> </ul>

<sup>4</sup> Benchmarking reports will not identify services without explicit consent

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

## **Annex 6: Acceptable Use Agreement**

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

In using the ROOT, 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 to use the system in a way that complies with existing standards and expectations about fair processing in accordance with Data Protection Legislation<sup>5</sup>. Use of the ROOT is fully monitored and audited.

- □ I understand that it is my responsibility to use the ROOT in a way that complies with existing standards and expectations about fair processing in accordance with Data Protection Legislation<sup>5</sup>
- □ I am aware that the use of the ROOT is fully monitored and audited and that any demonstrable misuse of the ROOT will result in the suspension/revoking of system use.
- □ I will not attempt to use someone else's login details to access the ROOT
- □ 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<sup>6</sup>
- 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 when unattended.

## Any demonstrable misuse of the RCSLT Online Outcome Tool will result in the suspension/revoking of system use.

 <sup>&</sup>lt;sup>5</sup> "Data Protection Legislation" means (i) the Regulation (EU) 2016/279 General Data Protection Regulation (GDPR) and (ii) the Data Protection Act 2018
 <sup>6</sup> Please note, there is test environment available to use with 'dummy data' for training purposes

## **Annex 7: Data Processing Agreement**

A Data Processing Agreement will be required between the organisation providing the speech and language therapy service (the data controller) and Different Class Solutions Ltd (the data processor). Different Class Solutions Ltd has a GDPR-compliant data processing agreement that can be used (see below), which can be completed electronically. Alternatively, organisations can use their own documentation.

To request an electronic copy of the Data Processing Agreement please contact <u>ROOT@rcslt.org</u>, confirming the name and address of your employing organisation and the contact details of your data protection officer (where relevant).

Alternatively, organisations can use their own documentation.

## DATA PROCESSING AGREEMENT

Between

[Name of organisation]

and

**Different Class Solutions Ltd** 

BETWEEN:

(1)

which is located at

(the "Data Controller")

AND

(2) Different Class Solutions Ltd, a company registered in England and Wales with number 06600477, having its registered office at 17 King Street, Newcastle, Staffordshire, ST5 1JF (the "Data Processor").

#### BACKGROUND

- (A) The Royal College of Speech and Language Therapists ("RCSLT") commissioned the development of the RCSLT Online Outcome Tool to support its members collecting outcomes data and to assist with demonstrating the impact of therapy for individuals with speech, language, communication and swallowing needs. The RCSLT Online Outcome Tool ("ROOT") has been developed, and is managed and hosted by, Different Class Solutions Ltd to collect and collate therapy outcome measures data and generate aggregated data reports;
- (B) To the extent that users of the ROOT transfer Personal Data onto it, they are data controllers and Different Class Solutions Ltd is a data processor, in each case for the purposes of the Data Protection Legislation;
- (C) The Data Protection Legislation places obligations upon a Data Controller to ensure that any Data Processor it engages provides sufficient assurances that the processing of the data carried out on its behalf is secure;
- (D) This Agreement exists to ensure that both the Data Controller and Data Processor comply with the Data Protection Principles contained in the Data Protection Legislation and all terms within the Data Protection Legislation; and
- (E) Prior to the date of this Agreement, the Data Processor has achieved ISO 27001 compliance.

#### **IT IS AGREED**

- 1. DEFINITIONS AND INTERPRETATION
- 1.1 In this Agreement:

"Act" means the Data Protection Act 2018;

"Data" means any information of whatever nature that, by whatever means, is made available to the Data Processor by the Data Controller, is accessed by the Data Processor on the authority of the Data Controller or is otherwise received by the Data Processor on the Data Controller's behalf, and shall include, without limitation, any Personal Data;

"Data Controller", "Data Processor", "Data Subject", "Personal Data" and "Processing" shall have the same meanings as are assigned to those terms in the Data Protection Legislation;

"Data Protection Legislation" means (i) the Regulation (EU) 2016/279 General Data Protection Regulation (GDPR) and any national implementing laws, regulations and secondary legislation, as amended or updated from time to time, in the UK, unless and until the GDPR is no longer directly applicable in the UK, and then (ii) any successor legislation to the GDPR or the Act;

"Schedule 1" means the "Schedule 1 THE SERVICES" annexed to and forming part of this Agreement;

"Schedule 2" means the "Schedule 2 DATA ITEMS (FIELDS) REQUIRED TO BE PROCESSED FOR RCSLT ONLINE OUTCOME TOOL" annexed to and forming part of this Agreement; and

"Service/Services" are the Services provided by the Data Processor identified in Schedule 1 (being the provision of services relating to the RCSLT Online Outcome Tool).

- 1.2 In this Agreement any reference, express or implied, to an enactment (which includes any legislation in any jurisdiction) includes references to:
  - (a) that enactment as re-enacted, amended, extended or applied by or under any other enactment (before, on or after the date of this Agreement);
  - (b) any enactment which that enactment re-enacts (with or without modification); and
  - (c) any subordinate legislation made (before, on or after the date of this Agreement) under that enactment, as re-enacted, amended, extended or applied as described in clause 1.2(a), or under any enactment referred to in clause 1.2(b).
- 1.3 In this Agreement:
  - (a) references to a person include an individual, a body corporate and an unincorporated association of persons;
  - (b) references to a party to this Agreement include references to the successors or assignees (immediate or otherwise) of that party.
- 1.4 Clauses 1.1 to 1.3 apply unless the contrary intention appears.
- 2. APPLICATION OF THIS AGREEMENT

- 2.1 This Agreement shall apply to:
  - (a) all Data extracted by the Data Processor for processing;
  - (b) all Data transmitted to the Data Processor for processing;
  - (c) all Data accessed by the Data Processor on the authority of the Data Controller for processing; and
  - (b) all Data otherwise received by the Data Processor for processing on the Data Controller's behalf;

from the date of this Agreement and in relation to the Services.

- 3. DATA PROCESSING
- 3.1 In consideration of the undertakings provided by the Data Controller in clause 4, the Data Processor agrees to process the Data to which this Agreement applies by reason of clause 2 in accordance with the terms and conditions set out in this Agreement, and in particular the Data Processor agrees that it shall:
  - (a) process the Data at all times in accordance with the Data Protection Legislation and in full compliance with the data protection principles contained therein and solely for the purposes connected with provision by the Data Processor of the Services and in the manner specified from time to time by and under the instructions of the Data Controller in writing and for no other purpose or in any manner except with the express prior written consent of the Data Controller;
  - (b) implement technical and organisational measures to safeguard the Data from unauthorised or unlawful processing or accidental loss, disclosure, destruction or damage, where such measures shall ensure a level of security appropriate to the harm that might result from unauthorised or unlawful processing or accidental loss, destruction or damage and to the nature of the Data to be protected (these measures may include, where appropriate, pseudonymising and encrypting the Data, ensuring confidentiality, integrity, availability and resilience of its systems and services, ensuring that availability of and access to the Data can be restored in a timely manner after an incident, and regularly assessing and evaluating the effectiveness of the technical and organisational measures adopted by it);
  - (c) ensure that each of its employees, agents and subcontractors are made aware of its safeguarding obligations under this Agreement with regard to the security and protection of the Data and of the Data Subjects and shall require that they enter into binding obligations with the Data Processor in order to maintain the levels of security and protection provided for in this Agreement;
  - (d) not divulge the Data whether directly or indirectly to any person, firm or company or otherwise without the express prior written consent of the Data Controller except to

- (e) those of its employees, agents and subcontractors who are engaged in the processing of the Data and are subject to the binding obligations referred to in clause 3.1(c) or except as may be required by any law or regulation;
- (f) inform the Data Controller within two (2) working days in the event that the Data Processor receives a request from a Data Subject seeking to exercise their rights under the Data Protection Legislation in relation to the Data and not to respond to the Data Subject other than to acknowledge receipt of the request. The Data Processor further agrees to assist the Data Controller with all Data Subject information requests which may be received from any Data Subject in relation to any Data;
- (g) in the event that the Data Processor receives a request for any information contained in the Data pursuant to Freedom of Information Act 2000, or the Environmental Information Regulations 2004, not respond to the person making such request but to inform the Data Controller within two (2) working days, and the Data Processor further agrees to assist the Data Controller with all such requests for information which may be received from any person within such timescales as may be prescribed by the Data Controller. The parties agree that upon the Data Controller receiving a Freedom of Information Act request for disclosure of the whole or part of this Agreement the Data Controller will consult with the Data Processor before making any disclosure and that the Data Processor will respond to that request within five (5) working days. The parties also agree that the ultimate decision as to whether or not to release any or all the information requested will be at the sole discretion of the Data Controller after taking account of the Data Processor's representations;
- (h) assist the Data Controller with all its obligations under the Data Protection Legislation with respect of security, breach notifications, impact assessments and consultations with supervisory authorities or regulators;
- (i) not process or transfer the Data outside of the European Economic Area except with the express prior written authority of the Data Controller and the following conditions are fulfilled:
  - the Data Controller or the Data Processor has appropriate safeguards in relation to the transfer;
  - the data subject has enforceable rights and effective legal remedies;
  - the Data Processor complies with its obligations under the Data Protection Legislation by providing an adequate level of protection to any Data that is transferred;
  - the Data Processor complies with reasonable instructions notified to it in advance by the Data Controller with respect to the processing of the Data; and
  - the Data Processor enters into a written agreement with the third-party

processor incorporating terms which are substantially similar to those set out in this clause 3.1.

As between the Data Processor and the Data Controller, the Data Processor shall remain fully liable for all acts or omissions of any third-party processor appointed by it pursuant to this clause 3.1(h);

- (j) maintain complete and accurate records and information to demonstrate its compliance with this Agreement and allow its data processing facilities, procedures and documentation to be submitted for scrutiny by the Data Controller or its representatives in order to ascertain compliance with the terms of this Agreement within ten (10) working days of such a request from the Data Controller;
- (k) notify the Data Controller without undue delay on becoming aware of a Personal Data breach, and no later than 72 hours after becoming aware of the breach; and
- (I) at the written direction of the Data Controller, delete or return the Data and copies thereof to the Data Controller on termination of this Agreement except as required by applicable law to store the Data and except for one copy that it may retain and use for a period of up to one year for back-up and audit purposes only.
- 3.2 In accordance with the data protection principles contained in the Data Protection Legislation, only extract, transmit and process such Personal Data as is appropriate for the provision of the Services or as required by law or any regulatory body. All data items that are required to be extracted, transmitted or processed shall be listed in Schedule 2. Any changes to the number of data items listed in Schedule2 shall be agreed by both parties and Schedule 2 revised prior to commencement of processing. Any personal or confidential Data transported by portable storage media shall be encrypted or password protected as appropriate and handled only by named persons according to an agreed method statement. All such Data must be wiped from the storage media used for transporting the Data or destroyed such that it cannot be recovered once the Data has been transferred to the target system.
- 3.3 The parties agree, accept and acknowledge that RCSLT will audit the use of the ROOT from time to time and will therefore have access to the Personal Data contained thereon.
- 3.4 The parties agree, accept and acknowledge that the RCSLT may provide support to users of the ROOT and so will have access to the Personal Data to provide this support.
- 4. OBLIGATIONS OF THE DATA CONTROLLER
- 4.1 In consideration of the obligations undertaken by the Data Processor in clause 3, the Data Controller agrees that it shall ensure that it complies at all times with the Data Protection Legislation, and, in particular, the Data Controller shall ensure that any disclosure of Personal Data made by it either directly or indirectly to the Data Processor is lawful (meaning the Data Controller must ensure that it (and any organisation through which the Personal Data is transferred by it to the Data Processor) has all necessary appropriate consents and notices in

place to enable the lawful transfer of the Personal Data to the Data Processor for the duration and purposes of this Agreement) and that such Personal Data is true, accurate and correct. The Data Processor also agrees that it shall ensure that Personal Data is only transferred to the Data Processor to the extent necessary in connection with its access to, and receipt of, the Services.

#### 5. TERMINATION

- 5.1 This Agreement shall terminate automatically upon termination or expiry of: (i) the Data Processor's obligations in relation to the Services and/or the ROOT and/or (ii) the Data Processor's appointment to manage and host the ROOT, and on termination of this Agreement the Data Processor shall within 30 days securely deliver to the Data Controller or destroy, at the Data Controller's sole option, all the Data Controller's Data in its possession or under its control and in non-proprietary file formats that can be read by readily available office productivity software (save as set out in clause 3.1(k)).
- 5.2 The Data Controller shall be entitled to terminate this Agreement forthwith by notice in writing to the Data Processor if:-
  - (a) the Data Processor is in material or persistent breach of this Agreement which, in the case of a breach capable of remedy, shall not have been remedied within fourteen (14) days from the date of receipt by the Data Processor of a notice from the Data Controller identifying the breach and requiring its remedy; or
  - (b) the Data Processor becomes insolvent, has a receiver, administrator, or administrative receiver appointed over the whole or any part of its assets, enters into any composition with its creditors, or has an order made or resolution passed for it to be wound up (otherwise than in furtherance of a scheme for solvent amalgamation or reconstruction).
- 6. LIMITATION OF LIABILITY
- 6.1 **Nothing in this Agreement limits any liability which cannot legally be limited**, including but not limited to liability for:
  - (a) death or personal injury caused by negligence;
  - (b) fraud or fraudulent misrepresentation; and
  - (c) breach of the terms implied by section 12 of the Sale of Goods Act 1979 or section 2 of the Supply of Goods and Services Act 1982 (title and quiet possession).
  - (d) Data breaches as covered by the Data Protection Legislation
- 6.2 Subject to clause 6.1, the Data Processor's total liability to the Data Controller shall not exceed £500,000. The Data Processor's total liability includes liability in contract, tort (including negligence), breach of statutory duty, or otherwise, arising under or in connection with this Agreement.

#### 7. GOVERNING LAW

- 7.1 This Agreement will be governed by English law, and the parties submit to the exclusive jurisdiction of the English courts for all purposes connected with this Agreement, including the enforcement of any award or judgment made under or in connection with it.
- 8. WAIVER
- 8.1 Failure by either party to exercise or enforce any rights available to that party or the giving of any forbearance, delay or indulgence shall not be construed as a waiver of that party's rights under this Agreement.

#### 9. INVALIDITY

9.1 If any term or provision of this Agreement shall be held to be illegal or unenforceable in whole or in part under any enactment or rule of law such term or provision or part shall to that extent be deemed not to form part of this Agreement but the enforceability of the remainder of this Agreement shall not be affected provided however that if any term or provision or part of this Agreement is severed as illegal or unenforceable, the parties shall seek to agree to modify this Agreement to the extent necessary to render it lawful and enforceable and as nearly as possible to reflect the intentions of the parties embodied in this Agreement including without limitation the illegal or unenforceable term or provision or part.

#### 10. ASSIGNMENT

10.1 This Agreement shall not be assigned by the Data Processor without the express written agreement of the Data Controller.

#### 11. DATA RETENTION POLICY

11.1 The Data Controller may be required to comply with the Data Retention Guidelines as issued by the Service/Setting/Teams Legitimate Authority and amended from time to time. This may require certain data to be identified for retention and made available to the Data Controller in electronic form by the Data Processor.

#### 12. ENTIRE AGREEMENT

- 12.1 This Agreement and the documents attached to or referred to in this Agreement shall constitute the entire understanding between the parties and shall supersede all prior agreements, negotiations and discussions between the parties. In particular the parties warrant and represent to each other that in entering into this Agreement they have not relied upon any statement of fact or opinion made by the other, its officers, employees or agents which has not been included expressly in this Agreement. Further, each party hereby irrevocably and unconditionally waives any right it may have:
  - (a) to rescind this Agreement by virtue of any misrepresentation;
  - (b) to claim damages for any misrepresentation whether or not contained in this

#### (c) Agreement;

save in each case where such misrepresentation or warranty was made fraudulently.

#### 13. NOTICES

13.1 Notices shall be in writing and shall be sent to the other party marked for the attention of the person at the address set out below. Notices may be sent by first-class mail, facsimile transmission or email provided that facsimile and email transmissions are confirmed within 24 hours by first-class mail confirmation of a copy. Correctly-addressed notices sent by first-class mail shall be deemed to have been delivered 72 hours after posting and correctly directed facsimile and email transmissions shall be deemed to have been delivered instantaneously on transmission providing that they are confirmed as set out as above.

If for the Data Controller:

Email:

If for the Data Processor: Patrick Guest, Different Class Solutions Ltd, 17 King Street, Newcastle, Staffordshire, ST5 1JF; Fax: 0845 2244013; Email: paddy@different-class.com

SIGNED for and on behalt	of
by:	
Name:	
Position:	
Signature:	
Date:	
SIGNED for and on behal	f of Different Class Solutions Ltd by:
Name:	Patrick Guest
Position:	Director
Signature:	
Date:	

#### SCHEDULE 1

#### THE SERVICES

The ROOT collects pseudonymised data about individuals receiving speech and language therapy and generates reports on speech and language therapy outcomes for individual patients and groups of patients. It has been developed to support speech and language therapy services with monitoring, evaluating and reporting on outcomes delivered by their service.

The Data Processor will continue to host and support the ROOT (including backing up the data and securely storing those backups), provided the conditions below continue to be met

The parties agree, accept and acknowledge that the Data Processor's obligations to deliver the Services to the Data Controller are conditional on the continued appointment by RCSLT of the Data Processor to manage and host the ROOT.

#### SCHEDULE 2

#### DATA ITEMS (FIELDS) REQUIRED TO BE PROCESSED FOR ROOT

This Schedule 2 lists the Data Items that the Data Controller authorises to be entered into the ROOT managed by the Data Processor named in this Data Processing Agreement. The Data Items shared will be agreed with the organisation. In compliance with the data protection principles contained in the Data Protection Legislation, the Data Controller does not authorise Personal Data to be transmitted, passed to, or extracted by the Data Processor for any reason other than the specified and lawful Purpose. Authority will not be given to a Data Processor to extract or pass Personal Data that is excessive or is not relevant to the stated Purpose.

In relation to system users:

- The user's name
- The user's email address
- The IP address that the user connects

#### from In relation to patients:

- A pseudonymised local patient identifier
- Gender
- Year of birth
- Medical diagnoses
- Communication and swallowing disorder descriptor(s)
- Therapy Outcome Measure (TOMs) scale
- Therapy Outcome Measure (TOMs) scores
- Date of TOMs rating
- Type of TOMs rating (start-of-episode/interim/end-of-episode/discharge)
- Any other patient or rating data item that may from time to time be added to the ROOT, provided that data item does not contain any personally identifiable information

## Annex 8: Terms of use

In using the ROOT, our organisation understands and agrees that:

- It is the responsibility of the individual organisations to ensure that their data sharing transactions comply with data protection legislation and their own local protocols. This includes responsibility for ensuring that any data shared with the ROOT is permitted by the organisation and for completing and regularly reviewing the data processing agreement in place with Different Class Solutions Ltd.
- The ROOT is provided by RCSLT for use by speech and language therapists. Access to the ROOT is provided to speech and language therapy services free of charge as a benefit of RCSLT membership (subject to review).
- RCSLT reserves the right to withdraw access to the ROOT at any time for individual users and organisations.
- □ Any data stored in the database is a pseudonymised copy of the data recorded in the organisation's local speech and language therapy records.
- Data provided by the organisation will contribute to a national dataset on speech and language therapy outcomes and the data will be used for benchmarking purposes.
   Individual organisations will not be identifiable in benchmarking reports available to ROOT users from other participating organisations.
- The ROOT is protected by copyright. With the exception of the downloadable reports, no part of the site may be copied, reproduced, published, modified, transmitted or broadcast without the prior permission of RCSLT.

## Annex 9: Frequently Asked Questions

#### 1. Why is the information being shared?

Information is being shared with the RCSLT Online Outcome Tool 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

#### 2. What information is being shared?

In relation to system users:

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

In relation to individuals receiving speech and language therapy:

- A pseudonymised local patient identifier
- Gender
- Year of birth
- Medical diagnoses
- Communication and swallowing disorder descriptor(s)
- Therapy Outcome Measure (TOMs) scale
- Therapy Outcome Measure (TOMs) scores
- Date of TOMs rating
- Type of TOMs rating (start-of-episode/interim/end-of-episode/discharge)
- Any other patient or rating data item that may from time to time be added to the ROOT, provided that data item does not contain any personally identifiable information

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 is already collected by the organisations prior to their involvement with this project. ROOT provides 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 ROOT collects personal data about the individuals using the ROOT. Each individual user will be required to consent to their details being held in relation to use of the system prior to access being granted.

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 involve using information about individuals for a purpose it is not currently used for?

The use of the ROOT involves the sharing of data that has been pseudonymised. The ROOT generates 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.

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

Information about the individuals using the ROOT will only be used to in relation to their use of the system. Users are asked to consent to their details being held in relation to use of the system prior to access being granted and are informed about how their information will be used.

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 a UK data centre in Derby and are hosted by a third party supplier, Heart Internet. Their data centre is monitored by CCTV both externally and internally. All CCTV images are recorded and stored for 3 months. The building is surrounded by an 8ft perimeter fence. Gates are locked outside of normal business hours. There are two locking doors to go through for access to each of the separate data halls within the data centre. These are locked and can only be opened using Secure Fobs which are only held by named employees of Heart Internet.

All data is stored and used in compliance with ISO standard 27001

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

No, the servers are located in a UK data centre in Derby.

#### 9. Who will have access to the information?

As outlined in detail in Annex 5, there are four different types of user:

 'Local users' are individuals with access the ROOT, 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 that have been appointed by their organisation to monitor and validate access to the ROOT. 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 RCSLT Online Outcome Tool?

To be compliant with the national data opt out, you need to assess whether the sharing of data with the RCSLT Online Outcome Tool is in scope of the national data opt-out policy. More information about the national data opt out is provided on the <u>NHS Digital website</u>.

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 <u>does not</u> 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.