



# **Data sharing agreement**

**Between:**

**The Royal College of Speech and Language  
Therapists**

**and**

**Organisation name (RCSLT to populate)**

## Introduction

A data sharing agreement between the parties sending and receiving data forms part of compliance with the accountability principle, under the GDPR and the Data Protection Act 2018.

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.

What is included in a data sharing agreement:

1. Parties to the agreement
2. Purpose of the data sharing initiative
3. Organisations involved in the data sharing
4. Responsibilities of each controller
5. Personal data items being shared
6. Lawful basis and special category data
7. Access and individual rights
8. Information governance arrangements
9. Under what circumstances will the data be accessed?
10. How will the data be stored?
11. How will the data be returned / destroyed?
12. Review frequency
13. Further details (Annex)
14. Signatures

# Data sharing agreement

## 1. Parties to the agreement:

**Data controller:** Royal College of Speech and Language Therapists  
**Address:** 2 White Hart Yard, London, SE1 1NX  
**Phone:** 0207 378 3018  
**Email:** dpo@rcslt.org

**Data controller:** Organisation name (RCSLT to populate)

**Address:** Please complete

**Phone:** Please complete

**Email:** Please complete

## 2. Purpose of the data sharing initiative:

### Primary aims:

For practising speech and language therapists:

- a) increase reflective practice leading to improvements in patient care, professional development and informing clinical decision making

At a service/local level:

- b) demonstrate the impact of speech and language therapy
- c) inform service change/quality improvement
- d) inform resourcing decisions
- e) benchmark the effectiveness of speech and language therapy services
- f) inform commissioning
- g) ensure services are of good quality for service users and sustainable for the future

### Secondary aims:

At a national level:

- h) provide evidence to present to commissioning and funding bodies about the value of speech and language therapy
- i) demonstrate how the speech and language therapy profession contributes to the delivery of policies and frameworks across the UK
- j) influence key decision makers
- k) support research and development of the evidence base for speech and language therapy.

### **Why the data sharing is necessary to achieve those aims:**

The processing of personal data about speech and language therapists and other individuals using the RCSLT Online Outcome Tool (ROOT) is required to ensure that the individuals accessing the ROOT have a legitimate reason for doing so. This is required to ensure the fidelity of the outcome data collected and to enable use of the system to be audited. It is also required to support users of the system, including in instances whereby help is requested.

ROOT users upload or enter pseudonymised patient data to the database. The RCSLT and its data processor are able to access the pseudonymised data, however, it is effectively anonymous to the RCSLT and its data processor, as they do not hold the key to re-identify the data. Only the controller submitting the data holds the key necessary to re-identify their data held within the ROOT. ROOT users from other speech and language therapy services will have access to anonymised analytics and reports on the data, supporting aims (a) – (g). They will not be able to access the pseudonymised data, however.

By having users populate the ROOT database, the RCSLT is developing a dataset about the outcomes of speech and language therapy. A consistent approach to data collection across the profession and the sharing of pseudonymised patient data supports benchmarking (aim 'e') and achievement of aims (h) – (k) at a national level. In order to achieve these aims, the RCSLT will share anonymised data and will use fully anonymised portions of the patient data held within the ROOT to produce its own reports, metrics, statistics and summaries. These will be shared with a range of audiences and partners, including the RCSLT membership, policy makers and higher education institutions. The findings will be published in a number of different formats, including policy briefings, academic publications and presentations, some of which will be made publicly available via the RCSLT website.

### **The benefits we hope to bring to individuals or to society more widely:**

The processing of personal data about speech and language therapists is critical for this project, which is having benefits to individuals and the broader society. The profession is using the data on speech and language therapy outcomes to improve the quality of care provided to individuals receiving speech and language therapy. The data is also being used to support decisions about the planning and redesign of services, which has the potential to optimise use of resources in the NHS and other providers. The findings from the data are also being used to demonstrate the impact of speech and language therapy to key stakeholders, including policy-makers, funders and commissioners, as part of RCSLT influencing and lobbying work to ensure that the value of speech and language therapy is recognised. This

is essential as part of our ongoing campaigning to improve access to SLT services for people with communication and swallowing needs in the UK.

(Examples available at: <https://rcslt-root.org/Content/root-publications-resources-and-useful-links>)

### 3. Organisations involved in the data sharing:

| <b>Individual data controllers</b>              |  |                 |  |                  |
|---|--|-----------------|--|------------------|
| <b>Organisation</b>                             | <b>Responsible Person</b>                          | <b>Name</b>     | <b>Email address</b>   | <b>Telephone</b> |
| Royal College of Speech and Language Therapists | Head of Corporate Services/Data Protection Officer | Jonathan Bowles | dpo@rcslt.org  | 0207 378 3018    |
| Organisation name (RCSLT to populate)           | Data Protection Officer                            | Please complete | Please complete  | Please complete  |
| <b>Data processor</b>                           |  |                 |  |                  |
| <b>Organisation</b>                             | <b>Responsible Person</b>                          | <b>Name</b>     | <b>Email address</b>   | <b>Telephone</b> |
| Different Class Solutions Ltd                   | Director/Data Protection Officer                   | Paddy Guest     | <a href="mailto:paddy@different-class.com">paddy@different-class.com</a> | 0333 0888 338    |

#### 4. Responsibilities of each controller:

Determination of respective responsibilities under the Regulations:

##### **RCSLT**

- Ensures that all ROOT user data is processed and retained in accordance with the Regulations.
- Responds to subject access requests in respect to ROOT user data.
- Manages the secure platform used for hosting the pseudonymised ROOT data.
- Ensures the required data processing agreement is in place with the data processor for the ROOT database
- Provides oversight of the data processor and their activities
- Handles the communication of any requests to the data processor from the controller (for example erasure of data).
- Reporting any breaches that may occur within the ROOT site, due to technical faults and vulnerabilities or parties being able to bypass site controls.
- Initiating a routine review of this data sharing agreement on a biennial basis
- Ensures all its staff with access to the ROOT are aware of responsibilities in line with data protection legislation
- Supports the Controller (as appropriate) in fulfilling data subject access requests, or data breach reports and investigations.

##### **Organisation name (RCSLT to populate)**

- Reporting any data breaches occurring due to data loss in transit / transfer, compromise, loss or theft of ROOT user credentials, compromise, loss or theft of the unique patient identifiers used to ensure pseudonymisation of the patient data submitted to the ROOT.
- Ensuring only staff with legitimate reason for accessing the ROOT are granted access to the ROOT (and with appropriate level of access) and that accounts are de-activated when no longer needed
- Ensuring all patient data is appropriately and effectively pseudonymised/de-personalised prior to sharing
- Initiating amendment to this agreement in the event that there is a change in the personal data items being shared (section 5)
- Ensures all staff with access to the ROOT are aware of responsibilities in line with data protection legislation
- Determines the appropriate retention period for their data on the ROOT site and ensures that the data is managed in accordance with this determination
- Responds to any subject access requests from patients
- Routinely reviews the information provided to ensure it is up to date

- Informs patients about how pseudonymised/de-personalised data about them is used (for example, in their privacy notice)

## 5. Personal data items being shared

*In some cases it may be appropriate to attach 'permissions' to certain data items, so that only particular members of staff or staff in specific roles are allowed to access them; for example, staff who have received appropriate training.*

Personal data collected about the individuals using the ROOT includes:

- Name
- Employing organisation
- Email address
- RCSLT membership number (where applicable)
- The IP address that the user connects from

Who has access?

- RCSLT staff with system administration responsibility
- Different Class Solutions Ltd staff with system administration responsibility
- Staff at **Organisation name (RCSLT to populate)** who have been appointed as system administrators on behalf of their organisation

The data collected about the individuals receiving speech and language therapy includes:

- 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)
- End of episode/discharge code
- [Optional - delete if not applicable]: Method of service delivery (face-to-face (in-person) only; remote only; mixed (face-to-face and remote))
- [Optional delete if not applicable]: Direction of care (to record whether the objective of therapy is to improve, sustain, or manage decline)
- [Optional - delete if not applicable]: Total contact time
- [Optional - delete if not applicable]: Total number of contacts
- [Optional – delete if not applicable]: Ethnicity
- [Optional – delete if not applicable]: Requirement for interpreter

- [Optional – delete if not applicable]: Language profile
  - [Optional – delete if not applicable]: Deprivation Decile, based on postcode
  - 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
- 
- A pseudonymised local patient identifier
  - Gender
  - Year of birth
  - Ethnicity
  - Medical diagnoses (including ENT diagnoses)
  - Hospital admission history
  - Reason for referral to SLT
  - Past medical history
  - Date of first COVID positive result
  - Patient reported speech and language therapy symptoms
  - Intubation and/or tracheostomy required to manage COVID-19
  - Total number of days with tracheostomy and/or intubation
  - Date and source of referral to speech and language therapy
  - FEES/VFSS completed
  - Other AHPs involved in care pathway
  - Communication and swallowing disorder descriptor(s)
  - Outcome measures used
  - 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)
  - Type of therapy
  - Return to work status
  - Method of service delivery
  - Total number of contacts
  - End of episode/discharge code
  - [Optional delete if not applicable]: Direction of care (to record whether the objective of therapy is to improve, sustain, or manage decline)
  - [Optional - delete if not applicable]: Total contact time

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 locally, if required, but additional data shared with the ROOT by users of the system must comply with local information governance policies and frameworks. Additional fields that will be submitted to the ROOT may be listed below:



Please complete

This list should be reviewed whenever the data sharing agreement is reviewed.

The relevant party should initiate amendment to this data sharing agreement in the event that there is a change in the personal data items being shared.

Who has access?

- RCSLT staff with system administration responsibility
- Different Class Solutions Ltd staff with system administration responsibility
- All staff at **Organisation name (RCSLT to populate)** with access to the ROOT

## 6. Lawful basis and special category data

|   | RCSLT  | Organisation name (RCSLT to populate) |
|---|--|---------------------------------------|
| <b>Personal data collected about the individuals using the ROOT (staff)</b> | Legitimate interests   | Please complete                       |
| <b>Pseudo-anonymised patient data</b>                                       | Legitimate interests   | Please complete                       |
| <b>Special category data</b>  | Reasons of public interest in the area of public health (GDPR article 9(2)(i)) | Please complete                       |

## 7. Access and individual rights:

In all instances related to patient data under this agreement, the point of contact for data subjects will be **Organisation name (RCSLT to populate)**.

The organisation takes full responsibility for managing subject access requests and ensuring that the data subjects are informed about use of their personal data. Details regarding patients' rights are included in the information governance pack.

In all instances related to users of the ROOT, the RCSLT will be the point of contact for data subject access requests.

## 8. Information governance arrangements:

In order to:

- have detailed advice about which datasets they can share, to prevent irrelevant or excessive information being disclosed, the ROOT is configured such that data can only be shared for the agreed fields.
- make sure that the data organisations are uploading is accurate (for example by requiring a periodic sampling exercise and data quality analysis) each organisation can routinely run reports on their data (both in aggregated form and raw form). Each user also has a dashboard displaying key statistics to enable them to continually monitor the accuracy of the data submitted to the ROOT.
- record data in the same format (abiding by open standards when applicable) the RCSLT provide a document defining each field to promote consistency. Additionally, the ROOT is built with data standards embedded.
- have common rules for the retention and deletion of data items, as appropriate to their nature and content, and procedures for dealing with cases where different organisations may have different statutory or professional retention or deletion rules:
  - the pseudonymised patient data may currently remain on the system for as long as the organisation wish to participate in this project. The agreement and use of the service will be reviewed every two years, at which time each controller will reassess the basis and appropriateness for continued use of the system.
  - the personal data collected about the individuals using the ROOT will be retained indefinitely for active accounts; inactive accounts will be monitored and individuals notified every 18 months.
- have common technical and organisational security arrangements, including the transmission of the data and procedures for dealing with any breach of the agreement in a timely manner; the agreements currently in place state: "notify the person named in Clause 3, immediately in instances where a data breach is identified or suspected. The UK GDPR introduces a duty to

report certain personal data breaches to the relevant supervisory authority within 72 hours of becoming aware of the breach, where feasible”.

- ensure their staff are properly trained and are aware of their responsibilities for any data they have access to; this is set out as part of the acceptable use policy that new users sign
- have procedures for dealing with access requests, complaints or queries from members of the public; these should be directed to the RCSLT data protection officer ([dpo@rslt.org](mailto:dpo@rslt.org)) for users of the ROOT, and to the data protection officer at **Organisation name (RCSLT to populate)** for patients.
- the ongoing effectiveness of the data sharing initiative and the agreement that governs it; the RCSLT currently sets a review period of two years
- have procedures for dealing with the termination of the data sharing initiative, including the deletion of shared data or its return to the organisation that supplied it originally; upon the written agreement of the Data Controllers, the agreement may be terminated at any stage. The RCSLT will be responsible for arranging the permanent deletion of any data upon 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 three months for back-up and audit purposes only.

## 9. Under what circumstances will the data be accessed?

ROOT users' data:

- Accessed by staff at RCSLT/Different Class Solutions Ltd for the purposes of administration of the system, providing technical support and audit
- Accessed by staff at **Organisation name (RCSLT to populate)** for management of user accounts and audit

Pseudonymised patient data:

- Accessed by staff at **Organisation name (RCSLT to populate)** to support patient care, update records, audit, analysis
- Accessed by staff at RCSLT/Different Class Solutions Ltd for the purposes of providing technical support
- Accessed by staff at RCSLT to support analysis

## 10. How will the data be stored?

The data is stored on a securely hosted web system utilising SQL Server 2016 or later and ASP.net 4.8. 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.

The servers are located in UK data centres, on UK-only nodes. The data centres are provided by Microsoft Azure, all meeting the security standards of ISO27001.

### **11. How will the data be returned/destroyed?**

If users cease to use the ROOT, the RCSLT will contact the Data Processors and instruct them to delete any personal data, including pseudonymised patient data and names and email addresses of ROOT users, 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 three months for back-up and audit purposes only. A copy of the Data can be provided to the Data Controller(s) on request.

The RCSLT will retain an anonymised copy of the outcomes dataset in the ROOT database for statistical purposes. Any patient identifiers, details about the staff members and the name of the organisation who provided the data will be deleted, rendering the dataset anonymised.

### **12. Review frequency:**

Every 2 years.

### **13. Further details (Annex)**

As per the ICO's guidance, it is good practice to have a data sharing agreement in place which set out the purpose of the data sharing, cover what happens to the data at each stage, set standards and help all the parties involved in sharing to be clear about their roles and responsibilities.

Having a data sharing agreement in place helps each party to demonstrate they are meeting your accountability obligations under the UK GDPR.

<https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/data-sharing/data-sharing-a-code-of-practice/data-sharing-agreements>

## 14. The agreement

By signing this document, each party agree to personal data being shared and processed in the ways set out above.

### **Signed for and on behalf of the RCSLT:**

Name: Jonathan Bowles

Position: Head of Corporate Services / Data Protection Officer

Date:

Signature:

### **Signed for and on behalf of Organisation name (RCSLT to populate)**

Name: Please complete

Position: Please complete

Date:

Signature:

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