

COVID-19 data collection

Information governance pack

Executive summary

The Royal College of Speech and Language Therapists (RCSLT) is supporting its members with capturing data on the management of patients with confirmed and suspected COVID-19. This data will help us to understand the impact on patients and those that care for them, be that in an acute, clinic or community setting.

This document has been developed to support speech and language therapy services with understanding the legal requirements and local policy relevant to their involvement in this project¹, and with demonstrating due diligence with regards information governance and data security legislation. Local and national policies and procedures must always be followed.

The RCSLT has developed a dataset, which includes fields to collect pseudonymised information about service delivery, the impact of interventions and patient outcomes. We have also developed the RCSLT COVID-19 Data Collection Tool, a secure, online system to enable speech and language therapists to submit de-personalised datasets to a national database, and generate reports on the data submitted. Locally, this will support speech and language therapy services with reviewing their outcomes, and nationally, it will support the profession to explore variation across the UK, to clarify lessons learned and inform preparations for future untoward health events and pandemics.

¹ This project is supporting service evaluation associated with change in service delivery. Ethics approval is not required.

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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.
- 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 data collected as part of this project 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 collecting this data 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 participate in this project 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 data can be submitted.

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1. Introduction

The RCSLT has developed a data collection template² to support the speech and language therapy profession with capturing data on the management of patients with confirmed and suspected COVID-19 in a consistent way. The template and supporting resources can be downloaded from the RCSLT COVID-19 Data Collection Tool (CDCT), [here](#).

To support the speech and language therapy profession with understanding and evaluating the data collected locally, the RCSLT has developed the CDCT, a secure, online system³ as part of the RCSLT Online Outcome Tool⁴ to enable speech and language therapists to submit de-personalised datasets, and generate reports on the data submitted. This data will contribute to a national database, which will support the speech and language therapy profession to explore variation across the UK, to clarify lessons learned and inform preparations for future events.

Alternatively, speech and language therapy services can use the data collection template to gather and analyse the data at a local level only using local tools.

2. Data collected as part of this project

A full list of the data collected about individuals receiving speech and language therapy is available in the guidance document, available to download [here](#). It is not necessary for services to collect all of this information. Services are encouraged to identify which fields are most relevant and useful locally.

The data collected about individuals receiving speech and language therapy is pseudonymised. Each patient should be allocated a unique patient identifier locally, which should be known only inside the organisation. Pseudonymised data falls within the scope of Data Protection Legislation, and therefore, a GDPR-compliant contract will

² Speech and language therapy services already using the RCSLT Online Outcome Tool (ROOT) can record this data directly on the ROOT. For more information, please contact root@rsl.org.

³ For further information about the security of the CDCT is available in Annex 1.

⁴ More information about the ROOT is available here: <https://rsl.org/Content/getting-ready-to-use-the-root>

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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 3.

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

A list of frequently asked questions is provided in Annex 2.

3. 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 as part of this project 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, or you can use your organisation's own documentation.

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To register to be involved in this project and request the data processing agreement please do so [here](#), 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 be involved in the project. 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 involved in this project 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.

Terms of use

Speech and language therapy services will be required to confirm that they agree to the terms of use (Annex 3) when registering to use the CDCT. They will also need to confirm that they have satisfied all local policies and procedures related to information governance, including completion of all documentation required by their organisation, before access to the online system will be granted.

4. Online data submission process

Once all documentation is completed, speech and language therapy services with authorisation to participate in this project will be invited to submit de-personalised datasets via the RCSLT COVID-19 Data Collection Tool (CDCT). Speech and language therapists will need to create an account and log-in to upload the spreadsheet. More

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information about the process of submitting the data is available in the guidance document, available [here](#).

Speech and language therapists will be reminded to check that the spreadsheet contains only the information that has been authorised each time that they upload a file. It is important that the spreadsheet has the same structure and format as the template, otherwise the submission will be rejected.

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 from organisations providing speech and language therapy to participate 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) 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 5). 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 CDCT 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

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use of the online system before being granted access. Users of the system must ensure that they use the system 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 will result in the suspension/revoking of system use.

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Annex 1: 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 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 CDCT 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 UK data centres. The data centres are provided by Heart Internet and Microsoft Azure, all meeting the security standards of ISO27001.

Audit

The specific content of any transactions and other system use is logged and monitored to look for unusual/unexpected use patterns that may be indicators of improper use. Regular audits of use will be undertaken by the data processor to monitor this and to ensure the Acceptable Use Agreement (Annex 6) is adhered to. The system provider, Different Class Solutions Ltd, maintains the right to monitor the volume of system use and navigation.

The RCSLT COVID-19 Data Collection Tool has been developed to be compatible with all modern, secure web browsers. Please be aware that, if using an out of date or insecure web browser, you will not be able to access all of the content and functionality available on the CDCT. This is likely to be the case if you are using a version of Internet Explorer older than version 11, for example.

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Annex 2: Frequently asked questions

1. Why is the information being shared?

The Royal College of Speech and Language Therapists (RCSLT) is supporting speech and language therapists with capturing data on the management of patients with confirmed and suspected COVID-19. The RCSLT has developed the RCSLT COVID-19 Data Collection Tool (CDCT), a secure, online system to enable speech and language therapists to submit de-personalised datasets to a national database, and generate reports on the data submitted.

Locally, this will support speech and language therapy services with reviewing their outcomes to:

- Evaluate the impact of SLT interventions on patient outcomes
- Evidence the impact of SLT input to decision makers and commissioners to inform service development in the future
- Share best practice and reflect on service outcomes
- Inform changes to service delivery

Nationally, the project will support the profession to explore variation across the UK, to clarify lessons learned and inform preparations for future untoward health events and pandemics.

More information about the project is available to download from <https://cdct.rcslt-root.org/Welcome>

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

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In relation to individuals receiving speech and language therapy, the data collected includes:

- A pseudonymised local patient identifier
- Gender
- Year of birth
- Medical diagnoses
- Communication and swallowing disorder descriptor(s)
- Details of speech and language therapy interventions provided
- Outcome measures

A full list of the data collected about individuals receiving speech and language therapy is set out in the data processing agreement and is also provided in the guidance document, available to download [here](#).

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

The pseudonymised data will be entered on to a spreadsheet before being uploaded to the CDCT. The data itself is already collected by speech and language therapists as part of their management of the patient.

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

The CDCT collects personal data about the speech and language therapists using the system. Each individual user will be required to consent to their details being held in relation to use of the CDCT 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

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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 RCSLT COVID-19 Data Collection Tool involve using information about individuals for a purpose it is not currently used for?

The use of the RCSLT COVID-19 Data Collection Tool involves the sharing of data that has been pseudonymised. The CDCT 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 CDCT 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 CDCT 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

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protect the data and prevent unauthorised access by anyone else. The data is stored using an encryption algorithm so that if anyone physically removed a disk or the server itself, then they would not be able to access the data. Thus all data is encrypted in the database and in transit.

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

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

No, the servers are located in UK data centres.

9. Who will have access to the information?

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

- 'Local users' are individuals with access the CDCT, as authorised by their organisation. They will 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 CDCT who have been appointed by their organisation to monitor and validate access to the system. 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 the system 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 complies with the standards of ISO 27001. The company also has access to aggregated data reports on outcomes at a team/service level and external benchmarking level.

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- Administrative users at RCSLT are able to access the pseudonymised data 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 unrestricted access to the servers where data is held. All data is stored on encrypted volumes. Only in cases of suspected system defects/errors and new developments will Different Class employees need to look at the raw data, 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. How long is the data retained for?

The data processor, Different Class Solutions Ltd, will process the data under instruction from the data controller, and will dispose of the data on request.

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Should an organisation wish to withdraw from the project and/or terminate the data processing agreement, Different Class Solutions Ltd will dispose of the data as instructed.

Once data is removed from the live system, it will be retained for up to 12 months in encrypted backups.

14. 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 COVID-19 Data Collection Tool?

To be compliant with the national data opt out, you need to assess whether the sharing of data with the CDCT is in scope of the national data opt-out policy. More information about the national data opt out is provided on the [NHS Digital website](#).

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

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Annex 3: Terms of use

In using the RCSLT COVID-19 Data Collection Tool (CDCT) to submit our data, 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 CDCT is permitted by the organisation and for completing and regularly reviewing the data processing agreement in place with Different Class Solutions Ltd.
- The CDCT is provided by RCSLT for use by speech and language therapists. Access to the CDCT is provided to speech and language therapy services free of charge as a benefit of RCSLT membership.
- RCSLT reserves the right to withdraw access to the CDCT 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 CDCT users from other participating organisations.
- The CDCT 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.

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Annex 4: Governance Arrangements: Organisational Administrative Roles and Responsibilities

Organisation	Roles and Responsibilities
Royal College of Speech and Language Therapists (RCSLT)	<ul style="list-style-type: none"> • Provides governance and scrutiny of the data processor on behalf of the data controllers • Ensures that organisations using the system are legitimate and have a justified purpose for accessing the system • Validates requests from organisations to use the system • Provides organisations with access to the CDCT
Different Class Solutions Ltd (Data Processor)	<ul style="list-style-type: none"> • Processes information from the user organisation • Provides a regular quality report to RCSLT and organisations on user log-ins / activity • Monitors the volume of system use and navigation⁵ • Completes relevant documentation with user organisations (e.g. Data Processing Agreements) • Complies with Data Protection Legislation • Registered with the Information Commissioner's Office (data protection registration number: Z2840119) • Has ISO 27001 and Cyber Essentials Plus certification/accreditation (Certificate no.: 5944466513017922)
Each organisation engaged in the project (Data Controllers)	<ul style="list-style-type: none"> • Appoints a local administrative user to manage users which will include: <ul style="list-style-type: none"> ○ adding users to the CDCT ○ changing user roles and privileges ○ monitoring users ○ removing/suspending users • Ensures that usernames are valid email addresses • Manages user accounts linked to their organisation • Assigns roles and permissions to users linked to their organisation • Ensures all organisation users agree to the Acceptable Use Agreement • Revokes /removes users <ul style="list-style-type: none"> ○ when the user leaves the organisation

⁵ 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.

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	<ul style="list-style-type: none">○ when a user acts in way contrary to the Acceptable Use Agreement (Annex 6)● Ensures that their organisation adheres to the principles of fair processing● Ensures that information security and records management standards are met (international, national and local)
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Annex 5: Users of the RCSLT COVID-19 Data Collection Tool

CDCT User	Description of access	Purpose
<p>Local user</p> <p><i>This might be a clinician or delegated to an administrator. Use of the system would mirror existing working practices.</i></p>	<ul style="list-style-type: none"> • Access to aggregated data reports on outcomes at a team/service level and external benchmarking level⁶ • Local users must comply with all policy, legislation and the local organisation's protocols, working in a way that mirrors existing working practices • Must also agree to the Acceptable Use Agreement (Annex 6) 	<ul style="list-style-type: none"> • To evaluate the impact of interventions • To evidence the impact of SLT input to decision makers and commissioners • To support sharing of best practice and reflect on service outcomes • To inform changes to service delivery
<p>Local admin</p> <p><i>User responsible for monitoring and validating access to the online tool for users within an organisation, in addition to "Local User" functions</i></p>	<ul style="list-style-type: none"> • Access to aggregated data reports on outcomes at a team/service level and external benchmarking level³ • Access to the data upload functions of the CDCT, where appropriate • Access to user administration functions • Access to reports monitoring appropriate use of the system and other audit reports • Local admins must comply with all policy, legislation and the local organisation's protocols, working in a way that mirrors existing working practices • Must agree to the Acceptable Use Agreement (Annex 6) 	<ul style="list-style-type: none"> • To evaluate the impact of interventions • To evidence the impact of SLT input to decision makers and commissioners • To support sharing of best practice and reflect on service outcomes • To inform changes to service delivery • To manage and validate user accounts for access to the CDCT • To monitor use of CDCT for auditing purposes

⁶ Benchmarking reports will not identify services without explicit consent

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<p>RCSLT administrative users</p>	<ul style="list-style-type: none"> • Access to user administration functions • Access to anonymised service-level and national-level reports (which do not contain data for fewer than 6 service users) • The user will have access to the pseudonymised patient data for the purposes of providing help and support to users • Must agree to the Acceptable Use Agreement (Annex 6) 	<ul style="list-style-type: none"> • To assist with technical and administrative enquiries • To support SLT services with service evaluation and service improvement • To support SLT services to benchmark the effectiveness of SLT services • To support development of the evidence base and identification of research priorities
<p>Different Class Solutions Ltd administrative users</p>	<ul style="list-style-type: none"> • This role has special access to all system features, functions, and data • The organisation is ISO 27001 certified, has achieved Cyber Essentials Plus accreditation and is registered with the Information Commissioner’s Office 	<ul style="list-style-type: none"> • To install, or upgrade computer components and software • To provide routine automation • To maintain security policies • To troubleshoot • To train or supervise staff; or offer technical support • To support the upkeep, configuration, and reliable operation of computer systems • To ensure that the uptime, performance, resources and security of the server and software meet the needs of the users

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Annex 6: Acceptable Use Agreement

The RCSLT COVID-19 Data Collection Tool (CDCT) has been developed to support speech and language therapy services with collecting, collating and analysing outcome data.

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

It is the responsibility of the users of the CDCT to use the system in a way that complies with existing standards and expectations about fair processing in accordance with Data Protection Legislation⁷. Use of the CDCT is fully monitored and audited.

- I understand that it is my responsibility to use the CDCT in a way that complies with existing standards and expectations about fair processing in accordance with Data Protection Legislation⁵
- I am aware that the use of the CDCT is fully monitored and audited and that any demonstrable misuse of the CDCT will result in the suspension/revoking of system use.
- I will not attempt to use someone else's login details to access the CDCT
- I will not allow anyone else to use my login details. I am aware that passwords should be kept securely and I will not disclose my password to anyone else.
- I will not attempt to search for information on a service user that I am not authorised to access
- I will not download information to use in ways that run counter to the system's objectives
- I will not attempt to access unauthorised areas
- I will not introduce any spurious or non-existent cases into the system⁸
- 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 CDCT when unattended.

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

⁷ "Data Protection Legislation" means (i) the Regulation (EU) 2016/279 General Data Protection Regulation (GDPR) and (ii) the Data Protection Act 2018

⁸ Please note, there is test environment available to use with 'dummy data' for training purposes

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