

# Guidance: DiADeM Terms and Conditions

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## 2. Definitions

The definitions of abbreviations and terms used in this document are detailed below.

ITEM	DEFINITION
Access	Actions that may result in: (i) the data being viewed or changed; (ii) operational aspects of IT systems to changed; or (iii) security settings of IT systems to viewed or changed.
Agreement [1]	DiADeM Service Use Agreement: Main
Agreement [2]	IT Services Agreement
Agreement [3]	DiADeM Service Use Agreement: Apperta-User
Agreement [4]	Data Processing Agreement: Apperta-inidus
Agreement [5]	Data Processing Agreement: User- inidus
Apperta	The Apperta Foundation C.I.C., Company registered in England and Wales registration number: 09483987, Registered address: 10 Queen Street Place, London, EC4R 1BE
Apperta Data and Systems	(i) any DataDC for which Apperta is the Data Controller; and (ii) all Apperta IT Systems
Apperta IT Systems	All IT systems that Apperta controls to undertake Processing of DataDD where: (i) processing includes management of the data processing; (ii) the IT systems are under the control of Apperta; and (iii) IT Systems include DiADeM Web Service Tools.
Apperta Personnel	Those persons directly employed by Apperta; and subcontractors and agents working under Apperta's direct control
Assessor	This is a User role, where the User is registered to carrying out the DiADeM assessment on patients.
Breach of Personal Data	A breach of personal data means a breach of security leading to the accidental or unlawful destruction, loss, alteration, unauthorised disclosure

	of, or access to, personal data. This includes breaches that are the result of both accidental and deliberate causes. It also means that a breach is more than just about losing personal data.
CDR	Clinical Data Repository
CESG	Communications-Electronics Security Group. This is now part of National Cyber Security Centre ( <a href="https://www.ncsc.gov.uk/">https://www.ncsc.gov.uk/</a> ). The UK government's National Technical Authority for Information Assurance (CESG), advises organisations on how to protect their information and information systems against today's threats.
Data Controller	The natural or legal person, public authority, agency or other body which, alone or jointly with others, determines the purposes and means of the processing of personal data, as defined by Article 4 of the GDPR.
Data Processor	A natural or legal person, public authority, agency or other body which processes personal data on behalf of the controller, as defined by Article 4 of the GDPR.
Data Protection Officer (DPO)	Information Governance Role, defined under Article 39 of the GDPR.
Data Subject	A natural person who is the owner of the Personal Data
DataDC	Data that is controlled by the Data Controller
DataDD	Any data that is stored on the DiADeM Service.
DiADeM	Diagnosing Advanced Dementia Mandate, a dementia diagnostic tool to support the diagnosis of people living with advanced dementia in care home settings. It is designed for use on people living with advanced dementia within a care home who do not have a formal diagnosis. In these cases a referral to memory services may not be feasible or desirable, and is likely to be distressing for the individual.
DiADeM app	The app that the Assessor downloads to their remote device which they use to undertake the DiADeM Assessment.
DiADeM Assessment	A tool that has been developed in 2015 by the Yorkshire & Humber Dementia and Older Peoples Mental Health Clinical Network (YH DOPMH CN) with input from a range of stakeholders including experts in the field of Dementia from

	across the health spectrum and in particular from Dr Graeme Finlayson and Dr Subha Thiyagesh who shared their existing protocols. The application has support from the Alzheimer's Society and its use for diagnosing Dementia in the care home setting has been recommended by Professor Alistair Burns the National Clinical Director for Dementia and Older People's Mental Health.
DiADeM Assessment Report	the report generated as an outcome of a completed DiADeM Assessment. This report is in a pdf format and the Assessor sends this to their selected Recipient.
DiADeM Authentication Service	The Authentication Service holds User information for the purposes of managing permitted access and sharing of information held by the Diadem Service.
DiADeM CDR Service	The CDR Service is used to hold patient data (includes sensitive data). It comprises the CDR server and demographics server.
DiADeM Service	The Diadem Service are the full suite of services through which the DiADeM is delivered to Users.
DiADeM web portal	The web portal through which Users gain access to the Diadem Service.
DiADeM Web Service Tools	The tools provided through which the User accesses the Diadem Service.
DPcdr	The Data Processor of the DiADeM CDR Service
DPIA	Data Protection Impact Assessment (refer to Article 35 of GDPR, and <a href="https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/accountability-and-governance/data-protection-impact-assessments/">https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/accountability-and-governance/data-protection-impact-assessments/</a> )
ITServices	All IT services that inidus provides to support the DiADeM Service
ehrID	The unique internal identifier for a single patient, created by the DiADeM CDR Service
GDPR	General Data Protection Regulations ( <a href="http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679&amp;qid=1490179745294&amp;from=en">http://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:32016R0679&amp;qid=1490179745294&amp;from=en</a> )
Information Commissioner's Office (ICO)	refer to <a href="https://ico.org.uk/">https://ico.org.uk/</a>
inidus	inidus Limited, Company registered in England and Wales registration number: 10733421, Registered address: The Oakley, Kidderminster Road, Droitwich, WR9 9AY
inidus Data and Systems	(i) any DataDC; and (ii) all inidus IT Systems
inidus IT Systems	All IT systems that inidus controls to undertake Data Processing of DataDD, including management of the data processing, where the systems are under the control of inidus
inidus Personnel	Those persons directly employed by inidus; and subcontractors and agents working under inidus' direct control

non-Clinical Auditor	This is a User role, where the User is able to obtain reports based on the full data held by the DiADeM Service. All reports are processed such that they contain NO patient Personal Data
Person identifiable Data (PID)	This is the same as Personal Data
Personal Data	Any data relating to an identified or identifiable natural person, as defined by Article 4 of the GDPR, that is stored on the inidus platform
PurposeDP	For inidus to discharge inidus' obligations as Data Processor of the DiADeM CDR Server
Privacy Impact Assessment (PIA)	Privacy Impact Assessment. This is defined under the Data Protection Act (refer to <a href="https://ico.org.uk/media/for-organisations/documents/1595/pia-code-of-practice.pdf">https://ico.org.uk/media/for-organisations/documents/1595/pia-code-of-practice.pdf</a> ). Note that, under the GDPR, the PIA is replaced by the DPIA.
Recipient	This is a User role, where the User is a clinician responsible for the long term care of the patient, or works for a clinician who is responsible for the patient's long term care. A Recipient is a person to whom an Assessor is able to send a DiADeM Assessment Report.
Retention Period	The time period that Personal Data is held by the DiADeM Service, after which point it being deleted.
Sensitive Data	Referred to as a special category of Personal Data within Article 9 of GDPR, and includes health data
Third Party	All persons or organisations who are not party to the agreement. Where one of the party is "inidus", then Third party excludes all inidus Personnel
User	The person who has registered on the DiADeM system to use the Diadem Service
User Role	The role that the User is registered on the Diadem Service. A User may register under one or more of the following roles types: (1) Assessor (2) Recipient (3) non-clinical Auditor
Working Hours	Working hours are defined as 9 a.m. to 5 p.m. on Monday to Friday, excluding bank holidays

### 3. Purpose of this document

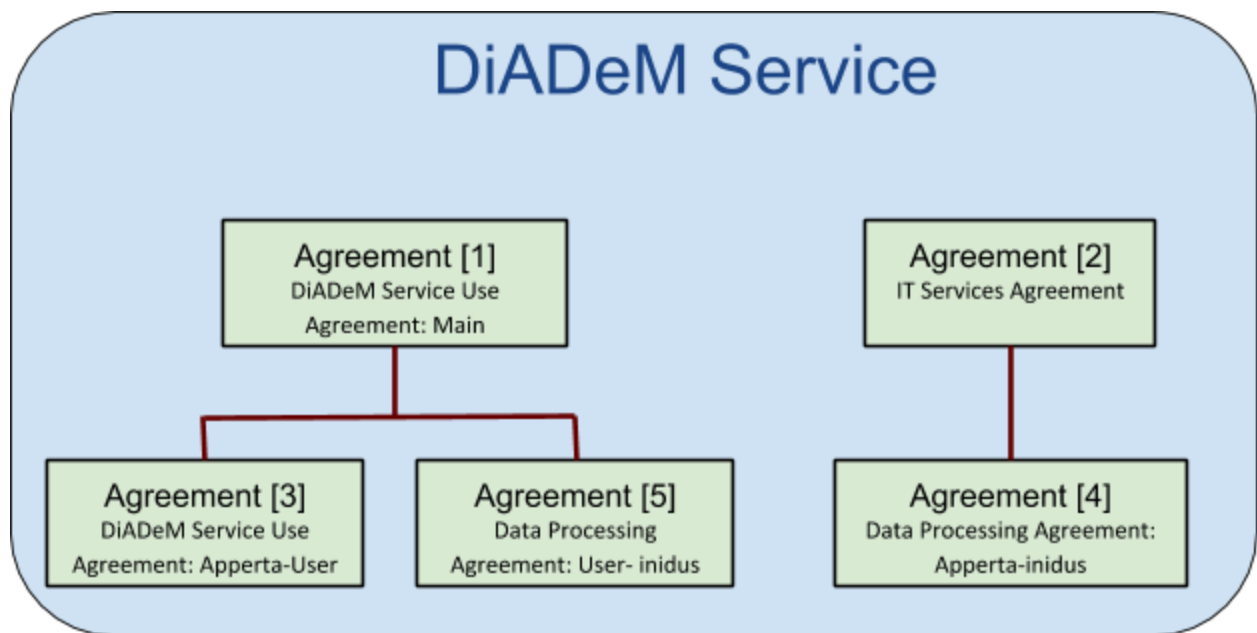
The purpose of this document is to provide guidance on how the DiADeM Terms and Conditions are structured.

The document also provides details on how specific problematic issues have been dealt with within the Terms and conditions.

## 4. Structure of Terms and Conditions

The figure below illustrates the structure of the agreement. The table following provides further information on the:

- Parties of each agreement
- Legal roles of each party
- Purpose of agreement



#	Name of agreement	Parties	Data Controller	Data Processor	Data Subject	Purpose of agreement
1	DiADeM Service Use Agreement: Main	Apperta User	Apperta (DiaDeM Authentication Service)			Master agreement, between Apperta and User
2	IT Services Agreement	Apperta inidus	Apperta	inidus		Master agreement between Apperta and inidus, for the supply of the DiADeM IT Services

3	DiADeM Service Use Agreement: Apperta-User	Apperta User	Apperta (DiaDeM Authentication Service)		User	Agreement between User and Apperta, for the registration and use of User on DiADeM.
4	Data Processing Agreement: Apperta-inidus	Apperta inidus	Apperta (DiaDeM Authentication Service)	inidus		Data Processing Agreement for DiADeM Authentication Service
5	Data Processing Agreement: User-inidus	User inidus	User (DiaDeM CDR Service)	inidus	User	Data Processing Agreement for DiADeM CDR Service

There are two master agreements: Agreement [1] and Agreement [2]. These are independent of each other.

The intention is that the User signs up during User Registration for the DiADeM Service with Agreement [1].

Agreement [2] is a supply agreement between Apperta and inidus. The agreement stipulates the rights and obligations of the Data Controller and the Data Processor, and GDPR requires that this agreement is in place.

Whilst at the top level, the two master agreements are independent, there is a certain degree of interconnection between the Agreement [1] and Agreement [2] and respective subordinate agreements. This is to address specific IG issues that are covered in the next sections of this document.

## 5. Issues

There are three issues which we cover within this document:

1. Issue 1: inidus - as the Data Processor of User DiADeM data for which the User is the Data Controller - has the User's identity and contact details.
2. Issue 2: There is a well-defined way in which all the agreements are terminated, and on termination, all DiADeM data is appropriately managed taking into account IG

3. Issue 3: In the event that inidus terminates provision of IT Services, a mechanism is in place to re-assign the User-inidus Data Processor agreement to the new IT Services provider

We discuss each issue on more detail below.

## 5.1. Issue 1: inidus - as the Data Processor of User DiADeM data for which the User is the Data Controller - has the User's identity and contact details

Under Agreement [5], inidus is the Data Processor of data on the DiADeM CDR Service, for which the User is the Data Controller.

It is a requirement from GDPR that the Data Processor must know the identity and contact details of the Data Controller.

The difficulty is that the User signs up to Agreement [5] with inidus using the DiADeM Web portal, and Apperta is the Data Controller for all the personal data the User enters onto this portal. inidus does not have any rights of access to the User's personal data.

Therefore a mechanism needs to be put in place by which Apperta is able to provide the identity and contact details to inidus of each Data Controller of the DiADeM CDR Service. The mechanism must satisfy GDPR.

## 5.2. Issue 2: There is a well-defined way in which all the agreements are terminated, and on termination, all DiADeM data is appropriately managed taking into account IG

Another way of phrasing this issue is that -- on termination of any agreement, there is no data left hanging without an authorised person acting as Data Controller.

It is necessary for GDPR to include full clarity on duration of contracts and how the contracts are terminated. The termination agreement must ensure that all aspects of IG is covered for personal data.



### 5.3. Issue 3: In the event that inidus terminates provision of IT Services, a mechanism is in place to re-assign the User-inidus Data Processor agreement to the new IT Services provider

The challenge is that the decision to change the IT Services provider is covered by Agreement [2], which is between Apperta and inidus, yet the data processing agreement for the DiADeM CDR Service is covered by Agreement [5] between the User and inidus.

In other words, Apperta is not a party to this data processor Agreement[5], and is not able to re-assign this Agreement [5].

Therefore a mechanism is required by which Apperta is able to re-assign the Data Processor Agreement [5].

## 6. Approaches

This section presents the approaches taken for each issue.

We take each issue in turn in the following subsections. For each issue, we present the specific wording that are incorporated into each agreement.

### 6.1. Issue 1: inidus - as the Data Processor of User DiADeM data for which the User is the Data Controller - has the User's identity and contact details

Agreement [1] -- DiADeM Service Use Agreement: Main

none
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## Agreement [2] -- IT Services Agreement

none

## Agreement [3] -- DiADeM Service Use Agreement: Apperta-User

### 8. User's Instructions to Apperta

1. For any **User** who is a **Data Controller** of **DataDD** held by the **DiADeM CDR Service**, the **User** instructs **Apperta** that **Apperta** is permitted and required to provide the following **User's DataDD** to the **DPcdr**, which is held on the **DiADeM Authentication Service**:
  - a. The Name of the **User**;
  - b. The contact details of the **User**; and
  - c. The **EHRIDs** for all **DataDD** for which the **User** is the **Data Controller**.

In the foregoing, items (a) and (b) are the **Personal Data** of the **User**, and item (c) does not constitute **Personal Data** in its form held on the **DiADeM Authentication Service**.

2. The **User** instructs **Apperta** that the disclosure of this **DataDD** to the **DPcdr** is for the sole purpose: To enable the **DPcdr** to discharge the **DPcdr's** obligations as **Data Processor** of the **DiADeM CDR Server**.
3. **Apperta** agrees to deliver to the **DPcdr** in a timely and prompt manner, the information detailed in clause (1) and regular updates, if and whenever there are changes to the information.
4. Where any **User** who ceases to be the **Data Controller** of any **DataDD** held by the **DiADeM CDR Service**, **Apperta** agrees to instruct the **DPcdr** to delete all **Subject Data** of the **User** that the **DPcdr** holds for the **Data Subject** that has been provided to the **DPcdr** under this **Agreement [3]**.

## Agreement [4] -- Data Processing Agreement: Apperta-inidus

### 9.2.2. Specific instruction to be issued by Apperta

1. **Apperta** will issue an API instruction in the form of an AQL query instruction to inidus, to obtain the following data from the **Data Service**:
  - a. For all **User**'s who are **Data Controllers** of data held by the **DiADeM Service**:
    - i. The Name of the **User**
    - ii. The contact details of the **User**
    - iii. The **ehrID** for all data for which they are the **User** is the **Data Controller**
2. **Apperta** will deliver the information obtained by this search, to **inidus**, and will instruct **inidus** to use the information for the sole **PurposeDP**.
3. **Apperta** will deliver updates to **inidus** of the information obtained by this search that are timely and prompt, whenever there are any changes to the **DataDD** corresponding to the data types detailed in clause (1).
4. Where and only if the situation pertains where the **User** is no longer a **Data Controller** of any **Data Subject's Data**, Apperta will instruct **inidus** to delete data supplied to **inidus**.

## Agreement [5] -- Data Processing Agreement: User- inidus

### 9.2.2. Specific instruction to be issued by the User

1. The **User** instructs **inidus** to use the following **DataDD** that **inidus** may hold regarding the **User's** data held by the DiADeM service for the sole **PurposeDP**:
  - a. The Name of the **User**;
  - b. The contact details of the **User**; and
  - c. The **ehrIDs** for all **DataDD** for which they are the **User** is the **Data Controller**.

6.2. Issue 2: There is a well-defined way in which all the agreements are terminated, and on termination, all DiADeM data is appropriately managed taking into account IG

#### 6.2.1. Agreement [1] -- DiADeM Service Use Agreement: Main

## 6. Duration

1. The duration of this **Agreement [1]** is indefinite

## 7. Notice

1. Either Party may serve notice at any time by issuing a “Notice of termination of DiADeM Service Registration” to the other party.
2. Where the **User** issues the “Notice of termination of DiADeM Service Registration”, the **User** will serve this notice using the **DiADeM Web Service Tools**.
3. The notice period for termination of this **Agreement [1]** is one complete calendar month.

## 9. End of Contract Provision

Where a “Notice of termination of DiADeM Service Registration” has been served by a **User** or **Apperta**:

1. At the commencement of the notice period **Apperta** will notify the **User** of all **DataDD** for which the **User** is the **Data Controller**;

2. The **User** will during the notice period manage all the **DataDD** for which the **User** is the **Data Controller** such that at the end of the notice period, there is no remaining **DataDD** for which the **User** is the **Data Controller** held within the **DiADeM Service**.
3. On termination of this contract, if there is any data of the **User** remaining on the **DiADeM Service** for which the **User** is the **Data Controller**, the **User** authorises the **DiADeM Web Service Tools** to instruct that this data is deleted.
4. On termination of this contract, **Apperta** will:
  - a. Delete all **Personal Data** of the **User** held by the **DiADEM Service** for which **Apperta** is a **Data Controller**.
  - b. Instruct **inidus** to delete all **Personal Data** of the **User** that **Apperta** has previously provided to **inidus** within **Apperta**'s capacity as **Data Controller of the Subject Data**, where **Apperta** provided the **Subject Data** for the sole **PurposeDP**.
  - c. Retain any information for which **Apperta** is legally bound according to the prevailing data protection legislation applicable to the UK; this clause taking precedence of the above clauses 5(a) and 5(b).
5. On completion of the notice period, the following individual agreements in which the **User** is a party will terminate:
  - a. **Agreement [1]** -- DiADeM Service Use Agreement: Main
  - b. **Agreement [3]** -- Apperta-User: DiADeM Service Use Agreement
  - c. **Agreement [5]** -- User - inidus: Data Processing Agreement

## Agreement [2] -- IT Services Agreement

### 7. Duration

1. The duration of this **Agreement [2]** is indefinite.

## 8. Notice

1. Either Party may serve notice at any time by issuing a “Notice of IT Services termination” to the other party.
2. **Apperta** and **inidus** agree that the notice period for termination of **IT Services** is three complete calendar months.

## 8. End of Contract Provision

Where a “Notice of IT Services termination” has been served:

1. **inidus** will assist and fully cooperate with **Apperta** to transfer the IT Services to another IT provider;
2. Where there are no **registered Users** for the **DiADeM Service**, then **inidus** will assist and fully cooperate with **Apperta** to close down the **DiADeM Service** in regards to the **IT Services**;
3. **Inidus** agrees to re-assign the **Agreement [5]** to another party determined by Apperta if requested to do so by Apperta;
4. Where **Agreement [5]** is reassigned, **inidus** discharges all future liabilities concerning **Agreement [5]**;
5. **Apperta** agrees to reimburse **inidus** reasonable costs that may be incurred by **inidus** to provide the required support;
6. At the end of the notice period:
  - a. **Apperta** will instruct **inidus** to delete all **DataDD** for which **Apperta** is the **Data Controller**;
  - b. **inidus** is permitted to freely delete any data that remains on IT systems that remain under the control of **inidus** on cessation of this contract, and that **inidus** had used to deliver IT Services for DiADeM: **inidus** understands that all **Data Controllers** will have had sufficient time to remove their data;
7. On completion of the notice period, the following agreements terminate:
  - a. **Agreement [2]** -- IT Services Agreement; and
  - b. **Agreement [4]** -- Data Processing Agreement: Apperta-inidus.

## Agreement [3] -- DiADeM Service Use Agreement: Apperta-User

### 5.1. Duration

1. This **Agreement [3]** is continuous whilst the **User** is a registered **User** of the **DiADeM Service**.
2. This **Agreement [3]** ceases when the **User** is no longer a registered **User**.

### 5.2. Notice

1. Notice may be served by the superior **Agreement [1]** issuing a “Notice of termination of DiADeM Service Registration”.
2. Where Notice is served, then the notice period of this **Agreement [3]** is the same as **Agreement [1]**.

### 5.3. End of Contract Provision

1. The end of contract provisions are as detailed in the superior **Agreement [1]**.

## Agreement [4] -- Data Processing Agreement: Apperta-inidus

### 6.1. Duration

1. The duration of this agreement is indefinite

### 6.2. Notice

1. Notice may be served by the superior agreement **Agreement [2]** issuing a “Notice of IT Services termination”.
2. Where Notice is served, then the notice period of this **Agreement [4]** is the same as **Agreement [2]**.

## 6.3. End of Contract Provisions

1. The end of contract provisions are as detailed in the superior **Agreement [2]**.

Agreement [5] -- Data Processing Agreement: User- inidus

## 6.1. Duration

1. The duration of this agreement is indefinite

## 6.2. Notice

1. Notice may be served by the superior **Agreement [1]** issuing a “Notice of termination of DiADeM Service Registration”.
2. Where Notice is served, then the notice period of this **Agreement [3]** is the same as **Agreement [1]**.

## 6.3. End of Contract Provisions

1. The end of contract provisions are as detailed in the superior **Agreement [1]**.

6.3. Issue 3: In the event that inidus terminates provision of IT Services, a mechanism is in place to re-assign the User-inidus Data Processor agreement to the new IT Services provider

### 6.3.1. Agreement [2] -- IT Services Agreement

Note, the clauses not relevant to issue 3 are greyed out below:



## 8. End of Contract Provision

Where a “Notice of IT Services termination” has been served:

1. **inidus** will assist and fully cooperate with **Apperta** to transfer the IT Services to another IT provider;
2. Where there are no **registered Users** for the **DiADeM Service**, then **inidus** will assist and fully cooperate with **Apperta** to close down the **DiADeM Service** in regards to the **IT Services**;
3. **Inidus** agrees to re-assign the **Agreement [5]** to another party determined by Apperta;
4. Where **Agreement [5]** is reassigned, **inidus** discharges all future liabilities concerning **Agreement [5]**;
5. **Apperta** agrees to reimburse **inidus** reasonable costs that may be incurred by **inidus** to provide the required support;
6. At the end of the notice period:
  - a. **Apperta** will instruct **inidus** to delete all **DataDD** for which **Apperta** is the **Data Controller**;
  - b. **inidus** is permitted to freely delete any data that remains on IT systems that remain under the control of **inidus** on cessation of this contract, and that **inidus** had used to deliver IT Services for DiADeM: **inidus** understands that all **Data Controllers** will have had sufficient time to remove their data;
7. On completion of the notice period, the following agreements terminate:
  - a. **Agreement [2]** -- IT Services Agreement; and
  - b. **Agreement [4]** -- Data Processing Agreement: Apperta-inidus.

### 6.3.2. Agreement [5] -- Data Processing Agreement: User- inidus

## 11.1. Reassignment

1. The **User** agrees that **inidus** may re-assign this **Agreement [5]** as directed by **Agreement [2]**.
2. Where **inidus** re-assigns this agreement, **inidus** discharges all future liabilities concerning **Agreement [5]**.