**FREED Network**

**Operational Agreement**

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* 1. Scope and Purpose
	2. This is an Operational Agreement (OA) for partner organisations joining the FREED Network. As signatories, the participating partner organisations have agreed to core requirements for terminology, practice and data sharing in relation to FREED (First episode Rapid Early intervention for Eating Disorders).
	3. With regard to data sharing and exchange of information, this OA is based on the NHS England Information Sharing Policy and was developed with reference to the UK Data Protection Act 2018 and the General Data Protection Regulation 2018 (GDPR), with input from the Information Governance team at the South London and Maudsley NHS Foundation Trust (SLaM). The GDPR has been retained in UK law after the UK’s exit from the European Union.

The OA has been agreed between the participating partner organisations in order to support the regular sharing of information for the purpose of evaluating the effectiveness of FREED.

It details the specific purposes for sharing and the personal information being shared, the required operational procedures, consent processes, and legal justification that underpins the disclosure/exchange of information.

It should be seen as supplementary to each partner organisation’s existing Information Governance processes.

* 1. This OA covers the exchange of information between the SLaM, the core FREED team at King’s College London (KCL), and [PLEASE INSERT NAME OF YOUR TEAM HERE].
	2. Partners may only use the information disclosed to them under this OA for the specific purpose(s) set out in this document.
	3. Partners joining the FREED Network and signing this OA do so for an initial period of 2 years, although partners are free to terminate their involvement with the FREED Network prior to this if they wish. Partners can renew their involvement after 2 years.
	4. Core Requirements of Partner Organisations

The FREED name and logo are trademarked. This means that only organisations who are part of the FREED Network who have signed the FREED operational agreement can use the logo and FREED name.

Partner organisations joining the FREED Network are expected to:

* Use the term ‘FREED’ to describe their early intervention pathway.
* Identify a FREED champion to manage and monitor the local implementation of FREED protocols.
* Commit to undertaking initial training in the FREED service model and care package.
* Commit to undertaking a 48-hour engagement call with potential FREED patients.
* Commit to using the FREED timelines as goals for assessment and treatment (2 weeks from referral to assessment and 4 weeks from referral to treatment).
* Commit to tailoring treatment to the developmental needs of young people, using the FREED care package resources as appropriate.
* Commit to equality and diversity
* Join FREED Network events and share learning as applicable (see Section 3).
* Collect and share core outcome data (see Section 4).
* If you wish to use the FREED logo on any new materials that you create, please check with us for agreement (giulia.diclemente@slam.nhs.uk or Jessica.griffiths2@slam.nhs.uk ).
* If you create presentations or papers that mention FREED, please send them to us so we can keep a record centrally (giulia.diclemente@slam.nhs.uk or Jessica.griffiths2@slam.nhs.uk ).
	1. **FREED Network Events and Learning**

As the FREED Network grows, we will organise learning events and opportunities for cross-site support. Learning events will include internal and external speakers and focus on developments in FREED, but also in early intervention for eating disorders and treatment innovations for eating disorders. We hope that site representatives will be able to participate at least annually in these events and that proximal sites will share learning within their regions. Confirmation of your attendance can be provided as part of your continued professional development.

Members of the FREED Network will receive access to new resources created by the SLaM FREED team, building on those already available. Collaboration across sites in the creation of new resources is also welcomed.

* 1. **Data Sharing – Information Governance and Fair Processing**

To continue building a case for FREED, we need to continue evaluating the model and its effectiveness in different services. We ask all teams in the FREED Network to gather the same core strands of data and provide these to us so that we can build a national data set.

The objectives of sharing the information covered by this agreement are:

* + - * + To further evaluate the effectiveness of FREED as a model of early intervention for eating disorders.
				+ To allow each partner site in the FREED Network to monitor the effectiveness of FREED in their service.
				+ To better understand cost and cost-effectiveness of implementing FREED in UK services.

The service users and/or carers which this agreement relates to include:

* + All patients treated via FREED in participating services.

The benefits to the service users include:

* + Ongoing service improvements, informed by treatment outcome data showing the local effectiveness of FREED.
	+ A stronger case for early intervention for eating disorders in the UK, informed by treatment outcome data showing the effectiveness of FREED across the FREED Network.

**4.1 Core Outcome Data**

Essential (mandatory) outcome data for sharing in the FREED network include:

* The number of 16 to 25-year-old patients seen through FREED, with baseline clinical characteristics including age and diagnosis.
* The percentage of FREED-eligible patients who received an engagement call within 48 hours of their referral being received.
* Time from referral to assessment.
* Time from referral to start of treatment.
* Duration of an untreated eating disorder.
* Treatment completion (yes/no), number of sessions attended, and type of treatment provided.
* Use of FREED care package resources.
* Eating Disorder Examination-Questionnaire (EDE-Q) data at pre-treatment and post-treatment (mid-treatment and follow-up is desirable).
* CORE-10 or CORE-OM data at pre-treatment and post-treatment (mid-treatment and follow-up is desirable) – or if preferred, the GAD-7 and PHQ-9
* BMI at pre-treatment and post-treatment (mid-treatment and follow-up is desirable).

The above outcome data will, in most cases, be routinely collected by eating disorder services.

Optional but desirable outcome data include:

* EQ5D-5L quality of life data at pre-treatment and post-treatment (mid-treatment and follow-up also desirable).
* Clinical Impairment Assessment (CIA) data at pre-treatment and post-treatment (mid-treatment and follow-up also desirable).
* The number of 16 to 25-year-old patients *not* seen through FREED, with baseline clinical characteristics including age and diagnosis.

We provide templates for recording and sharing these outcomes but can also work with local data processes if existing systems are in place for extracting electronic data.

We provide an information sheet explaining to patients that their de-identified data will be shared with the FREED Network unless they request otherwise (see Appendix A).

Prior to commencing FREED, we encourage services to conduct a baseline audit of process and clinical outcomes (as available) for 16 to 25-year-olds with an eating disorder of <3 years duration, as seen in the 2 years prior to FREED being introduced. In addition, a baseline audit of waiting times for all patients is useful as this will allow services to monitor whether introducing FREED impacts on waiting times for non-FREED patients.

We are not able to collect information on ethnicity and gender identity across the FREED Network, as these are protected personal characteristics and would require participants to provide active consent for their data to be shared. However, we recommend that each FREED Network team collects this information locally so they can monitor the accessibility of services and any under-served groups. Other personal characteristics may also be thought about locally (e.g., religion, sexual orientation).

**4.2 Legal Justification for Data Sharing**

All shared data will be used exclusively for the purpose of evaluating the effectiveness of FREED. Only de-identified data will be shared. Only pooled outcome data will be reported.

Trust ID numbers will be retained so that records can be amended if needed and duplicate entries detected. As Trust ID numbers will not be meaningful to anyone working outside of the original Trust, it will not be possible to identify patients from these numbers.

The responsibility of Data Controller for the information subject to this OA is held by SLaM. Data will be accessed and analysed by the core FREED team at SLaM and KCL. Data will not be shared with any other external parties without express permission from the original owners of the data.

The sharing of personal information covered by this agreement is not subject to informed consent. The justification for this is that the information offers significant benefits to the ongoing evaluation of FREED without requiring any personal patient information to be released. Moreover, the data to be collected and shared will form part of routine service evaluation processes for most services. This data sharing is covered by Article 6(1) of the General Data Protection Regulation (GDPR), namely, “*for the performance of a task carried out in the public interest*” as well as Article 9(2)(i), “*processing is necessary for reasons of public interest in the area of public health, such as ensuring high standards of quality and safety of healthcare*”.

The partners to this agreement recognise their duty under the UK Data Protection Act 2018 and the General Data Protection Regulation 2021 (GDPR) to provide information to individuals about fair processing. The sharing of information under this OA is covered by the FREED Network Information Sheet as well as any existing fair processing notices published by the partners to this agreement.

The FREED Network Information Sheet (Appendix A) outlines the data sharing processes for patients and gives the option of opting out of data sharing, without any implications for treatment received.

The SLaM FREED team have completed a Data Protection and Privacy Impact Assessment (DPIA). FREED Network data will be registered as an Information Asset at SLaM.

**4.3 Data Quality**

Information will only be collected using approved collection methods, ensuring the required information is complete and up-to-date.

All reasonable steps must be taken to ensure that anyone who has received incorrect information is notified, and the necessary amendments made.

**4.4 Retention and Disposal**

Information disclosed under this OA will not be held for longer than necessary to fulfil the purpose for which it was collected. Information will be disposed of securely in accordance with national guidance and each organisation’s local information retention and disposal policy.

**4.5 Subject Access and Freedom of Information**

Participating partner organisations acknowledge a duty to assist one another in meeting their individual responsibilities under the UK Data Protection Act 2018, the General Data Protection Regulation 2018 (GDPR), and Freedom of Information Act 2000 to provide information subject to this OA in response to any formal requests.

**4.6 Complaints**

Each partner organisation should have a formal procedure by which individuals can direct, their complaints regarding the application of this OA.

4.7 Operational Procedures for Sharing

Participating sites will be asked to send outcome data to the core FREED team at SLaM and KCL on a quarterly basis (3-monthly). Data will be shared electronically via encrypted email or secure file sharing processes. Data will be shared using the template provided by SLaM or, where existing systems are in place for electronic data management and sharing, using existing service processes. Paper records of questionnaire data will be retained by each partner site and stored and later disposed of in accordance with local protocols. Electronic data will be stored by SLaM in accordance with local protocols and is registered as an information asset.

* 1. **Breach of Agreement**

Any breach of this OA should be reported and investigated in line with each partner organisation’s incident reporting and management procedure and any relevant statutory guidance.

* 1. Contacts

The primary contact for matters relating to the operation and management of this OA are:

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| **Information Sharing Partner Organisations** |  **Responsible Person** |
| South London and Maudsley NHS Foundation Trust (SLaM) | Giulia Di Clemente, FREED National Co-Lead, Eating Disorders Service, giulia.diclemente@slam.nhs.uk Jessica Griffiths, FREED National Co-Lead, Eating Disorders Service, SLaM, jessica.griffiths2@slam.nhs.uk Claire Delaney-Pope, Interim Head of Information Governance, Claire.Delaney-Pope@slam.nhs.uk  |
| King’s College London | Prof. Ulrike Schmidt, FREED Executive Director, King’s College London, ulrike.schmidt@kcl.ac.uk  |
| INSERT NAME OF YOUR SERVICE | INSERT NAME OF RESPONSIBLE PERSON, TITLE AND EMAIL |

This OA will be subject to local approval and reviewed annually or sooner if appropriate.

* 1. Authorised Signatories

**In signing the document each signature is an undertaking to adopt the Agreement on behalf of their organisation for an initial period of 2 years, unless the Agreement is terminated in writing prior to this.**

Signed on behalf of:

Signature: Date:

Designation:

Name: Title:

Signed on behalf of: South London and Maudsley NHS Foundation Trust

Signature: Date:

Designation: Role:

Name: Title:

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*Appendix A*

**First Episode Rapid Early Intervention for Eating Disorders**

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| **FREED Network****Patient Information Sheet and Privacy Notice** |

FREED (First episode Rapid Early intervention for Eating Disorders) is an evidence-based treatment approach for 16 to 25-year-olds with an eating disorder of up to 3 years duration. FREED provides rapid access to treatment. It also adapts treatment to the specific needs of young people. More information is available at [www.FREEDfromED.co.uk](http://www.FREEDfromED.co.uk) .

FREED reduces waiting times and improves treatment outcomes compared to treatment-as-usual processes.

FREED was developed and piloted at the Maudsley Eating Disorders Service, which is part of the South London and Maudsley NHS Foundation Trust (SLaM). FREED is now used in eating disorder services across the UK – including Navigo CiC. Services using FREED form part of the FREED Network.

In time, we want FREED to be available to all young people with a recent onset eating disorder. To facilitate this, we need to continue evaluating the effectiveness of FREED.

Services in the FREED Network routinely share de-identified outcome data to a national FREED Network dataset. This dataset is managed by the FREED team at the Maudsley (SLaM) and King’s College London (KCL). It is used to evaluate the effectiveness of FREED.

‘Treatment outcome data’ includes time from referral to assessment and treatment; duration of an untreated eating disorder; type of treatment received; number of treatment sessions attended; Body Mass Index (BMI); scores on routine clinical questionnaires (assessing eating disorder symptoms and co-morbid difficulties); and diagnosis. Your age would also be shared, but not your date of birth.

Only de-identified information is shared. No names, contact information or other personal identifying details are shared.

When reporting results from the national FREED Network dataset, only pooled information is reported (i.e., average data from all patients who have provided information). No individual patients can ever be identified.

If you have questions regarding the FREED Network, or you do not want your de-identified information to be shared, please speak to staff at Navigo CiC in the first instance. You can ask for your information not to be shared and this will not impact your treatment in any way.

If you allow your information to be shared now, you can ask at a later date for it to be deleted from the FREED Network dataset.

If you have further questions, you can contact the FREED team at the Maudsley Hospital, SLaM, on giulia.diclemente@slam.nhs.uk (07546560884) or Jessica.griffiths2@slam.nhs.uk (07791551990); and/or the Head of Information Governance at SLaM, Claire Delaney-Pope, on 0203 228 3396 or Claire.Delaney-Pope@slam.nhs.uk .