EDCRN

Frequently Asked Questions (FAQ)

This FAQ sheet provides answers to common questions about the Eating Disorders Clinical Research Network (EDCRN). If you have further questions, please don't hesitate to email us at edcrn@kcl.ac.uk

General Information

What is the Eating Disorders Clinical Research Network (EDCRN)?

The EDCRN is an initiative led by King's College London (KCL) and South London and Maudsley NHS Foundation Trust, to establish a UK-wide network of child and adult eating disorder services. These services will collect the same standardised information on eating disorder symptoms, treatment, outcomes, demographics, risk factors and physical health markers. This will allow us to see who is being seen in UK eating disorder services and how current treatments perform across different groups.

Data are collected through a secure, NHS-compliant online platform that will collect information from patients, caregivers and clinicians

How does the EDCRN plan to improve care for individuals with eating disorders?

Currently, each eating disorder service in the UK collects information differently (e.g. using different outcome measures, collecting data in different formats). This means we lack standardised data across the country and do not have a national database to conduct research and identify areas for improvement.

EDCRN addresses this gap, facilitating research which can ultimately lead to more effective, personalised treatments which can benefit patients, caregivers and services.

What is the link between EDCRN and EDGI UK?

The Eating Disorders Genetics Initiative (EDGI) UK is an existing study to understand the genetic and environmental links to eating disorders. Participants with experience of eating disorders complete questionnaires online and provide a saliva sample. A subset of 1000 EDCRN participants will be invited to enrol in EDGI UK, providing a blood as well as saliva sample and enabling researchers to link clinical and genetic data, thus furthering our understanding of the influences of eating disorders. Excess treatment costs relating to taking blood samples for EDGI UK participation will be reimbursed to

sites via the SoECAT mechanism. EDCRN participants do not have to take part in EDGI UK; this is an optional, additional layer of participation.

How has the EDCRN involved people with lived and living experience?

People with lived and living experience (including caregivers) (PWLE) have been involved in the EDCRN since its' inception and continue to co-develop the Network's aims and activities through a Lived Experience Steering Committee. The EDCRN dataset was coproduced with a broad group of people with lived experience through a series of consensus-building workshops in early 2024. Additionally, the EDCRN has actively collaborated with Beat and F.E.A.S.T to establish advisory boards involving PWLE of eating disorders. There are 3 established boards (one for adults with lived experience, one for young people, and one for carers and supporters) that meet on a quarterly basis and act as a critical friend to the project. By incorporating these voices, the EDCRN benefits from invaluable personal insights that shape the research design and influence key aspects such as the frequency of questions, inclusion and exclusion criteria, platform design, patient materials, and data security concerns. These various strands of involvement help ensure that the Network remains responsive and impactful for those directly affected by eating disorders.

Participation in the EDCRN

Which services can take part in the EDCRN?

Any NHS eating disorder service operating in the UK is eligible to take part. EDCRN includes child/adolescent, adult and all-age or 0–25-year services and spans all regions of the UK.

What are the benefits to clinical teams of taking part?

There are both short and long-term benefits to joining the EDCRN. In the immediate term, the EDCRN platform has been designed to provide a user-friendly interface for both patients and clinical teams, significantly reducing staff burden in the collection of outcome measures (e.g. by automatically scoring questionnaires, providing data visualisations). Participating in EDCRN will provide services with data insights tailored to their local needs. In the longer term, the EDCRN will help address fundamental questions about treatment outcomes and support services in ongoing provision and evaluation.

What are the benefits to patients of taking part?

By taking part in the EDCRN, patients (and caregivers, as applicable) will have access to a user-friendly online platform which provides real-time insights about their symptoms. Patients can choose to complete additional optional questionnaires if these feel relevant to them and will have the option to take their online record with them if they move services, reducing the burden of having to tell their story multiple times. By taking part, patients will also be contributing to improved understandings of the factors influencing eating disorders – which will hopefully lead to service improvements and better, more personalised treatments.

Can private and charity providers take part?

Services commissioned to provide NHS treatment should be able to take part. At this stage individual private practitioners won't be able to take part. The EDCRN team are happy to discuss involvement from private and charity providers on a case-by-case basis.

Will it become mandatory for services to take part?

It is not mandatory to take part in the EDCRN. There is a new National Audit for Eating disorders which is mandatory. Taking part in EDCRN will make it easier to provide the data required for the audit.

Which patients are eligible to take part in the EDCRN?

Patients aged 8 and above who are receiving eating disorder treatment at any of the services participating in the Network can take part in the EDCRN. Younger children (under the age of 16) will normally need the consent of a parent or guardian to participate. More information on this is included in participant information leaflets. Parents/guardians are also able to take part if they are involved in their loved one's treatment, regardless of the age of their loved one.

Why is the EDCRN collecting data from caregivers as well as patients?

The EDCRN aims to collect information about caregivers, their well-being and their perspective on their loved one's eating. This applies to caregivers of adult patients as well as children/adolescents. The EDCRN gathers information from caregivers to better understand their well-being, daily functioning, and perspectives on their loved one's eating. This helps provide a more comprehensive view of how eating disorders affect not only the individual but also their family, work, and social life. By including caregivers

of both children and adults, we gain valuable insights into the broader impact of eating disorders and the unique challenges caregivers face. Caregivers of children and younger adolescents will also be asked to report on some of the symptoms/difficulties of their loved one.

Do patients need a formal diagnosis to take part in the study?

Participants must be receiving treatment for an eating disorder at a site participating in the EDCRN. Generally, this will involve them receiving an eating disorder diagnosis.

Is there a deadline for taking part?

There is no set deadline for taking part. However, please be aware that the study is currently only funded until October 2026. As we approach this deadline, requests to become involved will need to be considered more carefully.

The Dataset – composition, access, usage

What type of data will the EDCRN collect?

The EDCRN will collect demographic information, patient (and caregiver) reported outcome measures, physical health markers (e.g. blood test results) and treatment related data (e.g. the forms of therapy a person is receiving). These data (the "EDCRN dataset") have been agreed upon through consensus-building workshops with patients, caregivers, clinicians and researchers.

Most of the items in the dataset will be collected through patient-reported outcome measures which can be completed online at various time points throughout a person's treatment. In general, this will be at the start and end of treatment, as well as every three months whilst a person is receiving care. Though some (shorter) questionnaires will be asked at slightly more frequent intervals. The EDCRN dataset provides a comprehensive list of all the questionnaires and timepoints at which they will be asked.

What information do clinicians need to complete, and how frequently?

Clinical teams will be asked to enter some brief diagnostic and treatment-related data on the platform at assessment, the start of a patient's treatment and at the end of treatment.

At what time points is a patient asked to complete outcome measures?

This will depend on the outcome measure in question. In general , patients will complete measures ahead of their initial assessment with the service, at the start of treatment (if more than 1 month after assessment), at periodic intervals throughout treatment (mostly three-monthly but with some measures monthly and the ED-15/ED-15-Y available for completion on a weekly basis),, at discharge and when transitioning to a new service, if applicable. Patients will also be invited to complete outcome measures at periodic (6 months for the first year and annually thereafter) intervals for up to five years after being discharged but this will involve additional consent and individual responses to these follow-up questionnaires will not be shared with clinical teams. A full list of the outcome measures can be found in the EDCRN dataset document.

What considerations have been given to data security?

The EDCRN platform has been developed by Eclipse (Prescribing Services Ltd), an NHS-approved provider with extensive data security accreditation. Data will be stored within a secure data environment behind the NHS firewall.

Can clinicians use their service data for their own projects?

Clinicians can access all data relating to their patients to track and review progress within the online platform. Nominated lead/s within a service will have a higher level of data access, enabling them to see and download data for all patients in the service. This will enable services to use data for their own audit and evaluation purposes.

Clinical teams will also be able to view aggregate data for all services participating in the Network and see how they compare. Services will not be compared to each other in a named way.

Patients and caregivers (if applicable) will also be able to view their own data via the EDCRN platform.

We are already part of the FREED Network. Are there links between EDCRN and FREED?

The EDCRN has been developed with learning from the FREED Network in mind. As each service will have a nominated lead/s who can see and download data for all patients, this will also allow FREED Champions to benefit from EDCRN when collecting and managing data for FREED patients. For example, the EDCRN platform will ask

whether a patient is being seen through FREED or not and will collect information on Duration of Untreated Eating Disorder, waiting times, outcome measures, and treatment provided. Thus, it will not be necessary to separately enter this information into the FREED tracker. The FREED tracker is likely to remain helpful for managing FREED referrals and logging engagement calls.

Can patients choose not to have their data shared beyond their treatment team?

Approved members of the research team will be able to view identifiable information from participants only where necessary to conduct the research. External researchers and services will be able to access pseudonymised information for patients in the network. Necessary ethical approvals will be in place to facilitate this. Patients do not have to share their data with caregivers or if they move to a new service, but this is something they can choose to do if they wish.

How will EDCRN data be used in research?

External researchers can apply to use EDCRN data, but all personal details, like names and addresses, will be removed to ensure participants cannot be identified. The data will allow researchers to answer important new questions about eating disorders. By using the information collected through the EDCRN, researchers can better understand how common eating disorders are, who is affected, and the factors that contribute to their development. These factors can include things like genetics, co-occurring health conditions, or environmental influences such as stress or social pressures. The EDCRN will give researchers more reliable and detailed data, which will help them improve knowledge about eating disorders and work towards creating better, more personalised treatments.

Services will also be able to use the data for their own research and evaluation purposes. Insights such as these will advance our understanding of eating disorders and inform the development of improved, personalised treatments.

What happens if a patient moves to a different service?

If a patient moves to a different service (e.g. in a different location or from CAMHS to an adult service), they may provide consent to their record being shared with the new service, thus allowing their record to “follow” them from service to service. If this happens, the new service will be able to view all data relating to that patient as part of

the EDCRN. The old service will retain all data relating to the patient up until the point of transfer.

Expectations and supports

What supports will sites receive?

Clinical teams interested in joining the EDCRN will have the opportunity to have an initial exploratory call with members of the study team. If they join the Network, clinical teams will be provided with training and information materials about the study and using the platform. In addition to this, sites who participate in the EDCRN will become part of a collaborative Network of eating disorder service providers. This will be a space to share learnings, ideas and opportunities.

Is funding available for participating services?

EDCRN is adopted onto the CRN/RDN portfolio and participating sites can access accruals for patients recruited into the Network through existing CRN/RDN mechanisms. Additional funding will be available for participants enrolled into EDGI UK via CRN/RDN and SoECAT.

Is there a minimum requirement for services to take part? E.g. If Trusts will be receiving accruals will there be a 'recruitment target'?

The hope is that all patients receiving treatment will be invited to participate, though we understand not all will choose to do so. Recruitment targets can therefore be agreed in collaboration with the given service.

Is a local PI required?

Yes, all sites will be expected to have a local Principal Investigator (PI). Additionally, we are in the process of registering EDCRN for the Associate PI scheme.

How does my service express interest in getting involved?

For more information, or to express interest in getting involved, you can email the study team on EDCRN@kcl.ac.uk