



# FREED Inequalities Toolkit

## Purpose of the toolkit

This toolkit has been developed by KSS AHSN and Unity Insights to help better understand the local population needs or demographics of young people presenting with an eating disorder (ED) across Kent, Surrey and Sussex. The aim is to understand who is using and being offered the FREED programme and if this offer is equitable across the local population of young people who have an ED. This aligns with the adaptation of the Core20PLUS5 approach to focus on reducing health inequalities for young people, including those in the 20% most deprived of the national population and ethnic minority communities.

## What?

### What is the FREED programme?

First Episode Rapid Early Intervention for Eating Disorders (FREED) is a programme that targets 16 to 25 year olds who have had an ED (categorised by bulimia nervosa, anorexia nervosa, binge ED and other specified feeding or ED) for three years or less. The aim of this early intervention programme is to provide young people rapid access to treatment, the goal to start being treated within 4 weeks of referral.

## Why?

### Why do we measure health inequalities?

Health inequalities are said to exist when individuals with a social disadvantage have less access to effective treatment and relevant support, leading them to experience poor treatment outcomes or reduced quality of care. Monitoring how various aspects of health differ between various population groups is vital to identifying people from vulnerable groups.

Identifying areas that have unequal access or offer, based on the needs of the population, can inform areas that are driving possible inequalities in the ED system. Determining the areas in the pathway that require improvement may result in:

- Better care pathway as a result of subsequent pathway redesign
- Improved quality of care received by patients
- Improvements in the delivery of the service
- Service provision to be more appropriately tailored to patient needs

## What are the inequalities with regards to eating disorders?

The FREED programme aims to address the difficulties that young adults face when accessing help for their ED. Health inequalities with regards to EDs include, but are not limited to, clinician referral patterns, differences of patient experience with under-diagnosis and/or under-treatment and lack of support in accessing help for different population groups including those with protected characteristics (e.g. race, ethnicity, religion, sexuality, gender) or where you live.

"EDs have historically been thought to afflict "skinny, white, affluent girls". As such, higher-weight individuals, racial/ethnic minorities, those from socioeconomically disadvantaged backgrounds, and males may not recognise their need for treatment, may not be properly screened for EDs, and/or may not be referred to treatment."

K. R. Sonnevile., et al

"Anyone can be affected by an eating disorder, but eating disorders do not affect everyone equally. Some young people are less likely to be recognised and more likely to face barriers to receiving treatment."

Clinician (Eating Disorders)

### How?

How inequalities are measured across FREED Programmes in Kent, Surrey and Sussex



#### Engaging Partners

Gain commitment from key partners and stakeholders, including FREED Champions and Service Leads



#### Establishing Inequalities Measures

Agree metrics, outcomes, data sharing, Information Governance and start collecting data to establish baseline. Connect with Trust Information Governance (IG) Leads



#### Demonstrating Impact

Continuous data collection and review of impact, maintaining a health inequalities focus. Utilising data to support service innovation and improvement, to positively impact the care of young people with eating disorders



#### Providing Tailored Support

Regular meetings and peer support for the service. Feedback progress, share learning and celebrate success



Sustain and embed health inequalities focus to support better care

To measure inequalities in FREED the existing national tracker, used by services and submitted to South London and Maudesley NHS Foundation Trust as part of the FREED AHSN National Programme, was adapted by adding protected characteristics and demographic data.

As a third party provider, IG approval from the Mental Health Trust was sought to allow for patient-level data sharing. Training was provided to the FREED Champions and Clinical Leads to support on completing the inequalities data collection.

We also sought voices from those with lived experience including FREED service users:

"I already had baggage of being bullied, as I was being called freak, weirdo, not normal... I did not fit in and really started suffering at the age of 14/15. It all started with the bullying... ED is never just that alone, it ties it with other issues, depression, anxiety, seeking the control of eating as help"

17 Year Old Gay Male FREED Service User

"I would say [the FREED Programme] actually saved my life. I was told by my doctor that I wouldn't have made it through my 20s if I carried on the way I was acting, so I think early intervention eating disorders is so crucial. You don't want to waste your life; you do deserve food and you do deserve better"

FREED Service User

## Tips for measuring inequalities

1

Agree the demographic and protected characteristic information, building on the process and outcome metrics, based on local need to measure inequalities in ED. For example:

### Demographic and Protected Characteristics

### Process and Outcome Metrics

Demographic information (patient level)	Source
Age	Registered GP (specific Trust system)
Gender identity	
Sexual Orientation	
First language	
Ethnic group	
Estimated Deprivation Decile	
Highest educational attainment	
Religion or belief	
Registered GP Practice (can be used to estimate additional demographic information & geographic spread)	

- Access to service
- Referral waiting time
- Appointment waiting times
- 48-hour call waiting times
- Diagnosis\*
- Referral priority

\*Estimated deprivation decile would be derived from the patient's postcode or GP postcode

\*The diagnosis metric includes anorexia, avoidant/restrictive food intake disorder, binge eating disorder, bulimia and other specified feeding or eating disorders.

2

Engage with a wide range of stakeholders including Clinical Leads, ethics teams, IG teams and service users to help ensure the measurement analyses relevant data which will allow for higher quality insights. For example:

### Clinical Leads

Clinical Leads are involved in data collation and defining metrics that would be the most useful and relevant for the evaluation.

### Ethics Teams

Ethics teams are responsible for ensuring that teams are adhering to ethical guidelines within the evaluation practice, specifically when it includes vulnerable populations.

### Research teams

Work with research and development departments and the ED research clinic within the Trust.

### Service Users

Service users are a vital part of engagement in an evaluation as they bring in lived experience.

### IG Teams

IG teams ensure that data protection processes are followed and that patient data and information is shared safely and securely.

### Other stakeholders

Other stakeholders involved may include the Quality Improvement (QI) team or the Equality, Diversity and Inclusion (EDI) team.

3

Listen to the voices of experts by experience including young people themselves and parent/carers and ensure this includes a wide range of service users reflecting different protected characteristics and demographics as well as a wide range EDs. For example, through podcasts, social media, evaluation forms, suggestion boxes.

4

Share the data with system leads including commissioners and Integrated Care Boards to help develop data for quality improvement and pathway transformation.

5

Ensure IG approvals are sought if required. IG may not be an issue should the exercise be undertaken internally but may be required if a third party provider is involved which could cause delays in the analysis. Encourage teams to ensure data quality is prioritised as poor data recording and missing data can result in small samples. To improve the quality of data collected for future analysis, data collection should be conducted over a longer period of time or on an indefinite ongoing basis to increase sample size.

6

Engage your clinical teams to set realistic timeframes. Given the workforce capacity challenges in this pathway, consideration should be given to the strain data collection might present. Explore and develop approaches to facilitate the ongoing monitoring of key metrics with colleagues.

7

Consider workforce capacity and skillset by setting realistic timescales and ensuring the team is provided with training and information on why measuring inequalities is so important and how to do it.

**For more information visit:**

<https://improvements.kssahsn.net/our-work/eating-disorders/>

<https://freedfromed.co.uk/freed-for-all>