

# What information should eating disorder services collect?

Insights from two online workshops with people with lived & living experience, carers, clinicians & researchers



## Who are we?

The Eating Disorders Clinical Network (EDCRN) is led by clinicians, researchers, people with lived/living experience of eating disorders, and carers. We aim to set up UK-wide NHS research network spanning child and adult eating disorder services to enable a step change in the ability to conduct vital eating disorder research.



## What did we do?

In January and February 2024, we hosted two online workshops to understand what information eating disorder services should record as part of the EDCRN. The workshops were open to people with lived & living experience of eating disorders, carers, clinicians and researchers. We prioritised including voices that are typically underrepresented in eating disorder research. Each session was attended by between 20-25 people and facilitated by 6-9 researchers and people with lived & living experience.

Before the workshop, participants were sent a list of the possible measures/variables for eating disorder services to collect, based on previous research. During the workshop, participants were asked to comment on these and to share any of their own ideas.

## What did we learn?



Participants felt it was important for eating disorder services to collect information about eating disorder thoughts and behaviours, neurodiversity, other mental health conditions, waiting times, and social supports. The same was true of physical health markers such as blood tests measuring cardiac health, electrolyte levels and hormones.

Participants were less supportive of services collecting information about patients' motivation to change, which can fluctuate hugely, amidst concerns that this may influence the treatment offered. While important in some contexts, participants thought weight should not be the most important focus.

The distance of travel for treatment, transitions between services, and co-occurring physical health conditions were all seen as significant. Emphasis was placed on personalised care and clearly communicating with patients and clinicians the reasons why information is being collected.

## What next?

Asking services to use the same questionnaires and collect the same information will help us to understand who is being seen in eating disorder services nationally. We will also be able to learn which treatments they are getting, and whether these treatments work.

The contributions from the workshops will inform the information we ask services in the EDCRN to collect.

For more info see

[www.kcl.ac.uk/research/eating-disorders-clinical-research-network](http://www.kcl.ac.uk/research/eating-disorders-clinical-research-network)

