



# Early Intervention in the Real World

## The FREED Project (first episode and rapid early intervention in eating disorders): service model, feasibility and acceptability

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### Abstract

**Aim:** Eating disorders (EDs) are disabling disorders, predominantly affecting adolescents and young adults. Untreated symptoms have lasting effects on brain, body and behaviour. Care pathway-related barriers often prevent early detection and treatment of ED. The aim of this study was to assess the feasibility and acceptability of FREED (First Episode and Rapid Early Intervention for Eating Disorder), a novel service for young people (aged 18–25 years) with recent ED onset ( $\leq 3$  years), embedded in a specialist adult National Health Service ED service. Specifically, we assessed the impact of FREED on duration of time until specialist service contact (DUSC), duration of untreated ED (DUED) and wait-times for assessment and treatment compared with patients seen earlier in our service. Acceptability of FREED was also assessed.

**Methods:** Sixty individuals were recruited from September 2014 to

August 2015. Fifty-one of these were compared with 89 patients seen earlier.

**Results:** FREED patients, from areas with minimal National Health Service gatekeeping (14/51), had markedly shorter DUSC and DUED than controls (DUSC: 12.4 months vs. 16.2 months; DUED 13.0 months vs. 19.1 months), whereas those with complex gatekeeping (37/51) had shorter DUED (17.7 months), but longer DUSC (16.9 months) than controls. FREED patients waited significantly less time for both assessment and treatment than controls, had significantly better treatment uptake and were highly satisfied with the process of starting treatment.

**Conclusions:** FREED is a feasible and acceptable service which successfully reduced waiting times. Reductions in DUSC and DUED depend on gatekeeping arrangements. More research is required to establish clinical outcomes of FREED.

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### INTRODUCTION

Eating disorders (EDs) are severe mental disorders, causing death and disability. The peak age of onset is in adolescence and emerging adulthood.<sup>1,2</sup> Arguments for early intervention are compelling, given the lasting impact of symptoms (e.g. starvation) on brain, body and behaviour.<sup>3</sup> For example, it is increasingly recognized that over time, ED symptoms become rewarding and habitual.<sup>4</sup> Especially for anorexia nervosa, growing evidence supports a stage model of

illness, with intervention in the first 3 years of illness providing a critical window for full recovery.<sup>5</sup> However, despite the utility of an early intervention approach for EDs first being argued 10 years ago, analogous to developments in psychosis,<sup>6</sup> there has been no specific focus on early intervention in patients with first-episode ED.<sup>3</sup>

In the UK, as in other countries, ED services are divided into those for children and adolescents (age < 18 years) and adults (age  $\geq 18$  years). These services differ in terms of their culture and treatments

provided. Child and Adolescent ED services (CAEDS) typically provide family-based treatments, whereas in adult services, individual and group therapies are the predominant treatment modalities. The transition between services at age 18 is difficult for patients and families, as discontinuities in care create distress and delays and families may feel excluded from adult services.<sup>5</sup> In both CAEDS and adult ED services, prioritization of cases is typically in terms of medical risk, often defined by degree of weight loss/underweight.

Throughout the National Health Service (NHS), there is an ethos of gatekeeping to optimize the use of scarce resources. In many areas of the UK, there are restrictions in access to specialist care, in the form of commissioning panels that decide whether someone should be seen by a specialist service, or requiring patients to be first assessed by a generic mental health team. In some areas, only low-weight patients are allowed access to specialist care, which creates a perverse incentive for further weight loss in those who are perceived as 'not ill enough'. A UK survey of young people with EDs found that one-third had to wait over 6 months to access treatment. A further one-third reported waiting for over 18 months. Most reported that their ED deteriorated whilst they were waiting.<sup>7</sup> In response to this situation, the UK government recently set new standards for waiting times for children and adolescents with EDs,<sup>8</sup> specifying that urgent cases should be seen within 1 week and all cases within 4 weeks. However, these standards only apply to individuals younger than 18 years and the needs of emerging adults with EDs have not been considered.

Here, we describe a novel early intervention service specifically for emerging adults. The First Episode and Rapid Early Intervention for Eating Disorder (FREED) service is based on a 'stage of illness' model that prioritizes young people who have recently (within 3 years) developed an ED. The service model of FREED is based on the key principles for mental health care outlined by McGorry *et al.*,<sup>9</sup> that is it is holistic, proactive and optimistic, emphasizing early intervention and offering comprehensive, evidence-informed stepped care. FREED was set up as a 'service within a service' in an established catchment area-based NHS specialist ED service. The primary aim of this study was to assess the feasibility and acceptability of this new service on reducing duration of time until specialist service contact (DUSC), duration of untreated ED (DUED) and waiting times compared with previous practice within the service. A further aim was to compare different ways of assessing illness onset with a novel structured onset interview plus life chart versus clinician assessment (as captured in the initial assessment letter).

## METHODS

Ethical approval for the project was given by the National Research Ethics Service Committee London - South East (ref: 14/LO/0873).

### Participants

FREED participants were recruited from the adult ED Outpatient Service at the South London and Maudsley NHS Foundation Trust (SLaM), London, UK, during 1 year (September 2014 to August 2015). Inclusion criteria were: age 18–25 years, a primary Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) ED diagnosis and an ED illness duration of  $\leq 3$  years. Exclusion criteria were: need for immediate inpatient admission, severe learning disability and/or presence of a co-morbid physical/mental disorder requiring treatment in its own right (e.g. substance dependence).

For comparison, we carried out an audit of patients seen in our service during the 2 years prior to starting FREED. All patients referred during mid May 2012 - mid May 2014, aged 18–25 years, were identified from service records. Referral, assessment and treatment dates were extracted.

### Procedures

#### *Clinical procedures*

##### *NHS gatekeeping procedures*

Within the seven residential boroughs covered by the SLaM ED Service, there are multiple protocols for approving access to specialist services, some considerably more complex than others (e.g. involving generic mental health team assessments, commissioning panels or commissioner decisions). For individuals deemed eligible for FREED who came from a borough with complex gatekeeping arrangement (defined as approval for access to specialist care taking more than one week), the FREED team tracked funding processes and liaised with commissioners to speed up the process.

##### *The FREED model and care pathway*

Details of the FREED service model are described in Table 1 and contrasted with a conventional ED service model. The FREED service care pathway is described below.

##### *Screening*

All referrals for individuals aged between 18 and 25 years, where the available information indicates that the individual may have a recent-onset ED (or there is

## Early intervention in eating disorders

TABLE 1. Comparison of FREED service model with conventional ED service model

|                    | FREED   | Conventional ED service   |
|--------------------|---|---|
| Prioritization     | Based on the model of illness that emphasizes 'biological malleability' <sup>10</sup> during early illness stages and hence prioritizes these cases   | Prioritization based on diagnosis and/or severity of illness  |
| Access             | Easy access. Encourage early referral from primary care. Working to introduce self-referral in future   | Multiple service barriers to referral; early referrals not actively encouraged  |
| Aims and objective | To deliver a rapid, person-centred and effective service for young people with EDs that reduces duration of untreated ED and promotes early full recovery   | To deliver best possible care to all patients seen  |
| Approach           | Person-centred care determined by stage of illness  | One size fits all; standard packages of care determined by diagnosis or severity  |
| Care model         | Evidence-based treatments, developmentally tailored and appropriate for stage of illness  | Either child and adolescent-centred or adult-centred approach with either predominantly family-based or individual treatment approaches   |
| Engagement         | Active outreach to patient (e.g. 48-hour call)<br>Multiple modes of contact (e.g. emails, text and call)<br>Flexibility (e.g. changing timetable and, cancellations)<br>Information resources tailored to young people (e.g. information on role of social media in maintenance of ED symptoms and advice on responsible use of social media) | Onus on patient to contact service (e.g. opt in letter)<br>Traditional forms of contact (e.g. letters)<br>Administration team as initial point of contact<br>Limited flexibility reappointments |
| Assessment         | Biopsychosocial and person centred, including focus on young person's needs, priorities and strengths<br>Actively encourage family attendance<br>Psychoeducation emphasizing 'biological malleability'<br>Explore social media use  | Variable family involvement<br><br>Limited psychoeducation  |
| Treatment          | Tailored evidence-based treatments<br>Focus on early nutritional change<br>Family education, skills training and support<br>Use of technology (online interventions, using phones and apps)<br>Focus on transition management (e.g. university starter groups, close liaison with CAEDS)  | Variable focus on nutritional change<br>Variable family involvement<br>Variable use of technology<br>Some issues with transitions of care   |

CAEDS, Child and Adolescent ED services; ED, eating disorder; FREED, First Episode and Rapid Early Intervention for ED.

a lack of information regarding onset) are screened by telephone (within 48 hours of referral). During this call, individuals are asked to briefly explain their ED symptoms and history and are given information about the process of assessment and treatment. This is done in a friendly, informal and engaging fashion. If they are deemed eligible for FREED (and there are no gatekeeping arrangements restricting access to care), they are immediately booked in to the next available assessment (aiming for <2 weeks from the referral date received). If individuals are deemed ineligible for FREED (e.g. history of ED > 3 years), their referral is processed as per the usual service protocol (i.e. the patient is put on a waiting list).

### Assessment

The standard ED assessment protocol used in the service was adapted for FREED clinical assessments. This comprises a biopsychosocial, person-centred assessment which considers the young person within their family and social context, focusing on their needs, priorities and strengths. Where possible, family members and close others join a part of the assessment. Attention is paid to the young person's use of social media

and health-related apps, given ubiquitous use of these amongst young people and their known role in maintaining ED symptoms.<sup>11,12</sup> Assessing clinicians offer psycho-educational information about the effects of the illness on all aspects of the young person's life. This is done in a sensitive and motivational manner, emphasizing the malleability of the illness during early stages, as this is known to increase prognostic optimism and self-efficacy in recovering.<sup>10</sup> Families/carers are seen as a valuable recovery resource and are involved in supporting the young person as much as possible. A care plan is formulated collaboratively.

### Treatment/clinical management

Eligible individuals are rapidly allocated to a therapist (aiming for <2 weeks from assessment) to start an evidence-based stage-appropriate psychological intervention. Ongoing risk monitoring is an integral part of treatment. For young people with bulimic disorders (bulimia nervosa and binge ED) treatment is Cognitive Behavioural Therapy (CBT), delivered online, or individually face-to-face or in a group. For young people with anorexia nervosa, individual outpatient therapy using the Maudsley Model of Anorexia Nervosa

Treatment, a formulation-based treatment with a patient workbook, is typically used.<sup>13,14</sup> The choice of intervention and intensity depends on clinical need and patient preference. Sessions with family members/carers are an integral part of treatment. Pharmacotherapy (e.g. antidepressants) is added as appropriate. Early involvement of the team dietician is emphasized to provide an appropriate meal plan, particularly for young people with complex nutritional needs.

#### *Transition management*

This is a key focus as many young people who develop an ED are at the point of starting University and/or moving away from home for the first time. FREED offers University transition groups that focus on how to manage the eating-related and general challenges of University life.

#### *Research procedures*

Eligible participants were invited to participate in the FREED service evaluation study at assessment and were required to give their written, informed consent.

### **Outcomes**

#### *Onset interview plus life chart*

To accurately ascertain the onset and duration of prodromal symptoms and clinical ED in FREED, we developed and piloted a novel structured onset interview, including variables from the ED Diagnostic Scale (EDDS) and the ED Examination (EDE).<sup>15,16</sup> Information ascertained from the structured interview about onset, duration, frequency and severity of symptoms was then used to collaboratively complete a life chart. This uses individual 'anchor points' (e.g. birthdays, starting university, etc.) to help orientate the young person to the timing of onset.

The prodromal period was defined as a period of time where the person had one or several features of an ED for at least 3 months but at subclinical level. When symptoms reached a degree of severity that meets DSM-5 criteria for an ED or 'caseness', this was defined as the onset of the ED. In this study, we aimed to validate this novel structured interview plus life chart measure, by comparing it with the duration of prodromal symptoms and ED onset reported by clinicians based on their clinical assessment and detailed in the assessment letter.

#### *Duration of time until specialist service contact and duration of untreated ED*

The length of time (in months) between ED onset and the date patients attended their assessment is

defined as DUSC. The length of time (in months) between ED onset and start of an evidence-based treatment is defined as DUED. In FREED patients, when possible, ED onset as ascertained using the onset interview chart was used for DUSC and DUED calculations, otherwise ED onset reported in clinical assessment letters was used. ED onset information was only available from the clinical assessment letters for the audit cohort.

#### *Wait-times for assessment and treatment*

This was defined as the time period (in weeks) from the date the referral was made (e.g. by the General Practitioner (GP)) to the date patients attended for their assessment/had their first treatment session. We also calculated the wait-time between assessment and starting treatment (in weeks).

Treatment uptake was also calculated and defined as the number of people who were offered and commenced treatment after assessment. Patient satisfaction was assessed using visual analogue scales, after 3 months of enrolment in FREED services.

### **Analyses**

Statistical analyses were performed using IBM® SPSS® software (Version 22; Armonk, NY). To compare DUSC, DUED, wait-times and treatment uptake between FREED and audit patients, independent *t*-tests or chi-square tests were conducted. Prodromal period and onset assessed via interview plus life chart or clinical assessment letters were compared using a paired-sample *t*-test. Overall mean difference (in days) in ED prodrome or onset estimated by the two different methods of assessment was also calculated. All tests were two-tailed and the level of significance was set at  $\alpha = 0.05$ .

## **RESULTS**

### **Participant flow and baseline characteristics**

Figure 1 shows the participant flow through the study. Nine cases who were referred before the study period (i.e. prior to September 2014) but treated in the FREED service as pilot cases were not included in DUSC, DUED, waiting time and patient satisfaction analyses, but, however, were included when comparing the two methods of establishing prodromal period/ED onset. Table 2 gives demographic and clinical information for the FREED cohort and the comparison (audit) cohort. The two groups were very similar in age, sex, ED diagnoses and body mass index (BMI) at assessment.

### Comparison of DUSC and DUED in FREED and audit cohorts

Table 3 shows DUSC, DUED, wait-times from referral to assessment and treatment, and between assessment and treatment for the FREED and comparison cohorts. The FREED cohort was further divided according to whether participants came from a borough with minimal gatekeeping (i.e. access to specialist service approved within 1 week,  $n = 14$ ) or with complex gatekeeping arrangements (i.e. access approval took >1 week,  $n = 37$ ).

Overall, FREED patients had a non-significantly shorter DUSC and DUED compared with the audit cohort. In FREED patients with minimal gatekeeping, the difference in DUED approached significance  $F(77) = 3.37, P = 0.07$ .

### Wait-times for assessment and treatment in FREED and audit cohorts

Compared with patients from the audit cohort, FREED patients waited significantly less time from referral to both assessment ( $F(111.87) = 4.33, P < 0.001$ ) and treatment ( $F(86.27) = 27.93, P < 0.001$ ). These wait-times were also significantly shorter than for the

audit cohort in both FREED subgroups (i.e. minimal gatekeeping: wait-times for assessment ( $F(27.64) = 8.19, P < 0.001$ ) and treatment ( $F(76) = 13.35, P < 0.001$ ); complex gatekeeping: wait-times for assessment ( $F(124) = 3.11, P = 0.03$ ) and treatment ( $F(91.68) = 20.73, P < 0.001$ ). Moreover, wait-times between assessment and treatment were shorter for FREED patients than for controls ( $F(69.67) = 54.2, P < 0.001$ ). This was also true for FREED patients with minimal ( $F(71.28) = 17.38, P < 0.001$ ) or complex ( $F(73.12) = 36.99, P < 0.001$ ) gatekeeping.

### Comparison of different methods of onset assessments

In comparing the two methods of onset assessment, that is onset interview plus life chart versus clinical assessment letters used to establish prodromal period and ED onset, all 60 FREED patients were considered. In 41 patients, both methods were used to establish prodromal period and/or ED onset.

### Prodromal period

In 13 patients, both the date prodromal symptoms started and ED onset were reported using both

FIGURE 1. Participant flow diagram.

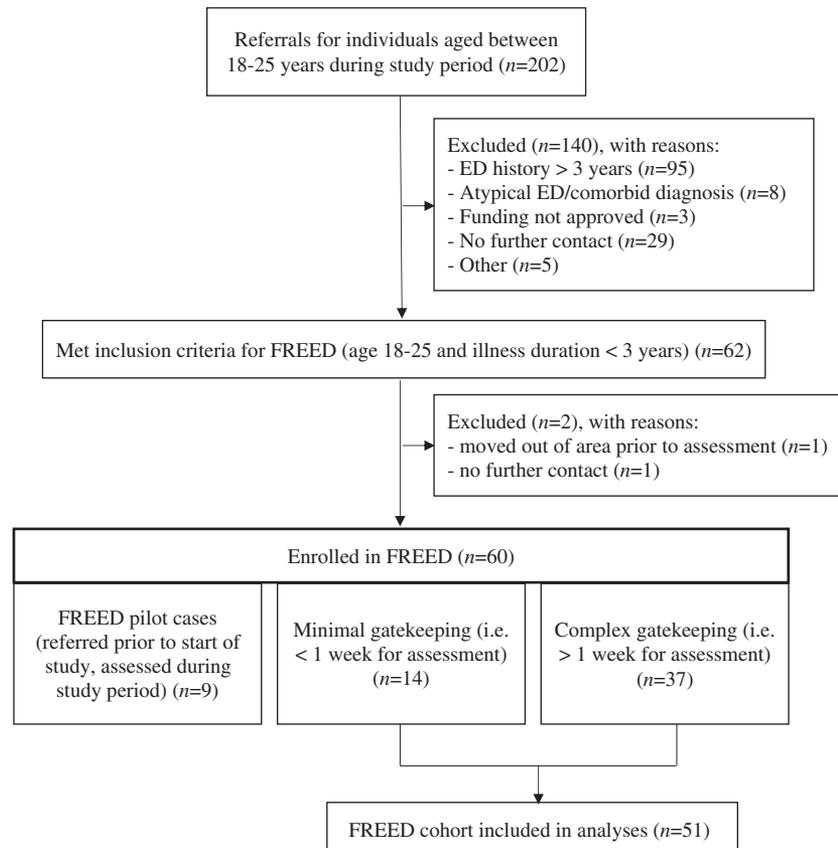


TABLE 2. Demographic and clinical information

|                                  | Audit cohort<br>(n = 89) | FREED cohort<br>(n = 51) |
|----------------------------------|--------------------------|--------------------------|
| Age on referral (M ± SD)         | 20.47 ± 1.99             | 20.64 ± 2.52             |
| Sex (F:M)                        | 87:2                     | 49:2                     |
| Diagnosis                        |                          |                          |
| AN (n, %)                        | 33 (37.9)                | 20 (39.2)                |
| BMI (kg/m <sup>2</sup> ; M ± SD) | 16.07 ± 1.90             | 16.80 ± 2.00             |
| BN (n, %)                        | 25 (28.1)                | 17 (33.3)                |
| BMI (kg/m <sup>2</sup> ; M ± SD) | 22.68 ± 3.58             | 22.55 ± 2.51†            |
| BED (n, %)                       | 4 (4.5)                  | —                        |
| BMI (kg/m <sup>2</sup> ; M ± SD) | 26.59 ± 4.16             | —                        |
| OSFED (n, %)                     | 25 (28.1)                | 14 (27.5)                |
| BMI (kg/m <sup>2</sup> ; M ± SD) | 20.51 ± 3.46             | 22.49 ± 5.45             |
| No ED (n, %)                     | 2 (0.02)                 | —                        |
| BMI (kg/m <sup>2</sup> ; M ± SD) | 18.48 ± 3.42             | —                        |

†Two missing BMI at assessment data replaced with BMI at first treatment session.

AN, anorexia nervosa; BED, binge ED; BMI, body mass index recorded at assessment; BN, bulimia nervosa; ED, eating disorder; FREED, First Episode and Rapid Early Intervention for ED; OSFED, other specified feeding or ED; SD, standard deviation.

methods. In these individuals, there was no significant difference in duration of prodromal period, as calculated using the onset interview plus life chart (18.14 ± 15.79 months) compared with clinical assessment letters (17.34 ± 16.58 months).

The prodromal period was established using only the onset interview or reported in clinical assessment letters, in 20 and 9 patients, respectively. Therefore, considering the two measures separately, the mean prodromal period established using the onset interview plus life chart was 23.20 months (±21.95, n = 33) compared with 14.29 months (±18.24, n = 22) clinical assessment letters.

### ED onset

In 38 patients, ED onset was reported using both measures. In these individuals, the mean difference

in ED onset estimation between these measures was 84.18 days (±131.08, minimum = 0, maximum = 548). The direction of difference was relatively equal; clinical assessment letters reported onset later (29%), earlier (37%) or the same (34%) as those established using the onset interview life chart.

### Treatment uptake and satisfaction with FREED service

Treatment uptake rates, that is the number of patients who were offered treatment and started it, were significantly better in FREED (100%) compared with the audit cohort (73%; 65/89,  $\chi^2 = (1, n = 140) = 16.60, P \leq 0.001$ ). FREED patients reported high levels of satisfaction regarding wait-times for both assessment and treatment (8.75 ± 1.72) and the process of starting treatment (8.85 ± 1.69; 0 = very dissatisfied, 10 = very satisfied).

### DISCUSSION

The FREED project evaluated the feasibility and acceptability of an innovative service development, aiming to reduce barriers to early care for young people with EDs. Overall, compared with patients seen earlier in our service, DUSC and DUED were only minimally reduced by FREED. This is disappointing, but was explained by the fact that 72.5% of participating patients came from boroughs with complex gatekeeping arrangements, which caused delays. In contrast, for patients (27.5%) from boroughs with minimal gatekeeping, DUED was reduced by nearly 6 months, from approximately 19 to 13 months. Only two other studies, both with a focus on anorexia nervosa, have previously reported DUED in first-episode cases. Reported illness duration was 21.6 and 25.1 months.<sup>17,18</sup> As anorexia nervosa is arguably the

TABLE 3. Process outcomes (M ± SD)

|   | Audit cohort<br>(n = 89) | FREED cohort<br>(n = 51) | FREED – minimal gatekeeping<br>(n = 14) | FREED – complex gatekeeping<br>(n = 37) |
|---|--------------------------|--------------------------|---|---|
| DUSC (in months)                                  | 16.16 ± 10.63            | 15.67 ± 10.04            | 12.45 ± 9.14                            | 16.89 ± 10.21                           |
| DUED (in months)                                  | 19.09 ± 11.67†           | 16.39 ± 10.08            | 13.04 ± 9.29***                         | 17.66 ± 10.20                           |
| Wait-time for assessment (in weeks)               | 9.94 ± 5.87              | 6.44 ± 5.38**            | 3.67 ± 3.35**                           | 7.48 ± 5.66*                            |
| Wait-time for treatment (in weeks)                | 19.87 ± 15.11†           | 9.59 ± 5.78**            | 6.25 ± 3.63**                           | 10.86 ± 5.97**                          |
| Wait-time from assessment to treatment (in weeks) | 10.07 ± 11.70†           | 3.16 ± 2.19**            | 2.58 ± 1.41**                           | 3.38 ± 2.40**                           |

\* $P \leq 0.05$ ; \*\* $P \leq 0.001$ ; \*\*\* $P = 0.07$  are in comparison to audit data.

†n = 65.

DUED, duration of untreated eating disorder; DUSC, duration of time until specialist service contact; FREED, First Episode and Rapid Early Intervention for ED; SD, standard deviation.

most serious ED and is visible to others, DUED is likely to be shorter in this condition than in other EDs. Our FREED cohort included the whole spectrum of EDs and as such the fact that we were able to shorten DUED to 13 months, if unimpeded by external constraints, is encouraging.

Importantly, in comparison to the patients seen earlier in our service, FREED patients waited approximately 35% less time for an assessment (63% in cases with minimal gatekeeping), 52% less time for treatment (69% reduction for cases with minimal gatekeeping) and 69% less time between their assessment and starting treatment (74% in cases with minimal gatekeeping). Patient engagement with the FREED service was excellent, with a 100% uptake of treatment, compared with 73% in the audit cohort. Moreover, patients reported high rates of satisfaction with FREED. Previous studies on EDs and other disorders have shown that waiting for treatment is not a neutral activity: it reduces treatment uptake, increases drop out and is associated with poorer outcomes.<sup>19–21</sup>

We used both a novel onset interview plus life chart and clinical assessment letters to determine illness prodrome and onset. In patients where both measures were used, duration of prodrome and illness onset were similar. However, when considering the prodromal period for all individuals across both methods, this was nearly 2 years long using the onset interview plus life chart compared with just over 1 year reported in assessment letters. This suggests that the duration of prodromal symptoms may be underestimated clinically. Moreover, in about one-third of cases each, clinicians considerably overestimated or underestimated when the ED reached caseness, i.e. ED onset. This is not surprising as illness onset can be defined in different ways. For research purposes, it is important to ensure a standardized assessment of prodromal symptoms and ED onset. Future studies should also make attempts to identify patients during the prodromal period, perhaps via early detection in schools and Universities.

Our illness duration criterion for selecting patients for FREED was based on evidence suggesting that EDs are most malleable during the first 3 years of illness,<sup>5</sup> whereas our age criterion (patients had to be between 18 and 25 years) was mainly chosen due to limited available resources. In this context, a potential concern is the impact of introducing a 'service within a service', such as FREED, on other patients with longer illness duration or outside the age range, who may be equally deserving of early care. Contrary to expectation, we did not find that introduction of FREED into our large specialist service increased waiting times for other patients. We believe that the introduction of FREED led us to examine our existing

administrative and clinical processes and address existing inefficiencies.

In conclusion, a significant challenge to implementing rapid early intervention for EDs within the NHS is the variability in gatekeeping processes. This led to a post-code lottery in terms of how rapidly young people, living in neighbouring boroughs in the same city, were able to access specialist care for their ED. Nonetheless, the FREED project has established the feasibility and acceptability of an early intervention ED service for young adults within the NHS. The next stage will be to explore the impact of this service innovation on clinical outcomes, service utilization and downstream NHS costs. This work is currently in progress. Ultimately, wider implementation of FREED can only be recommended once the effectiveness and cost-effectiveness of this model have been determined.

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