Lives at risk

The state of NHS adult community eating disorder services in England
Executive Summary

In 2017 the Parliamentary and Health Service Ombudsman (PHSO) – the final arbiter of NHS complaints in England – published a damning report into the treatment of adults with eating disorders, expressing alarm at failures to coordinate care, at low levels of knowledge among non-specialist doctors, and at the postcode lottery people face when trying to access quality treatment. It demonstrated that these problems lead to lives being lost and stressed the importance of parity between adult eating disorder services and those for children and young people (PHSO, 2017).

In 2018/2019 Beat conducted research into access, waiting times and staffing levels at adult community eating disorder services in England. We aimed to learn more about the capacity of these services and the consequences for patients, to enable us to make recommendations to the Government and the NHS.

The research comprised a Freedom of Information (FOI) request to all known providers of adult community eating disorder services and a series of eight in-depth interviews focusing on the impacts of long waiting times.

Research findings

Access

People with eating disorders face a postcode lottery to access specialist treatment. After accounting for the differences between the population sizes of the catchment areas as at 31 March 2018 seven times more people accessed the provider that treated the highest number of patients than the provider that treated the lowest number of patients. Some providers reported extremely low numbers of patients receiving treatment.

Waiting times

Waiting times from referral to start of treatment varied significantly between providers, with long waiting times in many areas.

Only 26% of adults started treatment within four weeks in 2017/2018, in contrast to 81% of routine referrals for children and young people. Almost one in five adults had to wait longer than 18 weeks in 2017/2018, with almost one in ten adults having to wait longer than 24 weeks to start treatment.

The average waiting time in 2017/2018 was nine weeks, with major variation between providers – a twelvefold difference between the shortest and longest average wait. The longest average waiting time was 5.5 months, with two other providers having averages longer than four months. Generally those services with shorter waiting times reported
disproportionally small caseloads, and those with higher caseloads reported longer waiting times.

**Staffing levels**

Staffing levels (after accounting for the population sizes of the different catchment areas) were similar among most providers, with the exception of five, which had distinctly more staff. The service with the most staff had nine times more than the fewest at 31 March 2018.

After accounting for differences in the numbers of patients treated, staffing levels varied significantly. There was a ninefold difference between the highest and lowest staff per patient ratios on 31 March 2018. The mean staff per patient as of 31 March 2018 was low at 6.4 WTE (Working time equivalent) per 100 patients, when compared to other community mental health services.

**Impacts of long waiting times**

The in-depth interviews found that long waiting times can have severe impacts on the welfare and safety of patients.

The participants reported the following key impacts:

- **Declining health and quality of life:** They described that during the time spent waiting after referral, they become more severely ill, and some felt that this led to them requiring longer and more intensive treatment.

- **Incentive to maintain or attempt to increase severity of illness:** Many participants reported that during the waiting time they developed perceptions about the criteria required to access treatment. They described having attempted to become more unwell or abandoning self-help efforts in order to access treatment more quickly.

- **Doubts about whether deserving of treatment:** Participants also reported having questioned whether they deserved to access or to continue in treatment, out of concerns about the needs of other patients on the waiting list, whom they worried might need treatment more than they did.

- **Risks to patient safety:** During this time, for many, their medical and psychological risk was not adequately monitored.
Key Recommendations

We make five recommendations for the Government and the NHS in England:

- The Department for Health and Social Care, NHS England and other arm’s length bodies, to prioritise the introduction of an Access and Waiting Time Standard for adult community eating disorder services, supported by sufficient funding and workforce planning. This would be a major step forward towards an NHS where all adults with an eating disorder can benefit from timely access to evidence-based treatment.

- NHS England, NHS Improvement and NHS Digital to ensure collection and publication of data concerning NHS adult community eating disorder services. This would assist service-users, campaigners and the voluntary sector in holding commissioners and providers to account.

- Sustainability and Transformation Partnerships (STPs)/Integrated Care Systems (ICSs) to include a specific focus on transforming adult community eating disorder services in their forthcoming five-year plans.

- Commissioners and providers to assess their services against the NICE Quality Standard, to help them monitor waiting times, access to evidence-based treatments, and coordination of care (including monitoring of risk).

- NHS adult community eating disorder services to review the way they manage their waiting lists and their communication with patients after referral and assessment to ensure communications and procedures are patient-centred.
Introduction

Adult community eating disorder services are a crucial part of the NHS mental health system. Eating disorders often begin in early adulthood. Long delays between eating disorders first developing and treatment being sought are common. Many of those who receive treatment as an adolescent still require treatment after they turn 18 and some will develop a long-term eating disorder requiring treatment across many years of life. Furthermore, some of those who receive effective treatment as a child or adolescent experience relapse in adulthood. Earlier this year the NHS National Medical Director acknowledged the existing evidence base supporting the importance of rapid direct access to adult eating disorders services (NHS, 2019a). The services designed to treat adults therefore deserve parity with children and young people’s services.

Beat conducted research in 2018/2019 to quantify key aspects of access, waiting times and staffing levels at adult community eating disorder services in England and to understand more about the impacts that long waiting times can have on patients. This report presents the findings of that research, along with recommendations for the Government and the NHS in England.

Brief outlines of the methodology used are included throughout the document, with more detail available in the Methodology section in Appendix 1. Also included among the Appendices are the stories of some people with lived experience, who received timely access to quality treatment from an adult community eating disorder service. Their experiences are a testament to the life-changing impact that rapid access to quality treatment can make.

What we know about current levels of access to treatment

Adults with eating disorders in England face a postcode lottery in terms of access to evidence-based treatment and support, although even the relatively well-resourced specialist services face significant limitations to their capacity. This typically means either long waiting lists or referral criteria based on severity, both of which can prevent early intervention (Royal College of Psychiatrists, 2019). Our Helpline staff often witness first-hand the disheartening impact of delayed treatment.

Many areas do not have a specialist community eating disorder service for adults (NHS Benchmarking Network, 2019). In these areas adults with eating disorders may be referred to a local Community Mental Health Team (CMHT) or other generic mental health service. CMHTs and other non-specialist mental health services are often not equipped to provide evidence-based treatment for people with eating disorders. Research with young people has found that starting treatment at a specialist community eating
disorder service, rather than a generic child and adolescent mental health service, is associated with lower likelihood of subsequent inpatient admission (House et al., 2012). NHS Digital data, supplied in answer to a parliamentary question requested by Beat, suggests that in 2017/2018, over a third of adults referred to a secondary care mental health service for whom an eating disorder was the primary reason for referral were not referred to a specialist eating disorder service (House of Commons, 2019).

When someone actively seeks help for an eating disorder, this is an important opportunity for the patient and the NHS. If they do not receive good quality care, some may be deterred from seeking treatment again in future (Gulliksen et al., 2015). Considering the high mortality rates (including suicide rates) of eating disorders, this creates serious risk (Arcelus et al., 2011).

In recent years a new model of early intervention for young adults with eating disorders has been developed called FREED (First Episode Rapid Early Intervention for Eating Disorders). FREED provides evidence-based treatment which is tailored to the specific needs of those in emerging adulthood. It operates as a dedicated care pathway within existing adult community eating disorder services and aims to provide treatment within 4 weeks of referral (FREED, 2019).

It has been very successful in reducing duration of untreated illness, however in some cases the team’s efforts to secure rapid access to treatment have been frustrated by complex gatekeeping arrangements being employed by some Clinical Commissioning Groups (CCGs). This can include referrals being reviewed by a panel of commissioners or requirements that referrals are first made to a non-specialist community mental health service (Brown et al., 2016).

FREED began within the adult eating disorder service at South London and Maudsley NHS Foundation Trust and has now expanded into eight other services. By 2020 it is hoped that FREED will be available to two thirds of the UK population (The Health Foundation, 2018). Current geographic variation in funding and staffing, may limit the ability of some of the new services which have adopted the FREED model to provide as comprehensive an offer as that currently operating at South London and Maudsley NHS Foundation Trust.

Some adult community eating disorder services only provide treatment for patients with anorexia nervosa who are below a certain Body Mass Index (BMI). Access to some services for people with bulimia can be based on frequency of bingeing and purging episodes. Many offer no treatment at all for people with binge eating disorder, despite its severity and high prevalence (Call, Walsh and Attia, 2013).

In 2016/2017, waiting times for adult community eating disorder services were among the longest of all community mental health services (NHS Benchmarking Network, 2019).
Staffing levels, as well as retention, wellbeing and training, are key factors in determining access to evidence-based treatment for adults with eating disorders.

Long delays in identification and access to treatment are common. This causes unnecessary distress to people with eating disorders and those who support them, and avoidable additional cost to the public purse (PwC, 2015). In our 2017 report ‘Delaying for years, denied for months’, Beat published two costed case study examples, comparing early intervention with a more common experience involving avoidable delays, including long waiting times, and leading to deterioration and the need for more intensive treatment. The estimated cost to the NHS of the latter case study was more than double the former (Beat, 2017a).

The Policy context

In recent years additional investment has been made into community eating disorder services for children and young people in England, to support the implementation of an ambitious national Access and Waiting Time Standard (NCCMH, 2015). This has enabled a significant increase in the number of children and young people with eating disorders accessing treatment, while also reducing waiting times (NHS England, 2019a). There is no mandatory national Access and Waiting Time Standard for adult community eating disorder services.

Overall investment by NHS Trusts in adult community mental health services has decreased significantly since 2012/2013 (NHS Benchmarking Network, 2019). The introduction and implementation of Access and Waiting Time Standards in select areas of community mental health during this period may have led to limited resources being focused on these higher profile areas, at the expense of other areas of mental health care, such as adult community eating disorder services (Kings Fund, 2018).

In 2017, the Parliamentary and Health Service Ombudsman (PHSO), the final arbiter of complaints against the NHS in England, published a report into the avoidable deaths of 19-year-old Averil Hart and two other unnamed individuals, titled: ‘Ignoring the alarms: How NHS eating disorder services are failing patients’ (PHSO, 2017). In this report, the Ombudsman referred to the current state of NHS provision for adults with an eating disorder as a ‘Cinderella service’, and highlighted significant variation in access to quality treatment, lack of coordination of care, and low levels of knowledge among non-specialist doctors. This report made a series of important recommendations for the Department of Health and Social Care, the NHS and the General Medical Council to prevent further tragedies.

Among the PHSO’s recommendations was that:
“The Department of Health [sic] and NHS England (NHSE) should review the existing quality and availability of adult eating disorder services to achieve parity with child and adolescent services.” (p.5)

In 2017, NHS England commissioned an audit of adult eating disorder services in England (DHSC, 2019a). The data from this audit has not been published. In 2018, NHS England commissioned the National Collaborating Centre for Mental Health (NCCMH) to create guidance for the NHS on best practice in adult eating disorder services, through liaison with an expert reference group (DHSC, 2019a). At time of writing this guidance has not yet been published.

NHS England and NHS Improvement’s Operational Planning and Contracting Guidance for 2019/2020 informs Clinical Commissioning Groups (CCGs) and providers that they should:

“Use additional 2019/20 baseline funding to stabilise and bolster core adult and older adult community mental health teams and services for people with the most complex needs, including people with diagnoses of personality disorder and eating disorders.” (NHS England and NHS Improvement, 2019a, p.6).

The long-term plan for the NHS in England includes an ambition to develop ‘integrated models of primary and community mental health care’ and to maintain and develop mental health services for people with complex needs. As part of this, the plan included a commitment to “test four-week waiting times for adult and older adult community mental health teams, with selected local areas” and to then “set clear standards for patients requiring access to community mental health treatment and roll them out across the NHS over the next decade.” (NHS, 2019b, p.69).

In March 2019, the interim report of ‘The Clinically-led Review of NHS Access Standards’ was published by the NHS National Medical Director (NHS, 2019a). This report recommended the testing of a four-week waiting times standard for adult community mental health teams, including for adults requiring eating disorders treatment in pilot areas during 2019/2020, with a plan for “full implementation” (p.8) of this and the other new standards “from April 2020” (p.21). Encouragingly, this report acknowledged that for adult eating disorder services there is “an existing evidence base for rapid direct access” (NHS, 2019a, p.12). However, the cautious nature of the wording in this report, and its ‘interim’ status, suggests that the testing may not necessarily lead to full implementation, at least in the near future.

An implementation framework for the NHS Long Term Plan was scheduled for publication in Spring 2019, although at time of writing this has not been published. Sustainability and Transformation Partnerships (STPs) and Integrated Care Systems (ICS) will be expected
to use this to inform the development of new five-year plans, due for publication in Autumn 2019 (DHSC, 2019b).

In May 2019 the Department of Health and Social Care stated, in written evidence to the Parliamentary Administration and Constitutional Affairs (PACAC) committee, that in 2019/2020 NHS England will:

“...start to fund a number of innovative models of services for adults with eating disorders across the country, to generate learning about how to achieve greater levels of parity with children and young people eating disorder services over the course of the Long Term Plan. These sites will be selected over coming months and will be given prime funding. Based on the learning from these sites, further investment in services for adults with eating disorders will be rolled out across the remaining years of the Long Term plan, supported by investment in workforce development.” (DHSC, 2019a, p.12).

Whilst additional investment in 2019/2020 would be welcome, the aim of achieving “greater levels” of parity with services for children and young people and the continued absence of a detailed timeline for future investment means that a considerable amount of uncertainty remains about the ambition and likely pace of these efforts.

In its report on progress against the recommendations made by the PHSO (2017), published on 18 June 2019, the Parliamentary Administration and Constitutional Affairs Committee (PACAC) called on the Department of Health and Social Care to take a leadership role. It called for the Government to set out a clear plan detailing the actions that will be taken in response to each of the Ombudsman’s recommendation, along with who is responsible, details of the funding that will be allocated and deadlines for completion. The PACAC committee concluded that there was a need for greater urgency in order to “reflect the fact that lives will continue to be lost under the status quo” (PACAC, 2019, para. 83).
Access, waiting times and staffing levels

In September 2018, Beat sent a Freedom of Information (FOI) request to NHS Trusts and other providers of adult community eating disorder services in England. There is no publicly available national directory of these services for us to refer to. We believe we received responses from 96% of providers, although two NHS Trusts only provided data for one of the two services they operate. More information can be found in the Methodology section (Appendix 1). The FOI questions are attached as Appendix 2.

Investigating the capacity of adult community eating disorder services and how this varies between areas is complex. Almost no relevant data is published by the NHS in England. We requested data on access and staffing levels as well as waiting times to provide as well-rounded a picture as possible, considering the cost of compliance limits within the FOI legislation (ICO, 2019).

We obtained two years’ worth of data. It should be noted that this is not sufficient to draw conclusions about trends.

Access

Our request asked providers to report the total number of adult patients accepted for treatment by their adult community eating disorder services on 31 March 2017 and 31 March 2018. We obtained the data for specific dates, to provide ‘snapshots’ of the size of caseloads. This approach was taken to aid comparison between areas. For more information see Appendices 1 and 2.

To account for differences between the population sizes of different catchment areas, these figures were combined with population data to calculate the caseload per 100,000 population for each provider. For the population of providers’ catchment areas this was based on 18+ year olds. The data obtained enabled this to be calculated for an estimated 83% of providers.

As shown in figure 1, the mean average caseload size was 33 patients per 100,000 population as at 31 March 2018. The median average was 26 per 100,000. **There was a sevenfold difference between the smallest and largest caseloads after accounting for differences in the population size of the catchment areas. Although levels of need and number of referrals will vary to some extent between areas, the extent of the variation shown in figure 1 is indicative of the postcode lottery in terms of access to treatment at**

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1 While we defined ‘caseload’ as “accepted referrals”, this differs from the definition often used by the NHS, which only counts patients who have attended at least two care contacts (face to face appointments).

2 In some other similar studies, the 18 – 64 or 16 – 64 year old population has been used as the denominator.

3 One provider which reported a caseload even smaller than AED44 was excluded from this analysis as its service was only commissioned to provide intensive treatment to people with severe anorexia nervosa.
adult community eating disorder services. This provides important context for the waiting times statistics reported in the next section.

A small number of the adult community eating disorder services provide day patient and/or home-based treatment. This will contribute towards the variation in the size of caseloads between providers shown in figure 1.

Figure 1.

Figure 2 shows the distribution of average (mean) caseloads when the providers in figure 1 are grouped by NHS England/NHS Improvement geographical region (NHS England, 2019b). The wide variation between the size of caseloads of individual providers is largely evened out when grouped by region, with the possible exception of North East and Yorkshire. However, it should be noted that there was a far greater proportion of missing data for this region.
Waiting Times

We requested data on the waiting times experienced by people referred to adult community eating disorder services for outpatient psychological intervention, broken down by the year their referrals were accepted (when they were ‘added to the caseload’) – 2016/2017 and 2017/2018.

For patients whose referral was accepted in 2016/2017, 37 providers provided data on waiting times, with 35 providers doing so for 2017/2018. We estimate that this equates to response rates of 79% and 74% respectively. However, two of these providers only provided waiting times data for one of their two services, and two of the providers who submitted waiting times data for both 2016/2017 and 2017/2018 were unable to provide median average waiting times. For more information see Appendices 1 and 2.
This data should be interpreted with caution, since there is no nationally agreed method and verification process for the measurement of waiting times at adult community eating disorder services in England.

As illustrated in figures 3 and 4, only 24% of patients whose referral to an adult community eating disorder service was accepted in 2016/2017 started treatment within four weeks from the date of referral. Only 26% of patients whose referral was accepted in 2017/2018 started treatment within four weeks, as shown in figures 5 and 6. In contrast, in 2017/2018, 75% of children and young people who were referred as an urgent case began treatment within one week, with 81% of all other (‘routine’) cases beginning treatment within four weeks from the date of referral (NHS England, 2019a). If aggregated, this amounts to 84% of children and young people beginning treatment within four weeks of referral.

As with access to treatment, there was significant variation between providers on waiting times. As shown in figures 3 and 5, the proportion of referrals beginning treatment within four weeks varied from 2% to 74% for 2016/2017 and between 3% and 89% in 2017/2018.

Figure 3.
Figure 4.

2016/2017 Waiting Times

Figure 5.

% waiting < 4 weeks in 2017/2018

Mean = 26%  
Median = 21%
Figure 4 shows that, 60% of patients whose referral was accepted in 2016/2017 started treatment within ten weeks from the date of referral. This mean average was 64% in 2017/2018 (figure 6). The proportion of referrals beginning treatment within ten weeks varied between providers from 14% to 99% for 2016/2017 and between 18% and 100% in 2017/2018.

A significant proportion of patients experienced very long waits. Of the 2016/2017 patients, 21% waited longer than 18 weeks, with 12% having to wait more than 24 weeks (see figure 4). For the 2017/2018 cohort, these figures were 17% and 8% respectively (see figure 6).

**Average waiting times**

Figures 7 and 8 also illustrate that patients in many areas experienced very long waiting times.

In 2016/2017, it is concerning to see that, at four providers, the mean waiting time was over 4.5 months, with one provider having a mean waiting time of six months. The mean average waiting time for patients whose referral was accepted in 2016/2017 was 11 weeks. This ranged between providers from three weeks to 26 weeks, representing a near ninefold difference. The median average was nine weeks, with a similarly wide range between providers.
In 2017/2018, the longest average waiting time was 5.5 months, with two other providers at over four months. The mean average waiting time for the patients whose referrals were accepted in 2017/2018 was nine weeks. The range between providers was from two to 24 weeks – a twelvefold difference. The median average was eight weeks, with a similarly wide range.
Figure 8.

A significant minority of providers experienced major changes in their waiting times between the two years. Of the 37 providers who reported data for 2016/2017, six experienced a change of 40% or greater between the two years. Among this group are AED25 and AED09. The mean waiting time for AED25 increased from ten to 17 weeks, whereas AED09 reduced their waiting time from 14 weeks to eight weeks.

Figure 9 illustrates the mean waiting times when the providers are grouped by NHS region (NHS England, 2019b). This shows that waiting times can vary widely between regions, with notably longer waiting times in London and the South East, although it is important to consider the accompanying variation in access to treatment, as shown in figures 1 and 2 and the variation in capacity of providers in terms of staffing levels as addressed in the next section. There are other factors which may lead to longer waiting times which we have been unable to collect data on in this research including duration of treatment.
Figure 9.

Reading across the data for both access to treatment and waiting times suggests that generally services with shorter waiting times are accessed by proportionately fewer patients, while on the other hand, services that provide treatment to a greater proportion of their catchment area have longer waiting times. In some cases, this is likely to be the result of the application of referral criteria that limit access.

AED31 reported a relatively low mean average waiting time of five weeks for 2017/2018, with a relatively high 46% of referrals beginning treatment within four weeks. However, it had the second lowest caseload per 100,000 population. While AED28 had the fourth largest caseload as a proportion of its local population (60 per 100,000 population), it had the sixth highest mean average waiting time for 2017/2018 (14 weeks), with only 18% of patients starting treatment within four weeks.

Some providers reported both relatively high caseloads and relatively low waiting times. To assess whether these providers were examples of best practice, a much greater depth of data would be needed, including (but not limited to) data on the duration of treatments offered and information on their approach towards patients who need extra support to develop motivation to engage in treatment.
**Staffing levels**

While several factors determine the capacity of adult community eating disorder services to meet the needs of their populations, the size of the workforce is of course extremely important. We included within the FOI a question about the size of the workforce on the final day of each of the last two tax years. As with the data requested on caseloads, this approach was taken to supply a snapshot to aid comparison between providers. The data was requested in the form of Working Time Equivalent (WTE) to make it comparable (as in: NHS Benchmarking, 2019). The population of providers’ catchment areas was based on people aged 18+. Usable data on staffing levels was obtained for approximately 70% of providers. For more information see Appendices 1 and 2.

**Figure 10** illustrates the range in staffing levels as a proportion of local population between providers. After accounting for population, staffing levels were similar among the majority of providers, with the exception of five that had distinctly more staff per 100,000 population than the average. The provider with the highest staffing levels had nine times as many staff as the provider with the lowest at 31 March 2018.

**Figure 10.**
Figure 11 shows staffing level (in WTE) when the providers are grouped by NHS England/NHS Improvement region (NHSE, 2019b). Staffing levels in London and the North East and Yorkshire regions were notably lower; however, data was only available for approximately half the providers in the latter region, and this was also the case for the Midlands.

![Staff (in WTE) per 100,000 population at 31 March 2018 for NHSE/I regions](image)

* Data available for only ~50% of providers

**Figure 11.**

The average (mean) staffing levels (in WTE) of providers on 31 March 2017 and 31 March 2018 were very similar. On 31 March 2017, this was 15.0 WTE, and on 31 March 2018 it was 14.8 WTE (the median averages were 12.3 WTE and 12.5 WTE respectively). However, a small number of providers did experience considerable changes as demonstrated in figure 12. A possible explanation for this could be that in some cases services are unable to secure cover for staff who go on maternity or long-term sick leave. This suggests a certain level of fragility, which may partly explain the variation between years in waiting times (see figures 7 and 8).
Proportionate to the number of patients (caseload), staffing levels varied significantly between providers as shown in figure 13. On both 31 March 2017 and 31 March 2018 there was a ninefold difference between the providers with the highest and lowest staffing levels. This suggests significant variation in the capacity of services.
On 31 March 2017, the mean WTE per 100 patients was 6.9, with a median of 6.4. On 31 March 2018, these averages were 6.4 and 5.7 respectively (see figure 13). These levels are low compared to other adult community mental health services. The NHS Benchmarking Network’s Community mental health stocktake for 2016/2017 reported that mother and baby services had a mean average of almost 8.0 WTE per 100 cases, and Early Intervention in Psychosis services had a mean average of over 9.0 WTE per 100 cases (NHS Benchmarking Network, 2019). Both these areas have received significant additional focus and funding under the Five Year Forward View for Mental Health strategy (Independent Mental Health Taskforce to the NHS in England, 2016). Low staffing levels in relation to the number of patients treated are concerning, as this is likely to indicate high staff workload. Insufficient staff leads to longer waiting times for patients and poor staff wellbeing, both of which can compromise treatment outcomes.

Figure 13.

On 31 March 2017, the mean WTE per 100 patients was 6.9, with a median of 6.4. On 31 March 2018, these averages were 6.4 and 5.7 respectively (see figure 13). These levels are low compared to other adult community mental health services. The NHS Benchmarking Network’s Community mental health stocktake for 2016/2017 reported that mother and baby services had a mean average of almost 8.0 WTE per 100 cases, and Early Intervention in Psychosis services had a mean average of over 9.0 WTE per 100 cases (NHS Benchmarking Network, 2019). Both these areas have received significant additional focus and funding under the Five Year Forward View for Mental Health strategy (Independent Mental Health Taskforce to the NHS in England, 2016). Low staffing levels in relation to the number of patients treated are concerning, as this is likely to indicate high staff workload. Insufficient staff leads to longer waiting times for patients and poor staff wellbeing, both of which can compromise treatment outcomes.
Impacts of long waiting times

Research has highlighted the value that people with eating disorders place on receiving specialist treatment and being able to access treatment quickly (Escobar-Koch et al., 2010; Mitrofan et al., 2019). However little qualitative research has been carried out to investigate what impacts these experiences may have.

To increase our understanding of what it is like to experience difficulties in accessing treatment from an adult community eating disorder service, we conducted eight in-depth interviews with people who have a) been referred to receive outpatient treatment at an adult community eating disorder service in England within the last seven years, and b) have had to wait more than four weeks from referral before they could start treatment. For participants who had experienced more than one referral fitting this criteria, the analysis was based on the most recent.

Participants completed an anonymous demographic questionnaire to enable us to present an overview of the group of people who took part. This information is presented in Table 1 below to help contextualise the findings. Information about the waiting times the participants experienced and discussed in the interviews is reported in Table 2.

For information on the design of the interviews and the method of analysis used please refer to Appendix 1. The interviews took place face-to-face in London or Warrington and on average took 48 minutes to complete. The duration of the interviews ranged from 37 to 61 minutes. Participants were asked about being referred to an adult community eating disorder service, including questions about accessing treatment and experience of treatment. A semi-structured approach was used and the ‘topic guide’, which was used as a framework for the interview, is included as Appendix 3.

Findings

The interview transcripts were subjected to thematic analysis following the framework of Braun and Clarke (2006). In response to the research question of ‘What are the impacts of long waiting times from referral to the start of outpatient treatment at an NHS adult community eating disorder services’, four main themes were identified following the coding of the interview transcripts (see thematic map in figure 14). These were:

- Declining health and quality of life
- Incentive to maintain or attempt to increase severity of illness
- Doubts about whether deserving of treatment
- Risks to patient safety

In the analysis that follows, each of the key themes are discussed in relation to the research question, through reference to quotes from participants that illustrate each theme. After each quote a pseudonym to distinguish the interviewees has been included.
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Table 1. Demographics of interviewees. AN: Anorexia Nervosa; BN: Bulimia Nervosa; EDNOS: Eating Disorder Not Otherwise Specified. ED: Eating Disorder. Please note: the order of rows in this table is not associated with the order in which participants are listed in Table 2 or quoted.
<table>
<thead>
<tr>
<th>Interviewee (Pseudonym)</th>
<th>Waiting time reported (from referral to start of treatment at an adult community eating disorder service) (approximate; in months)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Olivia</td>
<td>3</td>
</tr>
<tr>
<td>Henrietta</td>
<td>6</td>
</tr>
<tr>
<td>Naomi</td>
<td>4</td>
</tr>
<tr>
<td>Sally</td>
<td>3</td>
</tr>
<tr>
<td>Alice</td>
<td>7</td>
</tr>
<tr>
<td>Rose</td>
<td>2 (was still waiting at time of interview)</td>
</tr>
<tr>
<td>Isabel</td>
<td>3</td>
</tr>
<tr>
<td>Kim</td>
<td>10</td>
</tr>
</tbody>
</table>

Average waiting time = 4.75 months

*Table 2. Waiting times reported by Interview participants (relates to most recent referral for those who have had more than one).*

**What are the impacts of long waiting times from referral to the start of outpatient treatment at an NHS adult community eating disorder service?**

- Declining health and quality of life
- Incentive to maintain or attempt to increase severity of illness
- Doubts about whether deserving of treatment
- Risks to patient safety
  - Reliance on GPs and other non-specialist health professionals
  - Reliance on family/carers to prevent deterioration and obtain professional help

*Figure 14. Thematic map of interview themes and sub-themes*
Declining health and quality of life

Participants perceived the long waiting times they experienced as being responsible for extending their suffering, and many reported that their health and quality of life deteriorated significantly during this time.

Long waiting times can, in a variety of ways, be detrimental to health and quality of life. Initially, patients may feel disappointed if their expectations do not match up with the timescales services are operating to:

“Well, it was quite hard because they contacted you quite quickly. So obviously you see an email coming in and you’re like, ‘Oh great, when is it going to be?’ Then you see that date and it’s like…” (Olivia).

Participants reported feeling hopeless:

“…the initial six months was actually quite difficult, when you thought it was going to be six months. I thought, I can’t go on like this for six months, you know.” (Naomi)

“…I know three months generally is not a long time, but when you’re waiting for something that you’re hoping is going to save you, because at the moment your brain is trying to kill you, it is a very, very long time because you see like, you know, you get the email in January saying March/Easter time and you’re like, that’s forever that I’m stuck with myself. With my thoughts. With my brain and I just want this to go away now, because by that point I was wanting the treatment and then it’s not coming. It’s just like, I don’t want to live with this brain anymore.” (Olivia).

“So that’s why I then became suicidal, because I just could not see how things were going to change if I didn’t get treatment that I could afford.” (Alice).

Four participants described feeling like they were living “in limbo.”

Long waiting times can prolong or exacerbate fears that treatment may never be offered:

“I was very concerned that when it came to the assessment that I would then be rejected and didn’t really know...it was just a big period of uncertainty.” (Henrietta).

Some participants experienced feelings of rejection and anger:

“...by the time you’ve waited you just feel a bit abandoned and forgotten.” (Olivia).

“And when I got the 11 months one, it just felt like a joke. I just couldn’t believe that it was an 11-month waiting list when it has been referred from a crisis team. So I just didn’t reply [to the letter], because I think I was just really angry about it.” (Alice).

Typically during this time the eating disorder became more severe:
“...more and more things start to creep in and like, I was very rigid about a certain number of calories but then when I didn’t see my weight going down as frequently that became less calories...” (Kim)

“...I continued to not do well when I was waiting and then people started to notice, because it wasn’t like massively, physically obvious by the time that I made the GP referral.” (Kim)

“...I didn’t have the energy or even like the confidence to think that I could do that [continue volunteering] ...” (Kim)

“...I had not been weighing myself before, but then I had started weighing myself.” (Henrietta)

“I was spending so much time indulging in eating disorder behaviours...” (Henrietta)

“...from my own life it meant that I couldn’t socialise as easily.” (Naomi)

One of these participants noted that: “...in terms of frequency and intensity of behaviours, they worsened during that period. But I can’t say that they wouldn’t have worsened anyway.” (Henrietta).

As a result of this deterioration, some felt that they ended up requiring a longer course of treatment than they would have done if their treatment had begun rapidly after referral.

“...If I’d been seen by somebody in like July say, I probably would have needed like half or less of what I’m currently getting now.” (Kim)

“...I got more and more rules that I’d never had, like, I’d not had since this period in 2012 and a lot of those crept in, like after I had been to the GP and after I’d had the assessment and everything but once they’re in it’s really hard to reverse them so even now that I’ve dealt with a lot of other stuff there’s still rules that I’m trying to get rid of, which is frustrating.” (Kim)

“I think I would have been in a much better place physically because if I’d have started therapy in April say when I had my initial assessment, you know, I was **** heavier then. That’s a lot to try and bring yourself back up from and my behaviours weren’t as ingrained. So I think from that side of things I would have been in a better place to start sooner for sure...” (Naomi).

In contrast one participant reported a different kind of account, which reflects that people may not always associate long waiting times with deterioration in their health:

“But to be honest I was, I was in such a terrible place at that time that...those eight weeks extra didn’t necessarily make anything better or worse.” (Isabel).
Another participant reflected on how the support provided by friends and colleagues during the waiting period meant that it had affected relationships “but not necessarily in a negative way.” (Naomi).

If health and quality of life deteriorates, this may increase the duration or intensity of treatment required. The testimony from participants about the impact on the length of treatment required adds to the evidence that long waiting times to access outpatient treatment are a false economy, causing additional cost to the NHS (Royal College of Psychiatrists, 2019; PWC, 2015).

Access to evidence-based medical monitoring and support during the waiting time is of crucial importance, considering the risk of continued deterioration in health during this time.

This deterioration may lead to greater social isolation, making it less likely that the condition of the person with the eating disorder is monitored and signs of medical risk are spotted and acted upon.

**Incentive to maintain or attempt to increase severity of illness**

Participants explained how long waiting times raised awareness about the limited capacity of the services:

“...so aware of the fact that there’s a long waiting list and it’s a really in-demand service...” (Henrietta).

“...obviously, there’s huge waiting lists and they never stop letting you know that.” (Rose).

Experiencing long waiting times also contributed to perceptions about criteria required to access treatment and to do so quickly. These perceptions then in many cases led to abandoning efforts to reduce eating disordered behaviours, or led to efforts to become more unwell, including attempting to lose more weight, based on the belief that this may enable quicker access to treatment.

There was a perception that accessing treatment – or at least doing so quickly – would depend on becoming more unwell:

“...being aware generally of the fact that it is almost like a lottery or a game, and you have to, or feeling like I had to play the system a little bit and or that there will be this expectation that I would have to be at a certain weight or losing weight at a certain pace in order to be worthy of treatment.” (Henrietta)

“I really did think that the only way I would be seen would be if I lost more weight.” (Alice)
“...the waiting time is interesting because it doesn’t motivate people to even make any tiny change because you’re just like, ‘Well, what’s the point? I’ll just be living for longer in this hell, when if I am sicker I’ll get help sooner and then I can drag myself out of it better, you know, sooner,’ which is totally, because the further you are into something the harder it is to get out of it. I know that. So it’s not really a sound reasoning, but you’re not of sound mind anyway.” (Naomi)

One participant described her belief, at the time at least, that psychological distress would not be treated with the importance it deserved by the service when prioritising need, and that instead their focus would be on any physical or behavioural signs:

“...I guess I felt like I needed the support but I needed to prove that I needed the support and the only way of doing that, I felt, was through the physical, because I knew I needed support for other stuff as well, like for the psychological part, but I felt like that wasn’t really enough, that I also had to like look ‘not well’ or have behaviours.” (Kim)

Other factors were also believed to be important requirements for prioritisation:

“...only the most engaged and, this might seem really funny, the most engaged and worthy and deserving people are allowed treatment.” (Henrietta)

These concerns about criteria and prioritisation were distressing for participants:

“...And then it felt like I was in limbo between being really poorly – because I was really poorly – but not being ill enough [to access treatment]. And the only way I could see [to access treatment] would be to get more ill, which I wasn’t willing to do...” (Alice)

“It made me – I felt quite a lot like I was in limbo in the sense that I didn’t really know what to do with myself – whether I should be trying to improve matters by myself, or whether if I did that when it came to the assessment they would say, ‘Well, you’re doing fine by yourself, we’ll reject you,’ or whether I should be trying to be as ill as possible so that when I arrived at the assessment they would see that there was a problem and take it seriously...and I didn’t really know what the best strategy to do was and it was very disruptive to having to kind of juggle those two impulses and not know which was the right one.” (Henrietta).

Desperation to access treatment led some participants to either abandon efforts to begin recovery or actively pursue further deterioration in their health by intensifying eating disordered behaviours.

“...I felt this implicit pressure that if I improved, if I got better, then I wouldn’t be offered help, so it kind of gave me permission to be as like messed up as possible. And I justified it to myself by saying, ‘Well, if you, if you show that you can stop
bingeing, then they won’t take you seriously; they’ll think it’s just a non-issue. So just go to town.’ And that perpetuated the cycle of like guilt, restriction, anxiety and everything else. But I was very conscious of the fact that I was worried about my, how they would interpret my weight, so I felt pressure to lose weight more than I had before.” (Henrietta)

“...it kind of also made me feel a bit like, although I don’t think I would have been able to do much on my own, it made me feel a bit reluctant to do things on my own. I didn’t want to make some progress and then go and they say, like, ‘Why did you waste our time coming on a waiting list because you’re sorted already?’ So yes, I was reluctant to stop losing weight or to gain any weight or to do anything because I kind of felt like I had to be deserving of my place on the waiting list...”  

(Kim)

“...my motivation was very poor because I was thinking what’s the point in me making things slightly better for myself right now, when actually that would mean that my waiting time will be six months. You know, if I make some tiny changes now that are going to be incredibly difficult for me to make off my own back with no support to try and influence my weight so that it didn’t carry on dropping as fast, why should I do that, because if I do that that means I’m going to have to carry on living in this limbo without any help for even longer. Whereas if I just go with it and think, you know, sod it. I’m going to let the anorexia take over, which is easier for me at the time because that’s all I want to do, you know, then that means that I get I get seen sooner.”  

(Naomi)

This illustrates how awareness of the demand upon and capacity of adult eating disorder services can help form beliefs about the criteria required to access treatment, or to be prioritised by these services. When people who are desperate for the treatment and support available from services come to believe that they are not ‘ill enough’ to access them, this can lead to those people becoming more unwell. This may occur either through abandoning self-help efforts or attempting to actively intensify eating disordered behaviours such as restriction, bingeing, or purging.

An increase in severity of the eating disorder, especially if the person’s medical or suicide risk is not being properly monitored, risks their safety, as well as being likely to lead to further distress for family and other carers. Further deterioration may mean, as referred to in the preceding section, that longer or more intensive treatment is subsequently required.

It is crucial that adult community eating disorder services communicate with people on their waiting lists regularly, and in doing so that they provide encouragement and support to help address harmful thinking patterns and eating disordered behaviours.
Doubts about whether deserving of treatment

Participants expressed that they had come to doubt whether they were deserving of accessing treatment and connected this to concerns about the needs of other patients on the waiting list.

As part of the nature of the illnesses, many people with eating disorders may not believe themselves to be ill or may not be fully aware of the severity of their condition, especially initially. Long waiting times can reinforce such doubts:

“So it was actually quite good that people were saying, ‘No, we think you need to be seen sooner’, because I was like, oh, well, that means that there is something wrong then, and I do need I do sort of deserve to get some help then. So that was sort of a good thing, I think.” (Naomi)

Many participants reported that the length of the waiting list and the related awareness about the level of demand for treatment and low capacity of services led them to think during this time about others on the waiting list and their needs. They reported worrying during this time that others may need treatment more than they did, and this resulting in feelings of guilt:

“At every stage, you’re told, there’s a huge waiting list. You’ll be waiting, and it makes you feel guilty because you think, oh my word. I’m holding a place on a waiting list here and somebody else might be sicker than me.” (Rose)

“…really guilty for feeling annoyed [about long waiting time] because thinking like, I’m not I’m not that unwell and there’s obviously people who are priority…” (Kim)

This led one participant to draw comparisons between her level of need at that time and as it had been at a previous referral:

“…I kept remembering back to like when I was admitted [previously] and I did physically need to be there…” (Kim)

This participant was asked to attend nurse liaison appointments during the wait and the service organised this in such a way that several waiting list patients sat together in a waiting room. The participant described making comparisons with these other people and reaching judgements about their level of need, which led her to feel guilty about occupying a place on the waiting list:

“…we were all in the waiting room together and some of the people there were, like, most of the people there were very unwell and that was kind of hard to see because I wouldn’t do the comparing in like, oh I wish I was as good at being ill as that person is or whatever, but I would think that from a health perspective they
need to be seen more than me... people that I would have thought even should be like inpatient or day patient or whatever.” (Kim)

“It kind of was hard seeing other people there just because it brought back a lot of feelings like not being deserving of the treatment in the first place and kind of feeling like maybe I shouldn’t have asked or requested to be put on this service. Maybe I shouldn’t have asked for this support because maybe I don’t really need the support and maybe it’s something else that I need...I just felt a bit too well to be seen straight away.” (Kim)

This belief that other people needed treatment more than they did may have had influence when they were encouraged by others to check on the status of the referral:

“...whenever my parents would say, you need to ring the nurse liaison again and find out why you’re not being seen to, I would think of those people and think, like, well, it’s because I’m not as bad as those people are.” (Kim)

This participant, despite feeling that they may benefit from additional treatment sessions, reported being unlikely to request this due to concern about delaying somebody else from being able to begin treatment:

“...even though there might be things I’d still like to work on I don’t really want to take more sessions off someone else who is on the waiting list.” (Kim)

One participant reported feeling guilty about seeking treatment as a result of the apparent stress caused to staff by the length of the waiting list:

“They put so much guilt on the patients because you think staff are unhappy about it... Because really, the patients are to blame for that waiting list. At least, that’s how you’re made to feel. So, yes, the staff are frustrated as well, and you can tell. So it sort of makes it really awkward because you want to say, sorry, sorry. Sorry for having to ring you to refer me. Sorry. [Laughter]. Then, you think, that’s silly. [Laughter].” (Rose).

Low self-esteem is common in people with eating disorders. This may have made these participants more vulnerable to questioning whether they deserved treatment, by concluding that others were likely to have a greater need for treatment. It is possible that the waiting time itself may contribute to the development of these thinking patterns through having a negative effect on self-esteem.

It is highly concerning to hear about patients experiencing waiting times so long that they were led to question whether they deserved to access treatment at the service. Some of the quotes above highlight how long waiting times can reduce motivation to chase up a referral or to request an extension to the planned number of therapy sessions. Further research into this issue is warranted. It is possible that this may have
other consequences, such as contributing towards patients removing themselves from the waiting list or not attending first appointments.

This issue should be an important consideration for eating disorder services when communicating with patients who are awaiting assessment and the start of treatment. It is important that services are open about what they are able to provide, so that expectations about the speed of access are managed. Waiting times must be carefully explained, to avoid inadvertently creating or reinforcing any doubts about whether they are deserving of treatment. Eating disorder services must consistently validate the needs of the person (and their family/carers). They should also ensure that procedures designed to monitor patients’ health during the waiting period do not provide opportunities for harmful comparisons such as that described by Kim on page 27. In this case, this opportunity for comparison led to the participant experiencing feelings of guilt derived from the possibility that they might start treatment ahead of someone else. For other people such situations could also have been triggering, by facilitating unhealthy comparisons based on body size and/or shape.

**Risks to patient safety**

Participants explained that long waiting times led to situations where they were reliant on GPs and other non-specialist health professionals for monitoring of their physical and psychological health, and often led to an onus on family/carers to attempt to prevent further deterioration and secure access to specialist treatment.

**Reliance on GPs and other non-specialist health professionals**

Monitoring of physical health and other risks can be completely dependent on GPs and other non-specialist health professionals when waiting lists are in operation.

“…in that time what they ask is that the GP monitors your health measures. You know, so weight and blood pressure and bloods and all the usual stuff, and he was to liaise with them if anything was changing and he felt that my safety was at risk or anything like that, because obviously they want to prevent you from being admitted to hospital. So I was going to see my GP every two weeks and then my weight was just in freefall basically. So he just got in touch with them. ‘I think she needs to be seen now.’ And then within a week I was seen.” (Naomi).

This participant was fortunate to have a GP who was prepared to monitor their physical health, was able to recognise the warning signs and to advocate for them to receive treatment urgently. Many patients unfortunately do not receive such care:
“I was meant to have monthly like check-ups at the doctor’s. They did it once and refused to do it again.” (Isabel)

Psychological risk may not be addressed if monitoring is focused on physical health:

“I was offered to see the nurse liaison if I wanted to and she was – she’s a very nice and good nurse liaison. But she wasn’t able to offer any psychological support.” (Kim)

Comorbidities and suicidal ideation are common in eating disorders (NICE, 2017). This means that there are a wide range of professionals who may meet someone with an eating disorder and be expected to monitor their condition, when access to specialist treatment is subject to a long waiting list (Ayton and Ibrahim, 2018). It also highlights the importance of coordination of care, to ensure that they do not fall between the gaps, as illustrated by the experience of the participant outlined below:

“So the crisis team told me that I would be assessed [by the adult community eating disorder service] within, like, a month of them referring me. That’s why they were happy to discharge me, because they were like, ‘Well, it’s going to be followed up.’ So, I was discharged. Then a couple of weeks later, I got the letter to say it was 11 months for an assessment.” (Alice)

Reliance of this kind on GPs and other non-specialists presents risks to patient safety, especially if, as is often the case, people become more unwell as they wait for treatment. If GPs and other non-specialists are tasked with monitoring medical risk, it is important that they are able to consult with their local eating disorder services to obtain advice, including on the interpretation of blood test results.

In 2017, Beat conducted a survey among people who had experience of an eating disorder about seeking help from a GP for the first time. Half of the respondents rated the quality of care provided by this GP as either ‘Poor’ or ‘Very poor’ (Beat, 2017b). Many doctors have insufficient knowledge about eating disorders (PHSO, 2017). Some doctors hold stigmatising attitudes towards people with eating disorders, including even some psychiatrists (Jones, Saeidi and Morgan, 2013). Eating disorders are typically overlooked in medical training (PHSO, 2017).

Reliance on family/carers to prevent deterioration and obtain professional help

Two participants described that during the waiting time family and carers had become increasingly involved, attempting to prevent further deterioration and to obtain the specialist treatment they needed. Effectively this meant that the participants’ safety had become partly dependent on their loved ones.
“...by that time my partner and some of my friends had tried to be involved with helping me to overcome certain things and try and make sure that things didn’t carry on on a downward slope...” (Naomi)

“I think he understood a lot of the nuances and was very worried and could see that things were getting worse and he would – he’d been in touch with my girlfriend and they have a dynamic, you know, between the two of them and kind of work together to try and help...” (Naomi)

“...So, at that point, when I was in hospital, my family went into overdrive and they started... contacting the services, and trying to get them to take me on.” (Alice).
Conclusions and recommendations

The data presented in this report illustrates that people with eating disorders face a postcode lottery in terms of access, waiting times and staffing levels at adult community eating disorder services in England. It is imperative that this variation is fully accounted for when areas are selected to test the introduction of a 4 week waiting time standard (NHS, 2019a).

Many adult community eating disorder services are operating with very low capacity. The numbers of adults accessing treatment varies widely between providers, with some reporting proportionally very small caseloads. Most adults endure long waiting times. Most services have very low staffing levels. Some providers are among the worst performing in more than one or all three of these domains. Generally, services with short waiting times have relatively small caseloads, whereas those that provide access to a greater proportion of people needing treatment have longer waiting times.

The in-depth interviews found that long waiting times can have severe impacts on the welfare and safety of patients. It is common for health and quality of life to deteriorate during the time spent waiting and this may lead to patients requiring longer and more intensive treatment.

Experiencing a long waiting time can reinforce or create perceptions about the criteria required by a service to access treatment. When people are desperate to access treatment this may lead to them abandoning pro-recovery behaviours or attempting to become more severely unwell. Some people may question whether they deserve to access or continue in treatment, due to concerns about the needs of other patients on the waiting list, who they worry might need treatment more than they do.

This can lead to feelings of guilt. When patients are waiting to start treatment, they are often left wholly reliant on GPs or other non-specialist doctors to properly monitor medical and psychological risk. Unfortunately in many cases patients are either inadequately monitored or not monitored at all, presenting clear risks to their safety.

Recommendations

- The Department of Health and Social Care, NHS England, Health Education England and other relevant arm’s length bodies should, following the testing of the four-week waiting time standard, introduce an Access and Waiting Time Standard for adult eating disorder services as soon as possible, supported by sufficient investment and workforce planning. This standard should set an expectation of progressive improvement over time towards the attainment of 95% of adults accessing NICE-concordant treatment within 1 week of referral in
urgent cases, and within 4 weeks in all other cases. This would be a major step forward towards an NHS where all adults with an eating disorder can benefit from timely access to evidence-based treatment.

- **NHS England, NHS Improvement and NHS Digital** should ensure the collection and publication of data concerning access, waiting times and staffing levels, among other areas, at adult community eating disorder services. This would significantly enhance accountability.

- **Sustainability and Transformation Partnerships (STPs)/Integrated Care Systems (ICSs)** should, in their five-year plans (due for publication in Autumn 2019), set out how they will deliver implementation of national ambitions on adult eating disorders for their populations. These plans should be co-produced with experts by experience and clinical experts.

- **Commissioners and providers** should assess their services against the NICE Quality Standard for Eating Disorders, to help them monitor waiting times, access to evidence-based treatments, and coordination of care (including monitoring of risk). Commissioners should incorporate the ‘Quality measures’ of the NICE Quality standard for Eating Disorders into their contracts with providers.

A new Access and Waiting Time Standard for adult eating disorder services may raise awareness and expectations, and therefore increase the number of adults with eating disorders who are identified and referred to adult community eating disorder services. This has been the experience with the introduction of the Access and Waiting Time Standard for children and young people (NHS England, 2019a). This, in combination with the reduction or removal of referral criteria/access thresholds, may mean a continuation or increase in the length of waiting lists in the short term. With this in mind, the following recommendation is especially important:

- **Adult community eating disorder services,** in light of the findings from the interviews conducted for this research, should re-evaluate their communication with patients after referral and assessment and the way they manage their waiting lists to ensure that these are patient-centred. This re-evaluation should be carried out through consultation with former patients, carers and comparison with other services. Adult community eating disorder services should communicate regularly with people who are on their waiting list, providing support and encouraging pro-recovery behaviours and providing validation of their illness and the fact that they deserve treatment.
Acknowledgements

Beat would like to thank the people who gave their time to take part in a face-to-face interview and share their experiences of seeking and accessing outpatient treatment. We would also like to thank the NHS staff who were involved in responding to our Freedom of Information request.

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We would like to thank Dr Karina Allan and Emily Rothwell for assistance with the development of the interview topic guide and the analysis of the transcripts. Thank you also to Hannah Goran for proofreading and editing, Becky Steed for assistance with the administration of the Freedom of Information requests, and Anna Myerscough for help with data analysis.
Appendix 1: Methodology

Access, waiting times and staffing levels

To investigate access, waiting times and staffing levels at adult community eating disorder services in England, we submitted a Freedom of Information (FOI) request to providers in September 2018. A copy of the FOI request submitted is included in this report as Appendix 2.

There is no publicly available national directory of adult community eating disorder services in England to refer to. We believe that we received responses from 96% of relevant providers of these services. We sent the FOI request to 44 NHS Trusts and two Community Interest Companies (CICs). Every NHS Trust contacted responded. Two Trusts that each provide two adult community eating disorder services only provided data in relation to one of their services. Even when commissioned by the NHS, Community Interest Companies, as far as we are aware, are not subject to the 2000 Freedom of Information Act; we are therefore grateful that one of the two we contacted did respond. After the request was submitted, we learned of another relevant CIC provider that we had not contacted. While data completion was very good, not all providers were able to answer every question.

Two NHS Trusts answered ‘No’ to question 1 (see Appendix 2), due to differing concepts of what constitutes a ‘community eating disorder service’. This necessitated the submission of a second FOI request, which yielded data related only to outpatient treatment.

While most adult community eating disorder services in England accept patients from 18 years and over without an upper age limit, there is some variation between services in terms of age range. Some of the providers included in our analysis operate services that do not provide treatment for people who are over 65 years old. One service included in our analysis did not provide treatment for 18-year-olds. Four services provide treatment for people aged 16 and over. These were excluded from the analyses unless they were able to exclude 16- and 17-year-olds from the data they provided. Figures 1, 10 and 13 include five providers that offered treatment to small amounts of people aged 17 and over. Data from providers of ‘all-age’ and 0- to 25-year-old services was included when they were able to disaggregate it for patients aged 18 and over. A small number of providers included in the analysis experienced changes to the age ranges or catchment areas covered by their services during the two years studied or were due to experience this on 01/04/2018.
One provider included in the analysis of staffing levels only reported data on permanent staff in answer to question 7.

We have chosen to report the data in anonymised form, since a more comprehensive dataset would be required before valid comparisons could be made between the merits of individual providers. In figures 2, 9 and 11 we present average caseload size, waiting times and staffing levels (respectively) when the providers are grouped in line with the new administrative regions of NHS England/NHS Improvement (NHS England, 2019b).

Most of the providers were either unable or refused to provide data in response to Question 4 (the size of the population within their catchment area registered with a GP) and so, when analysing the data supplied in response to questions 5 – 7, we applied the most up-to-date population data available (at mid-year 2017) (ONS, 2018a; ONS, 2018b), based on information provided in response to questions 2 and 3.

We present two years’ worth of data in this report. It should be noted that this is not sufficient to infer trends in access, waiting times or staffing levels.

For question 5 we defined caseload as “accepted referrals”. This differs from the definition often used by the NHS, which only counts patients who have attended at least two care contacts (face to face appointments). This means that we have included a cohort of patients who were awaiting their second appointment, who would not necessarily be counted as part of the caseload in some similar studies.

Question 5 asked providers to report the size of the caseload of adult patients on 31 March 2017 and 31 March 2018. We requested data for specific dates, to provide ‘snapshots’ of the size of caseloads. This approach was taken to aid comparison between providers. If data had been requested on the total or average numbers of patients treated during the year, then these comparisons would be compromised by differences between providers in duration of treatment and the proportion of patients receiving more than one course of treatment within the same year, which we do not have data available to account for. A limitation of this approach is possible variability in caseload size within years, which we are not able to account for.

For question 6, we requested waiting times data based on the length of time between referral and the date of the second appointment. This is a commonly used approach designed to minimise the risk of obtaining data concerning only the wait between referral and assessment.

One provider reported the number of patients who had waited less than four weeks in each year as “Less than 5”, and another provider did the same for the number who had waited over 24 weeks. This practice is in line with guidance intended to prevent the inadvertent disclosure of personal information (ONS, 2019). In each of these instances, a figure of ‘3’ was entered for the analysis.
Question 7 asked providers to report the size of the workforce (in WTE) on 31 March 2017 and 31 March 2018. As with caseloads, we requested this data for specific dates to provide snapshots of the size of the workforce to aid comparison between providers. Similarly, this approach has the limitation of being unable to account for potential variability in the size of the workforce within these two years.

The data was requested in the form of Working Time Equivalent (WTE) to make it comparable, as headcounts will not reflect differences between providers in the proportion of staff working part time (NHS Benchmarking, 2019). The adult community eating disorders workforce contains the largest proportion of part time staff among all community mental health services, with only 54% of the workforce working more than 0.8 WTE (NHS Benchmarking Network, 2019).

**Impacts of long waiting times**

To develop our understanding of the impacts of long waiting times following referral to adult community eating disorder services in England, we conducted eight in-depth semi-structured interviews in 2018.

The research question used in the design and analysis of these interviews was ‘What are the impacts of long waiting times from referral to the start of outpatient treatment at an NHS adult eating disorder service?’ If a participant had experienced more than one long waiting time from referral to the start of outpatient treatment at an adult community eating disorder service in the last seven years, then only the most recent experience was coded and included in the analyses.

The timeframe for relevant referrals was set as being within the last seven years because conveying relatively recent experiences is likely to be more influential to policymakers. Another consideration was that the ‘No health without mental health’ strategy was published by the then Department of Health approximately seven-and-a-half years prior to the interviews being conducted. This strategy committed to the ambition of parity within the NHS between mental and physical health (HM Government, 2011). It was felt that a timeframe based on the publication of the Five Year Forward View for Mental Health (Independent Mental Health Taskforce to the NHS in England, 2016) may prevent the recruitment of sufficient participants, since we intended to conduct the interviews in-person.

All interviews were audio-taped and transcribed verbatim. Interviews were transcribed by EQ Transcription, who had signed a non-disclosure agreement. The researcher then checked the transcripts against the audio for accuracy and made corrections when necessary. Each participant was sent a copy of the transcript from their interview and invited to add any annotations or request changes. For analysis of the interview
transcripts, we used Braun and Clarke’s (2006) framework to conduct a thematic analysis of the data.

Thematic analysis is a method that enables the identification, analysis and reporting of patterns of meaning (themes) across a qualitative dataset. It is a flexible method that can usefully summarise key features across large data sets and is well suited to informing policy development (Braun and Clarke, 2006).

A good thematic analysis will be clear about the theoretical framework applied and the assumptions this implies about the nature of the data being analysed. This is required in order to enable evaluation of research, comparison and synthesis with similar studies, and to assist other researchers wishing to conduct research on similar topics in future (Braun and Clarke, 2006).

A ‘theme’ refers to a topic or issue identified within the data that is important in relation to the research question. Researchers must make judgements on what counts as a theme, which goes beyond counting how often a topic is mentioned. A consistent and transparent approach must be used (Braun and Clarke, 2006).

A theoretical thematic analysis was conducted using an essentialist/realist approach to detect semantic themes (for definitions of these terms see Braun and Clarke, 2006). This approach was chosen to match the research question. A theoretical thematic analysis is driven by the researcher’s interest in the area and provides a more detailed description of a particular aspect of the data – in this case the answer to our research question – rather than attempting to provide a rich description of the data overall (including issues raised that were not related to the research question). An essentialist/realist epistemology was applied as it enables the analysis to “theorise motivations, experience and meaning in a straight-forward way” (Braun and Clarke, 2006, p.14), through the underlying assumption that language reflects and enables the articulation of experience and meaning. The researcher must also decide at what level themes will be identified. To fit with the nature of our research question, we have coded semantically. In a semantic approach, themes are identified from what participants have said, without attempting to look beyond this (Braun and Clarke, 2006).

After initial coding, as part of the process of generating themes from these coded extracts, we followed the guidance that data within themes should fit together and describe the same phenomenon, while there should be clear distinctions between different themes (Braun and Clarke, 2006).

Thematic analysis is not a linear process; however, it can be described as occurring across a series of broad phases. These are outlined in figure 15 overleaf (Braun and Clarke, 2006).
After drafting a provisional set of codes and themes, assistance was sought from two experienced coders (working separately). This resulted in the coding of several additional extracts from the transcripts and the revision of some of the existing coding. This feedback and the rereading it inspired resulted in the renaming of two of the three draft themes, and the creation of a new theme. The final themes are illustrated in figure 14.

One limitation of the interview element of this study was that, as shown in Table 1, we were not able to recruit any males, any Black, Asian or Minority Ethnic participants, or anyone with experience of binge eating disorder (BED). While it is reasonable to assume that some impacts of experiencing long waiting times will be universal, there may be some impacts that are unique or more common among certain population groups, including those who do not fit the stereotype of people affected by eating disorders. Further research is required into the impacts of delays in accessing treatment – including long waiting times between referral and the start of treatment – as experienced by males, Black, Asian or Minority Ethnic people and people who have experienced binge eating disorder, among others.
Appendix 2: Freedom of Information (FOI) request submitted to providers of Adult community eating disorder services

Hello,

I am writing to you under the Freedom of Information Act 2000 to request information regarding your Community eating disorders service for Adults (if you provide one). Please do not provide data which relates to the treatment of children and young people (Under 18s) or Inpatient treatment.

1. Do you provide a Community eating disorders service for Adults?
   If yes, please answer the questions below. If no, there are no further questions.

2. What is the local catchment area of your Adult community eating disorders service?

3. What are the minimum and maximum (if applicable) ages that this service will provide treatment for?

4. Please state the GP-registered population (age 18+ years old) for the area covered by your Adult community eating disorders service, as it was on the dates below:
   a. 31 March 2017
   b. 31 March 2018

5. Please complete the table below, regarding the caseload of your Adult community eating disorders service at the dates specified:

<table>
<thead>
<tr>
<th>Caseload (accepted referrals) at your Adult community eating disorders service</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dates</td>
</tr>
<tr>
<td>At: 31st March 2017</td>
</tr>
<tr>
<td>At: 31st March 2018</td>
</tr>
</tbody>
</table>

6. Please complete the table below, regarding referral to start of treatment waiting times for outpatient psychological intervention at your Adult community eating disorders service.
Please state the total workforce (in WTE) working at your Adult community eating disorders service as it was on the dates below:

*Please include staff in post and bank and agency staff which were working on those dates.*

- a. 31 March 2017
- b. 31 March 2018
Appendix 3: Interview topic guide

FOR CONTEXT:

Would you mind telling me a little bit about yourself?

Prompts: age, where you’re based, work/study/hobbies etc.

Do you have an eating disorder now? Would you say you are in recovery or recovered?

Cover following: Type/s of ED experienced

[Introduce and ask them to use timeline when answering the next few questions]

When do you think you first developed an eating disorder?

When did you first realise it was an eating disorder?

Cover: What kind of contacts did you have, if any, with health or education (or other) professionals around this time?

[If applicable, based on answers to above]

Did you receive any treatment before you became an adult?

REFERRAL TO TREATMENT AS AN ADULT:

Now I’d like to move on to discuss your experiences of being referred to eating disorder treatment as an adult...

Have you been referred to an adult eating disorder service on more than one occasion?

[Return to timeline and ask that they plot referral/s on it, including approximate date of referral, date of assessment (if applicable) and start of treatment (if applicable). If they have had more than one referral, ask them to mark any which were rejected by the service with a red dot and any which had a long waiting time (over four weeks from referral to start of treatment) with an orange dot].

REJECTED REFERRAL – if applicable

When was this referral made? [Refer to timeline to confirm]

Who made the referral? What led up to this referral?

Cover: Involvement of health and/or education or other professionals.
Was this referral made to a specialist ED service? [to verify suitability of example]

Did you have an assessment?
[If so...]

How long did you have to wait before you had the assessment?

Why didn’t you receive treatment?
Cover: Did the service provide a reason, such as BMI, B/P frequency etc.?

How did this make you feel?

What impact was the eating disorder having on your life around this time and in the months that followed?

WAITING TIMES – if applicable

When was this referral made? [Refer to timeline to confirm]

Who made the referral? What led up to this referral?
Cover: Involvement of health and/or education or other professionals.

Was this referral made to a specialist ED service? [to verify suitability of example]
Cover: Travel distance

How long did you have to wait before you had an assessment?

How long was it between assessment and the start of your treatment?

How did this period of waiting make you feel?

What impact was the eating disorder having on your life during this time?

When you started having therapy appointments, what was that like?

Do you think it would have been any different if you’d started therapy sooner?

What kind of treatment did you receive?

Which kinds of professionals were involved during your time in treatment?

What was your experience of treatment like overall?

Would you have liked anything to have been different?
CONCLUDING

How are you doing now?

What do you think needs to be done to ensure that all adults with an eating disorder can receive the help they need, in the right place and at the right time?

FREED – A model of Early intervention

A model of early intervention has been developed for young adults with eating disorders: FREED (First episode Rapid Early Intervention for Eating Disorders). This was developed for young people up to age 25 with an eating disorder of less than three years’ duration. It aims to provide specialist, evidence-based treatment within four weeks of referral and to tailor treatment to the specific needs of young people. It provides a dedicated early intervention care pathway within eating disorders services.

What do you think about this approach?

Can you see any pros and cons of FREED?

Would FREED have made a difference to your care and recovery?

END

How has it been to talk to me about this today?

Is there anything else you would like to say about the topics we have discussed today, or do you have any questions you would like to ask me?
Appendix 4: Positive practice examples/case studies

Without the outpatient care I received as a step down from inpatient and day patient four years ago, there is no way that I could be living the life I am today. Four years ago, although physically recovered thanks to intensive treatment, I still had a very disordered mindset. I hated my body and my weight, I could only eat a limited range of 'safe' foods at very rigid times in certain 'safe' environments, I had no social life, and although I had a job, I wasn’t really engaging with it. By the time I was discharged from outpatient and from services altogether last year I was free of the vast majority of my anorexic rules, I had accepted my body, and more importantly, I was living a full life – something that my eating disorder had prevented me from for so long and I wasn’t sure I could ever do again.

Stepping down from inpatient and/or day patient is tough. You go from existing in a bubble where people understand you, support you, and guide you in every way, to being catapulted back into the real world where (especially as an adult) often the people around you don’t understand, may not be able to support you, and certainly do not guide you in any way. This is when the real work starts and you have to take full responsibility for yourself, and that’s terrifying, exhausting and fraught with danger. Outpatient treatment is crucial to dealing successfully with those challenges and avoiding relapse.

For over a year, I had weekly appointments involving a weigh-in followed by therapy. The appointments then gradually reduced in frequency until I was standing completely on my own two feet. Outpatient treatment was, for me, the perfect safety net while I learned how to live a healthy life outside of hospital. During a bad week that appointment was the light at the end of the tunnel. During a good week, it was the pleasure of knowing that I’d be able to celebrate of all the little triumphs I couldn’t necessarily share with the people around me on a daily basis. (Telling your colleagues that you’re proud of yourself because you’ve just willingly eaten a banana for the first time in ten years can be met with raised eyebrows!)

As someone who lives on their own, far away from any family, it made a world of difference to know that I had support. Those appointments helped me learn how to manage the trials and tribulations of real life without my eating disorder as a crutch, and while inpatient and day patient were wholly necessary parts of my recovery, there’s no way that I could have learned those skills from within the confines of a hospital environment.

I was lucky in the treatment I received. It both saved my life and gave me back my life. Everyone should have access to this kind of treatment, wherever they live.

Stacey Bateman
Whenever I tell people I had anorexia they always ask the same thing: ‘When did it begin?’ I’ve heard people describe their ‘journey’ into eating disorders, mine was more of a diversion. I didn’t realise I was on a subtle detour that’d eventually take me away from myself. It’s hard to tell when a social drinker becomes an alcoholic; it can be the same with anorexia. I forgot the fun of Christmas, birthdays, holidays – I just felt the dread of excess. I couldn’t remember what it felt like to feel comfortable in my own skin. I was never confident or self-assured. I always felt like I was lacking something, not good enough and a loser.

My thoughts became poisoned with self-doubt and fear, yet I still didn’t realise I had a problem. Anorexia became my normality, always playing in the background. It took over every aspect of my life – counting calories, constantly anxious, massive mood swings, always cold, linking weight loss with success. Yet I believed it was the best of me; if you took it away there was nothing left. I was so churned up in it I couldn’t see what was going on.

So I was scared to access treatment. I never felt ‘anorexic enough’. The thought of getting rid of this one thing, this way of making sense of the world, of coping of numbing life, that was terrifying to get rid of.

It wasn’t the anorexia that I went to the GP about; it was the depression. I was always mournful, depressing and down. I wanted to see other people but didn’t want to inflict myself on them. That made me lonely, on the outside of life looking in. I was waiting to be saved from my own life. I was forgotten on the shelf. I wanted a relationship so badly and was convinced I’d die sad and alone. I locked myself away and turned in on my own mind.

But the GP said that the depression might be a cause of the anorexia. At the time that seemed absurd. They were two different things. That was like saying my ankle was sprained because I’d had a cough last week.

In total I refused treatment for the anorexia four times. The GP kept on saying that I should be referred on, but I didn’t want that. I didn’t want to treat the anorexia. It was something I enjoyed, something I clung to. Like an abusive relationship, I couldn’t see that the anorexia was no good for me, that it was holding me back. I didn’t realise it was the cause of all my problems, not the solution.

In the end, someone from a ‘Talking therapies’ service got annoyed with me… and rightly so! I was annoying, I was stubborn. But the woman said, ‘You wouldn’t expect your laptop to work if you don’t charge it. The same is true of your brain.’ I’d never thought of it like that before, and although it was terrifying to get rid of the anorexia, to live in limbo with no mood, emotion or enjoyment was like a living purgatory.

They referred me to the eating disorder service. Six weeks later, treatment started. The treatment I got was incredible – my therapist was patient, kind and knowledgeable. It gave me a space to try and make sense of all of the subliminal knots I’d been tying myself into. As time went on and we talked more and more, I realised that the anorexia
wasn’t about weight, or calories, or exercise, or numbers. In fact, it was about numbing, running away, hiding and trying to cope.

Since treatment my life has completely changed. I got my dream job, moved flat and live with the love of my life! Yup, that’s as cheesy as hell, and it’s not all rainbows and unicorns, because life goes on. But, before treatment none of that would have been possible.

_Dave Chawner_
References


FREED (2019) What is FREED? Available at: https://freedfromed.co.uk/what-is-freed-for-patients-carers.


