London Assembly Health Committee – Eating Disorders in London - Survey Responses

This document summarises the responses to the London Assembly Health Committee's eating disorders survey, alongside its report, 'Eating Disorders in London'. The Committee would like to thank those who took the time to respond on such an important topic.

The survey was open from July to September 2023, and received 112 responses. Its aim was to hear from those with experience of eating disorders, those with experience of supporting someone with an eating disorder, and those who work in the sector. The survey was open to anyone who wanted to respond, rather than seeking to collect representative quantitative data. To reflect this, the survey design included a high number of open text box questions. Quotations from these responses have been used in the Committee's report.

Some quantitative questions were used to understand who responded to the survey and to make the questions most relevant to respondents. As the survey was not seeking to be representative, and due of the number of respondents, percentages are not used in the report and should be treated with caution. Each question includes a base, showing the number of respondents who saw the question based on the routing. All questions were optional and therefore the number of responses reflects this. Text responses are ordered alphabetically.

The Committee is grateful to staff at eating disorder charity Beat who advised on the phrasing of survey questions.

The Committee aims to publish all evidence it receives as part of its investigations, including all responses to surveys. In this instance, given the sensitive nature of the topic, some of the responses have been redacted where they contain details of a potentially distressing or triggering nature. These include references to suicide, self-harm, and specific figures relating to BMI or weight. The redactions have been done following the advice of eating disorder experts. A deliberately cautious approach has been taken in order to minimise any chance of harm, so the redactions are more extensive than may strictly be necessary. However, the vast majority of information received is being published and please note that some responses still contain details which readers may find distressing. Redactions have also been made to responses which could be used to identify respondents.

A small number of responses have not been published, due to being blank, irrelevant to the subject, or vexatious.

Views expressed in the survey represent the opinions of the respondents rather than those of the London Assembly.

Q: Which of the following best describes you:

Base: all respondents (n= 112)

I have personal experience of an eating disorder or disordered eating	75
I have supported someone with an eating disorder or disordered eating	33
I work with those experiencing eating disorders or disordered eating	16
Other	3

Q: If you or the person you are supporting have experienced an eating disorder or disordered eating at different times and would like to explain more, please use the box below:

Base: all respondents (n=112)

Anorexia
Anorexia (binge purge subtype) as well as other severe mental illness in my adolescence- spent a year attending outpatient mental health services daily
Anorexia and more recently restricted diet
Anorexia Nervosa Relapsed in 2016 - I was denied treatment from St Georges Mental Health Trust as I wasn't thin enough
Binge eating disorder [Redacted information]. Anorexia (multiple hospitalisations) Bulimia (for the longest duration- over a decade)
Binge eating disorder Bulimia
Binge eating mostly, some purging
Can't afford food
Daughter with anorexia.
Diagnosis switched between anorexia and bulimia and ednos several times because the focus was always on my weight. They would change the diagnosis when my weight went up or down and not when my thoughts or behaviours changed.
First presentation of Anorexia 1996 Relapse - 2019
I developed bulimia as a form of control and [Redacted information]. I'm unsure if I'm bulimic or anorexic because I don't necessarily binge and purge in cycles, but I throw up regularly after certain meals and usually at nighttime
I don't understand the question - it doesn't make sense!!
I experienced weight loss followed by a period of binge eating in my late teens then recovered then qualified as a psychologist and began practising as an eating disorder therapist and trainer in 1985
[Redacted information]. I was diagnosed with OSFED aged 16, anorexia aged 17 and anorexia B/P sub-type age 18. After weight restoring I experienced binge eating and have now lost weight, sub-clinical anorexia aged 23
I have been living with anorexia for almost ten years and only sought support this year
I have disordered eating due to ADHD and Stress and ODD
I have experienced anorexia after going through family trauma and wanting a something to control. I purged a few times and [Redacted information]. I lost some relationships and lost myself. I am in recovery now, fear, a meal plan, CBT and love has motivated me.
I have experienced different types of eating disorders for many years of my life on and off
I have experienced disordered eating for 35 years but was only diagnosed with anorexia 8 years ago.
I have experienced disordered eating since age 14 onwards, have been overweight in the past but underweight for around 20 years. Diagnosed with Anorexia binge/purge subtype in 2015
I have experienced ED since I was 6. I have cycled through restriction, binging and purging. I have asked for help many times at GP level but never received any. Recently found out a referral I was told was made 4 years ago and confirmed twice was in fact not made and my gp practice manager had tried to cover it up and lie to me. Even if this had been made when stated I would still be waiting for treatment. I've had real dental issues and had multiple medical staff be dismissive as I am not a bag of bones nor white. I am now 28 and have no hope I will be able to develop a health relationship with food owing to this neglect.
I have had an eating disorder probably due to traumatic experiences from my childhood and beyond and I need help

I have had some minimal periods of recovery and weight restoration during the many years I have had my ED but never for more than several months.
I have struggled an eating disorder (anorexia nervosa) since my teens. My experience of both accessing support and receiving support in the NHS over a period of nearly 9 years was okay at best and harmful at worst. There are huge stigmas (amongst professionals and the public) and resources are far too limited meaning support was rarely adequate or comprehensive. My health has declined recently and despite being more aware (and working in the NHS myself) I am finding it really hard to access the right support at the time of need.
In my own experience, my eating disorder continues to affect my life. For many, it may be a short term illness. However, questions to define the length of the illness is not helpful in those with severe illness, which continues to affect them throughout their adult life. My condition has improved, and is not currently life threatening but still has a presence in my functioning.
In times of stress (education, work, personal relationships)
It emerged from childhood really, and has always been there.
I've had an eating disorder anorexia and arfid for most of my life and I supported my friend who died in 2019 from anorexia
I've struggled from the age of 8 till 29 (which is my current age). I've had periods of times where I am a healthy weight but it's never been consistent I guess that's because I've been denied access to any form of support or treatment.
Mainly EDOS but a diagnosis and admission for AN in the early 2000s (not in London)
Most of it was untreated and undiagnosed then later on it was diagnosed
My daughter is in recovery and is no longer in immediate physical danger ([Redacted information]) but her disordered relationship with food and body dismorphia are still a daily challenge
My daughter Started with slight binge eating/ disordered eating in 6th form in 2019. This settled. She her A levels were cancelled in 2020 due to covid and she went to University but the covid isolation and experience triggered anorexia. She was formally diagnosed anorexia nervosa in December 2022
My daughter was discharged from services before making a full recovery.
My daughter was I. Hospital for one year. She was discharged one month ago. She was fed through NG tube for 6 months. And then supported with a stringent new an to get back to eating. She still struggles a lot and we have had very limited community support. One hour of camhs per week since discharge
My personal experience was 2015-2018 around the time I was in college to university. I work with young people and often eating disorders are something I support with.
Myself 1990- present with periods of recovery due to pregnancy or treatment. My daughter 2010 until her death in [Redacted information]
Only resident in London 2016 to 2019
since childhood
Suffered with Ed's on and off for a few years but recently got diagnosed beinf a student in london
They tend to change from restrictive to non restrictive on a monthly/ yearly basis
Was made worse throughout the lockdown, what was already brewing became my clutch
Working with eating disorder service users since 2020 (to present day)

Q: Which of the following types of support, if any, have you experienced about an eating disorder or disordered eating? Please select all that apply.

Base: respondents with personal experience of an eating disorder (n=75)

I have spoken to my GP	54
I have had an eating disorder assessment or diagnosis	49
I have received treatment	46
I have received support from a charity	15
I have received support from family or friends	50
Other	8
None of the above	6

Q: What type(s) of services, if any, do you have experience of in London? Please select all that apply.

Base: respondents with personal experience of an eating disorder (n=75)

Child and Adolescent Mental Health Services (CAMHS) in London	24
Adult eating disorder services in London	55
I experienced some services outside of London	29
I live in London but experienced services outside of London	0
Other (please specify)	19
None of the above	20

Q: What was your experience of speaking to your GP about an eating disorder or disordered eating in London?

Base: respondents with personal experience of an eating disorder who had spoken to their GP (n=54)

Absolutely terrible. My GP was unaware that anorexia can cause elevated LDL levels and told me that I was eating too many 'good fatty' foods (avocados, eggs, nuts etc) and should cut down on them. Months later clinicians at the eating disorder clinic and a different GP told me that raised ldl cholesterol is common in patients with anorexia and it stabilises once the body is no longer in starvation. But the damage was already done by the first GP - his advice caused me to restrict even further and has made recovery even harder. The same GP also made other unhelpful and triggering comments that someone with adequate knowledge of anorexia would not make. I am afraid to see GPs now because I fear they will do or say things that will make me even worse.
Advised of long waiting list
As it was my student Gp in london, I was nervous about going and as the appointment was initially meant to be about me fainting the eating disorder topic didn't come up until I heavily mentioned that it might be one of the things causing my fainting and after I mentioned it I was met with an option to try and eat more and it's when I said I think it might be harder and more serious than that, that I was referred to eating disorder specialists.
At first the GP surgery did not take it seriously via the e-consult form, only when my husband called and told them to read it properly did they help. They gave me a GP with experience who referred me straight away

Awful. I was turned away as a teenager when my Mum first took me to the GP. Despite having lost a considerable amount of weight, the GP told my Mum that I was okay and just to encourage me to 'eat a bit more'. My health continued to decline over the following months and following our next visit to the GP 9 months later I was taken straight to A&E for a week long admission. Over the years I have seen the GP for several physical health concerns related to my eating disorder - there has been a continued lack of compassion and understanding. I repeatedly have to do the research myself (eg into menstrual health difficulties). I also have to remind professionals that change is possible. Recently I was told by my GP that for someone of my age who has struggled as long as I have 'it's likely i won't ever recover'. My GP recently has failed to do medical monitoring despite me complaining of regular chest pains, dizziness and fatigue and despite being asked to by my dietician. [Redacted information]. Plus, BMI should NOT be a criteria for entering treatment. It simply perpetuated the message that I wasn't worthy of treatment and should loose more weight, [Redacted information].
GP brushed it off, said the numbers don't add up and that I have a healthy BMI now and accused me of not telling the truth. This was after so long of trying to bring the courage to reach out.
GP was supportive, but not empowered
GP's have been very supportive, but not very knowledgeable, I've often had to tell them exactly what I need rather than being able to rely on them for advice. It has been very difficult to obtain any continuity in who I have seen so I've had to repeatedly explain things and fight to get appointments, repeat prescriptions etc.
Horrible. They laughed it off.
I found it very scary and did not enjoy the process which involved weighing etc
I have a very experienced GP who is understanding and listens but is aware of the limitations of specialist support and that I would be unlikely to qualify due to not being underweight enough
I haven't experienced this in London but it's mostly been poor. Misunderstandings, acting like it's not really severe and then I get to treatment and they are telling me why I let it get so bad....yet the GP acted like it was nothing.
I saw about 3 different people at my GP and 2 were kind of invalidating as I wasn't very underweight yet so they weren't very concerned/didn't really do anything, but the last one I saw was really nice and made me feel seen and sent a referral to Ed services even though I didn't want him to send it and the time, and I think it might have saved my life.
In London - my GP had no real understanding of an eating disorder. They weighed me - talked me through a referral and that was it. I found it really triggering especially when I was then not given support
Initially, not good, as the GP I was with then didn't even know where to refer me to, and then said it was a waste of their time to weigh me. I subsequently changed GP practice.
It took three appointments Over 4 months m to get any referral. This was in 2019 and after submitting a DSAR and checking with service I found my GP practice never made referral and knowingly lied to me in writing twice stating I was on the list. If I had not known how to do this I would never have known. Nonetheless I would still be waiting for assessment even if made. I've mentioned my ED since I was around 13 to GPS/ nurses and all have been dismissive. In fact a male GP made a leering comment about how he had admired my lovely figure when I disclosed this [Redacted information]. I strongly feel my race (black) means I am overlooked and not fitting in narrow definitions of who has an ED. It is painful to be vulnerable and open up and be met with rejection/ apathy or be told to focus on exercise and diet (as my dentist did this year and many GP + nurses have in the past). When I have been in binge cycles and gained weight rapidly GPS ave said I should lose weight and ignored when I said that I'm struggling with binging as a result of sexual abuse and needing to feel undesirable. No support offered and repeated disclosures rarely noted in medical history.

When I've purged or restricted and [Redacted information]. I've been praised and nobody asked any questions even when I've said it's as a result of ED. Never had any health monitoring. I feel dehumanised. I am more able than some to navigate systems but am still failed so fear for even more marginalised
It was difficult to initially speak to them and admit what I was doing. They didn't seem too concerned as my weight then was classed at healthy. They only took me seriously when I was severely underweight and hospitalised.
It was good and my referral to camhs was accepted
It was tough to actually say the words outloud, but they were very supportive and helped me to access support/go on a waiting list very quickly
It was very supportive as I already had a diagnosis from childhood, and my GP was in Holborn where many students were registered and received mental health support
Lacked understanding
My GP did not recognise the severity of the condition. This was only identified when I was assessed at the Mausdley hospital and was at high risk of complications.
My GP had very poor knowledge on eating disorders, especially outside of severe anorexia or bulimia.
My GP was fairly understanding and helpful with my referral. However they did not give me weekly checkups as they were supposed to at one point during my treatment and were very unhelpful
My GP was originally quite dismissive. My anorexia began around 2 years ago. I was obese and after losing a few stones I had mentioned to loved ones that I think my relationship with food was unhealthy, but they were dismissive and congratulated the weightloss. In total, I have [Redacted information] and now that I am underweight people have taken the issue seriously. However, because my starting diet weight was high, my anorexic body is only just under the bmi measure of 'underweight'. When I went to the GP because my bmi was healthy, they did not take me seriously until I had an emotional breakdown about how my mental health was ruining my day to day life. The GP didn't know what to do, made me an appointment with a different GP who I also cried to, it was only then I got a referral to the ED services.
My GP was very kind and supportive, but had little knowledge of eating disorders and how to treat or advise around this
my parent contacted the GP via telephone call. they referred me for an appointment at the hospital later that day. the only reason things moved so fast was due to my extremely low weight. if it hadn't been for that, i assume i would have been dismissed or put on a waiting list.
My periods stopped and so the appointment was about that but it led to question about restricted eating. I was told to drink a glass of milk before bed every night
Nationwide, Poor. Since it's long term, they just act as if I know best. Also in London specifically I couldn't get GP appointment so ended up moving to see a gp
No awareness at all. Said it was good the amount of weight I lost. Had to wait longer until I was in a physical health unit to get referred for help.
Not acknowledged or taken seriously - no action taken.
Not very helpful or empathetic
Okay, in that he monitored my weight and referred me to eating disorder services
One brushed it off even though I had moved to London only two years after inpatient stay. I was relapsing and it was shrugged off. I was in hospital this year for a kidney infection and I asked the nurse not to read out my weight because of my history and she did and as I cried she told me "it's not bad". My current gp was really good when I said I was finding things difficult with accidental weight loss following infection saying that if things felt that they

were moving in that direction to let her know. I felt supported even though I was trying not to make it a big deal
Positive as they agreed to refer me to the eating disorder service
Reacted without judgement and wirh compassion and urgency, making a referral to specialists quickly
Recommend a blood test for vitamin deficiency
Referral to ED service and preliminary tests only.
They did not understand; denied I was unwell.
they didn't give it adequate concern as it was only short appointments so they just said I had to [Redacted information] to be healthy weight and recommended some calorie shakes and that was it - I then had to get weighed every so often but I received no support and they made little effort to poke into why I was so skinny - I had just cited that my anxiety made me unable to eat
They put me on a waiting list with no idea of how long an assessment would take. My mother rang the local GP and their response was I don't have an eating disorder because I "am eating". In actual fact I wasn't eating, this was a lie and I was hiding food. But the GP turned me away with no assessment-mental or physical.
They were quite dismissive of my eating disorder at the time as I didn't fit the stereotype of what a person with an eating disorder looks like. I went back time and time again to ask for help from my GP and they were dismissive every time I had to get sicker and sicker.
They wherent very helpful they said the would put another referal through hut id previously had 3 others and nothing happend
This was decades ago before people knew anything about eating disorders - and I asked my GP why I was having problems controlling my eating, he had no idea. Now I understand it was because I had a year or two of restraint
Under educated yet well intended. They told me I may have hypothyroidism this lends itself to weight gain which the ED team were very disappointed that he told me
Very good when I raised the issue but since being discharged my GP has not followed guidance from service. Not proactive at all. Nor has it been considered in my history for other issues
Very positive and supportive. My GP supported me for months after referring me to Eating Disorder services, while waiting for assessment.
When I finally managed to see my Gp she listened while I told her what was happening, she asked a few questions and agreed there was an issue and so referred me for help.
While my GP was supportive and listened, she had very little knowledge or understanding about eating disorders and often would recommend things that are not suitable for someone with an eating disorder, particularly around weight and exercise.

Q: What was your experience of receiving an eating disorder assessment or diagnosis in London?

Base: respondents with personal experience of an eating disorder who had an eating disorder assessment or diagnosis (n=49)

Before I was even diagnosed with an eating disorder, I went to the doctor with my mum as my blood pressure was very low. The doctor did the routine tests they do at hospitals so blood tests etc. She asked me about my eating patterns (she already suspected I had issues with food) but I lied and pretended everything was fine. The doctor wanted to see me again (she later said it was because she was concerned, probably knew I had lied) so some time later I had another appointment and I was diagnosed officially. She referred me to the CAMHS eating disorder service, MCCAED and it took about 2 months for me to have the first

assessment/meeting with the MCCAED team. The waiting during those two months was a really horrible and tough experience for me because on the one hand my mum understandably, wanted that I start recovery immediately (with her help of course) but at the same time this was impossible without professional help during those two months of waiting. So I really felt helpless and lost. From what I remember my mum was paying for online therapy sessions with a Polish therapist in the meantime before I received support from MCCAED.
Diagnosed before moving
Fast referral, assessment, diagnosis, treatments and intervention. All staff were very caring and supportive.
First time round they weren't inclusive of my whole history, next time round they were more thorough and gave me an accurate diagnosis.
Had one but never got a diagnosis. Just an assessment. Then on a very long waiting list. The assessment didn't help because I wasn't seen as sick enough.
Had to go private
Hard and traumatic. Made to feel that I wasn't sick enough as my BMI wasn't low enough
I found it very very stressful as someone who is above normal weight having to sit alongside some very unwell adults, I felt like a time waster and a fraud not to mention all the self hatred and disgust. Once I got into the appt I was not in a great place and found it difficult to open up, it wasn't helped by it being a male dr
I have had several eating disorders assessments and have generally found them quite difficult, often the assessor will focus only on the eating disorder symptoms and not on other areas which may be having a huge impact on the eating disorder, for example other physical and mental health problems and the impact of neurodivergence.
I have had several eating disorders assessments, 2 in person and one online. I personally find any kind of assessment very stressful and anxiety provoking mainly because I always feel I don't deserve treatment, especially because weight and BMI seem to be the main factor for meeting referral criteria and being accepted for treatment. [Redacted information}.
I haven't received treatment in London
I reached out via IAPs, the assessment process can be really difficult, you have phone calls with people who ask really triggering questions and it can be extremely emotional, then you're left waiting for call backs and the correct referrals. I wasn't waiting a long time luckily but it was really hard in between the calls and assessments as you've opened the wounds but don't have a plan, which can worsen the anxiety
I received treatment from a local eating disorders clinic, that I only received access to because a family member is a clinical psychiatrist within the NHS.
I recieved a lot of support during my diagnosis and was able to access inpatient treatment promptly.
I was assessed very quickly but then felt a bit left in limbo as I was put on the waiting list for treatment which was over a year long
I was quite young so it was mostly communicated to my parents. I wish I had been explained more about the diagnosis eg EDNOS vs Anorexia
I was referred to the ED Unit in [Redacted information] - and wasn't thin enough to get treatment. This meant that I was left in limbo and put on anti depressants. I have been shocked at the wording around this - telling someone with AN you aren't thin enough causes a huge amount of shame.
I would have benefitted a few years ago when I relapsed badly but when I tried talking to GP he was really dismissive. I lost a lot of weight and my kidneys because badly infected again. (My kidneys are damaged from eating disorder).
Initially, after the first assessment, no further services were offered to me at that time as [Redacted information]. I was put on an Outpatient waiting list, but about 6 months later,

was offered a 16 week group course at the Maudsley hospital, with individual sessions between the group sessions. This was extremely beneficial for me, and even though I'm still recovering, I'm gradually getting better.
It was a slow process to re-access services as an adult in London. I had an existing diagnosis but was not prioritised for care for 2 months (waiting for assessment) as [Redacted information]
It was difficult and daunting, I was forced to go to the service and threatened that I would be sanctioned if I didn't. I felt my nurse was harsh at me when my weight dropped. But the service also saved my life so I am grateful.
It was on zoom with [Redacted information] and it was in the comfort of my own room and I felt very comfortable and able to open up as the lady I spoke to was lovely .
It's hard for me to recall this as my initial assessment / diagnosis was many years ago, but my memory of this is that it was stressful - I felt blamed by professionals for not coping better and for not adhering to treatment regimes. The focus was ALWAYS on weight, to the neglect of my emotional needs.
Long wait for initial assessment. Half an hour with ED Specialist Consultant before diagnosis made.
Mixed. I received the diagnosis of 'atypical anorexia' which then became anorexia. I found the initial diagnosis to be unhelpful - clearly I was on a rapid trajectory towards becoming underweight enough to be classed as simply anorexic, so why the differentiation? The assessment itself was okay, although I felt that one or the two people who assessed me could have shown more care and empathy.
My treatment centre were fantastic but I had to wait a long time
Ok
Once at the ED centre, the assessment and diagnosis was very quick and the people were great.
Once I was referred to CAEDS, i had an assessment within a few weeks. It was very well organised and I felt validated. I was diagnosed on the day with anorexia nervosa and recommended treatment.
Outside of london - not in london - poor.
Pretty quickly after my initial assessment
received my diagnosis in hospital through CAMHS. was a very quick process; pretty basic, surface-level questions.
Spent ~6 months in Simmons House - was transferred to the royal free children's eating disorder unit where I spent -6 months attending daily as an outpatient. I was the only outpatient on the ward and was not allowed to be admitted as an inpatient due to [Redacted information] and binging. This meant that I was really at risk at night - and my parents had to constantly monitor and even restrain me. Simmons house couldn't handle anorexia and the royal free couldn't handle [Redacted information] or binge/purging - eating disorder services should be able to handle complex mental illness, which frequently occur alongside eating disorders
The main issue was waiting 5 months for my "urgent" assessment once I'd been referred to the service in 2022 as taking the step of going to my GP and admitting to myself that I was sick sent me on a downward spiral. The assessment itself was fine, although I knew enough to know how to answer the questions. Being told there was an 18 month wait for any treatment, and it being made clear that even that wouldn't be sufficient to help me recover was soul destroying. The clear message was that I had to get dangerously ill before I would actually get any access to the level of support I needed.
The Maudsley were excellent, in particular the doctor who assessed me [Redacted information]

The person doing my assessment was really nice, but I had to wait really long for my assessment letter and diagnosis (around 2/3 months) as the person that did my assessment went on leave, and during that time I got a lot worse.
The wait list was significantly long. In the period of waiting for an assessment and then waiting for treatment my symptoms and weight drastically worsened. Waiting for an assessment and treatment made my eating disorder worse. I felt I needed to be good enough at my eating disorder to get help / be taken seriously.
The waiting list was extremely long even just to get a referral and assessment but the actual assessment itself was good
They attached numerous diagnoses onto me, not just the eating disorder, which made it even harder to get help.
They were judgemental and didn't really know what to do with me again as I didn't fit the stereotype I have a number of admissions to an acute hospital due to ED complications and symptoms and the ED service didn't know how to handle that
Vague and unhelpful - lack of knowledge or advice
Very long waiting time; service unhelpful due to a lot changing during that time; only group interventions offered
Very quick, letter within 2 weeks. Diagnosis easy treatment difficult
waited 2 years for the referral and initial assessment which was such a poor consultation it put me back into a very low place and relapsed very badly. After this, it was another 9 months wait and they rang for a repeat assessment as they said the original one was done too long ago. Again very poor consultation skills and questions asked and responses given. Group talking therapy service was offered which I declined due to severe social anxiety. A private clinic was recruited by Vincent Square to help with backlog of referrals and I was able to get an appointment through them instead.

Q: What was your experience of treatment for an eating disorder or disordered eating in London?

Base: respondents with personal experience of an eating disorder who have received treatment (n=46)

A long and confusing process. Mis communicated constantly over whether I needed weekly check ins whilst on the waitlist, I was accidentally given the wrong patients results (the conversation about having to go inpatient), never told what was happening
All about funding. Spoken so much about money and charging sessions throughout the support it felt like a transaction and always on a limit and felt that it was a tick box. Didn't feel individualised or taken into account my identity or feelings. Moved therapist and was reminded about the funding but she was more understand and just reminded the sessions. The mode of therapy and person working with me was out of my control. I was told what therapy I would get without any discussion with me. I was then told it has to be online even though I have issues with cameras because that therapist only worked from home. Wasn't taken into consideration my past or other difficulties. However when i verbalised a bit more loudly for my needs they were listened too by another therapist who helped me work through what would be best. I started seeing her face to face and linked my ED to PTSD and she adapted my care for that. Also believed I am autistic but cannot assess me for that so I'm on another wait list which is more anxiety provoking, if the ED team who suspect that would assess and diagnose I believe the care would have been fitted to me better.
Camhs dietician review was helpful Camhs CBT was also helpful but the short amount of sessions makes it difficult to achieve much

Currently in treatment via online video calls, very grateful to have these sessions although sporadic due to availability of therapist.
Diabolocial. I never reached a healthy weight. There was no treatment as such. No care in the community. I became a revolving door patient, readmitted many times.
Disjointed, traumatic, and bewildering. Without sharing every detail of my treatment, I was seen in both child and adult services and went through a range of different treatment intensities (inpatient, day patient, outpatient). My treatment always felt blaming - I was told off for failing to gain weight, for failing treatment, for failing to overcome the illness. I experienced numerous changes (e.g., changing therapists 3 times in 6 months, around a time when I was also admitted to inpatient treatment). I was transitioned from a general child mental health ward (with no specialist support for EDs) on my 18th birthday to an adult ED ward far away from home. This was terrifying. I was discharged from hospital [Redacted information] and let to go to university despite being so so unwell and without any ongoing support. I was also discharged from [Redacted information] due to funding running out in my mid 20s - yet I was not better. This would not happen in physical health. Recovery requires a holistic, compassionate and person centred approach to care. I'm sad to say that this was never achieved in the NHS. I am now accessing private therapy and dietetic support, as I could not wait the 12 months that my local service wait list required. This has shown me that care can be supportive and encouraging, firm and yet person centred.
Excellent once I was with them
Good. Cognitive Analytic Therapy for 24 sessions, plus follow ups. It has led me to the state I am stably in now, partial recovery. It wasn't really long enough.
Had to go private and travel
Have not had outside of GP input
I am still waiting to access treatment and the support whilst waiting is being cut. This has made it very difficult and I don't feel like professionals have communicated properly. I have advocated for myself to ask for check-in calls and chased up when this hasn't happened. If I hadn't done this I would have been alone
I didnt qualify for treatment
I had a full assessment and referred to hospital for a week. I then received therapy over zoom calls, but for the last 3 months before I was discharged, I had to contact with them- they never responded until I received my letter through the post.
I had a mixed experience with treatment. I received treatment from the Intensive treatment programme for young people at the Maudsley which was a very negative experience. I felt that the method of treatment was ineffective and just reinforced my fear of food, leading to further issues with disordered eating.
I had to wait a year for treatment without any support. Once I did have the treatment it was good and useful however It was given to me too late and therefore it was even harder to take in because I had become even more unwell throughout the time I was left unsupported.
I have found most of my treatment to be one size fits all rather than focusing on individual needs. Often the time limited nature of treatments will get you to a minimum healthy weight and then discharge you when although physically stable, mentally you are struggling more than you were before treatment. Sadly this just means rapid deterioration and going round in circles being re-referred and discharged. If the time could be invested to help people get to full recovery this would be a much better use of resources in the longer term and a lot less distressing for patients accessing services.
I have found treatment fragmented and mostly ineffective. It always feels too limited and guided by weight alone. There is always more focus on physical state than mental state. As soon as you have weight restored they want to discharge you, which is when your mental state is most fragile and the time you need more support not less. This often leads to relapse and so you keep going round in circles. I also feel they are too focused on just the eating

disorder and not the whole person, there are often other mental and physical health problems impacting on your eating disorder that just get ignored and no one wants to help.
I haven't been receiving treatment for very long at all, but all I know is that the staff I've seen so far have all been really nice and haven't said anything triggering to me, whereas the GP and crisis team have been quite triggering and made me want to get worse. ED services actually kind of make me want to get better.
I speak very highly of the care I recieved as an inpatient, day patient and outpatient. However, I feel the support is now not available for me. I am not physically compromised or with a risky BMI but do not feel recovered or free from the illness. As I am not underweight, I dont feel able to ask for help.
I was in a day service for 9 months and am now receiving outpatient treatment. The treatment was good at day service but very numbers focused
I was lucky to get treatment - but the treatment was not great. I only attended due to constant threat of sectioning in teir 4. Staff used threats of sectioning (which would lead to force feeding etc) to control behaviour. [Redacted information] and binge/purging were seen as bad behaviour rather than symptoms. I begged to be admitted to the ward o was on due to binging which occurred at home - which was frequently followed by [Redacted information]. I was told that binging and [Redacted information] meant I could not be treated as an inpatient. I had an incident [Redacted information] - following this I was not allowed on the ward for a week. Leaving me with no support when I was most at risk. When I felt most unsafe and asked for help I refused. I received minimal therapy (a few sessions) and no treatment for the co-occurring mental health conditions. My mother was frequently asked for ADHD and autism assessments- these were refused as eating was the priority (and only focus). [Redacted information]. I had to frequently undress to my underwear in front of a nurse to check to see if I had [Redacted information] - and frequently threatened with sectioning for [Redacted information]. The treatment I received was coercive and only focused on restriction (and only really to the extent of following my meal plan and gaining weight). I was isolated , and isolation from my peers was encouraged. It felt like behaviour management and not treatment. The staff were in no way able to handle neurodiversity. I have trauma as a result of the treatment but despite this I know I was lucky to receive it. However years later when i develops bulimia (over COVID) I hid this from everyone and was determined never to seek treatment.
I'm currently on the waiting list for treatment after my diagnosis as the wait time is a few months
I'm still in treatment currently. At present, I'm in an EDU in [Redacted information] for anorexia, and also received community ED NHS support prior to admission.
In patient care was a mixture of good and terrible both in the same establishment,two separate admissions, agency inexperienced staff,unsafe practices and unkind attitudes. Outpatients was lacklustre and focussed on physical health. Day Hospital very regimented and not therapeutic. Overall emphasis on weight restoration and discharge. Very little or no Psychological Therapy leading to relapses I feel as the root of ED is never addressed. Long waits for all provision of any service.
It was a mixed experience. Ultimately my life was saved by the eating disorder ward and outpatient support, but I became more unwell when my autism diagnosis (pre-existing before my admission) was not acknowledged on admission. I was on the ward for 6 months before my diagnosis was verified by a document sent from my CAMHS unit (I was never asked to provide evidence of this and did not have any document to provide on admission). I remained in the inpatient service for 15 months before receiving transitional outpatient care and then being discharged
It was difficult but saved my life. The service provided therapy, physical monitoring but I feel there was not enough focus on long term mental health recovery which is not sustainable to just focus on physical health

I've had to rounds of treatment as a day patient, with a period of outpatient therapy in between. The first day patient admission was to an NHS facility. It was okay, although as the only man on the unit I did find that I was sometimes excluded from activities because of my gender, and there wasn't a toilet for male patients, which made me feel welcome! It did sometimes feel like we were lowest priority for the staff, with the very limited therapeutic interventions rescheduled or cancelled because they had management meetings or training. Staff often had quite a paternalistic attitude towards patients and our views, although rarely punitive. It was only occasionally that I felt that my asserting my views and needs where taken as a being obstructive and held against me, it was more often that I was ignored or patronised.
Mostly bad. Initially I saw a dietician who was 'new' to working with people with eating disorders. She seemed to find it impossible to help me reduce my fear of food and see it as a positive thing. Instead she was hyper fixated on portion sizes and documenting my eating habits, which in itself led me to reduce further, become more controlled and fear food even more. There were so many comments she made that were really unhelpful and damaging towards someone with anorexia and showed her lack of experience in this area. Now I have nurse monitoring, and while the nurse is far more empathetic, experienced, encouraging and supportive, I find the weigh-ins to be very triggering and they feed the anorexia, making me restrict further to avoid the weight restoration. The waiting list for psychotherapy seems to be very long and I've been told that by the time I can see someone I will probably be too unwell to benefit from it at all.
My experience of treatment has been truly really positive. The support I have received from MCCAED was incredibly helpful and I will be forever grateful for it. Firstly, I had family therapy sessions with my eating disorder therapist. These included me and my mum. The therapist was the kindest person and was always very understanding and empathetic which made me feel safe and comfortable to discuss my experiences with an eating disorder. Throughout the family therapy I also met a dietitian twice who equipped me with fantastic resources to challenge my ed. There were also regular check ins in person to check my physical health etc. Crucially, throughout my treatment we did not just focus on my eating disorder but the underlying issues that caused it which again, was absolutely detrimental to my full recovery. I received another therapist to help me deal with my other mental illness and I was put on medication. With that in mind, having both therapies simultaneously was hugely helpful since my eating disorder and my other problems were closely intertwined with one another so it was important to address both of these issues.
None. Told to stay on medication but no further support.
Ok
Outside of london - varied. Depending on which institution
Poor as it wasn't adapted to include my neurodivergent traits - I'm autistic. Discharged after mandatory 20 sessions CBT which didn't result in much improvement
Private counselling focused on meal plans
Received help through the 'edp' eating disorder project in tower hamlets. They were amazing, I had 1-1 therapy and group therapy, generous amount of sessions 20+ and I honestly wouldn't be where I am today without it. Invaluable support that I know isn't on offer in every borough. Feel very lucky that I was living where I was when I realised and reached out for help.
Unfortunately treatment was almost impossible as I was expected to travel quite a distance and I have other health issues that made this very difficult and so I didn't carry on for long as no other provision could be made.
very complex. poor therapists, poor care/ treatment, poor therapy, poor access to support. overall, a bad experience.
Very good as explained in previous question. Helpful, supportive and very beneficial.

Very good. I was given as much agency as possible in treatment and decisions and the treatment plan revolved around me personally. I was seen regularly and further intervention provided when lower levels didn't suffice.
Very long waiting time; service unhelpful due to a lot changing during that time; only group interventions offered

Q: What barriers or challenges, if any, do you or did you experience to receiving support for an eating disorder or disordered eating in London?

Base: respondents with personal experience of an eating disorder (n=75)

Access to NHS services! Very high thresholds.
Age as I am in my 60's I felt that what little services there were are geared towards the younger patients with less duration of illness. The long-standing nature of my ED was both a barrier and a challenge. Services were reluctant to provide care/support as I was seen and described as chronic and enduring, hence not worth trying to help.
All the weight requirements and they say you havent been struggling long enough or your not sick enough
Although the diagnosis was quick, the waiting list for treatment is 2/3 months so I am yet to receive treatment and even then the treatment is cbt. I haven't been guided towards fixing my relationship with food or how to increase my calories with meal/snack ideas. It's a lot of relying on self help
As an adult was told was normal to be aware of weight etc and gp said my loss of periods was because I ran. Although under weight was dismissed as being a stressed working adult
As its disordered eating , not eating disorder it has never been mentioned , only when i was in serious crisis once and was going to be sectioned
BMI
BMI not low enough. Autism not considered during treatment
Can't access them because I'll never be sick enough. Even when I have been it's not sick enough to need support.
Competitive sports (dance, ice skating, gymnastics) My only role models have disordered eating
Cost of therapy and the wait on the NHS list
Cost/ waiting list of therapists
Didn't realise I had disordered eating for all of that time. Drastic weight changes didn't seem problematic to any medical person or family around me. Maybe something university's campus start considering more often considering how many people starve at university or develop poor eating habits.
distance from eating disorder clinic to where i live. had to travel from Walthamstow to Barking minimum twice a week for months on end.
Fear of asking for help, I present well on the surface but continue to struggle with eating disorders behind closed doors
Finding appropriate support outlets, outreach, support groups and general service access is very poor to none
I am a nurse so don't feel able to seek help
I had definitely raised alarm bells with drs before I reached out via IAPs and I was told I had a suspected eating disorder but no one gave me the help I needed. I feel I should have been referred before it got as bad as it did when I ended up referring myself, I feel as an overweight individual I have fallen through the gaps a lot of the time and was struggling for years before anyone truly heard me.
I have addressed many of these before. Barriers to referral - it would be great to be able to self refer as the GP makes referral SO hard, both in terms of their lack of compassion and in

terms of them focusing on weight over and above all other difficulties.   Lack of sufficient intensive support - it would be great have more resource for intensive treatments (in the community and day programs).   Challenges for those over aged 25. Lots of great work has gone into early intervention / prevention for teens to early 20s, but what about those who have been struggling for a long time or those who develop an eating disorder later in life? Challenges in the disjointedness of services - mental and physical healthcare doesn't seem to ever communicate. Yet, eating disorders affect an individuals mental and physical health. Better communication and understanding is needed from both sides.
I moved between notifying my gp and being seen by the specialists - it meant i changed borough and had to be referred. I had to do a lot of chasing to get seen
i realise i struggled a while ago (2011/2012 is when symptoms first developed). however, there was absolutely no messaging or education about eating disorders at the time. In schools or the community. So I had no skills or knowledge to understand what was happening to me, or that what I was going through was a problem. The only way I realised something was wrong was when I opened my A Level Psychology textbook and found the diagnostic criteria for anorexia nervosa, and thought... is this me? However, I did not feel equipped to reach out for help firstly because I did not know services existed, but mainly because I had big issues with help-seeking - I was too scared to tell anyone. Maybe if there was better education and awareness in schools, I may have known what to do.
I think for me the biggest barrier for early treatment was weight/BMI not being low enough to access treatment. Another problem was past trauma being ignored as well as difficulties getting Autism diagnosis/assessment within the NHS and instead being labelled with EUPD. I feel trying to treat the eating disorder without trying to understand what may be contributing to it is not only traumatising but is ineffective and a waste of time and resources. Eating disorders need longer term treatment to give people the opportunity to fully recover.
I think I was actually extremely lucky to receive support for my eating disorder because despite waiting 2 months to receive help, I do realise that some people had and have to wait much longer.   Nevertheless, I would definitely say that the waiting time was absolutely a challenge to receiving support as it just took so long and as I mentioned in another answer, those two months were incredibly challenging for me, navigating an eating disorder diagnosis but being in a sort of standstill point where I didn't know what to do, was angry, confused and really lost. So without doubt, I feel that the waiting times to receive support for an eating disorder continue to be a very prevalent barrier. I have experienced a form of it but as I have already mentioned, some people have to wait even longer which can certainly discourage them from even seeking support.
I tried therapy, without success
I was lucky that my referral got accepted. I know there are many young people who fall between the gaps because they are "not unwell enough"
I was passing out and fainting for a while, and it's only once I had multiple blood tests and appointments did I have the courage to mention it to my Gp, if I didn't mention it I don't think they would've asked me about my eating even though various blood tests showed I was deficient in nutrients and vitamins.
I was refused treatment because my weight wasn't low enough.
In 1965 there was no literature or internet or understanding of eating difficulties. Now it is different and I simply represent clients, that is another story altogether. Despite NICE Guidances GPs largely dont know how to assess or manage eating disorder patients and there are issues with funding so that most cases that are not deemed extreme have no access to help
Initially being told my BMI was not low enough to meet referral criteria to access services. Other diagnosis such as personality disorder being given as a way to direct you to alternative services when this isn't the right diagnosis and being denied proper assessment of

neurodiverse issues and forced to access private assessments for autism and ADHD when this should be standard given the high rates in eating disorders. This has meant a lack of recognition of individual needs when trying to access services and therefore experiencing further trauma in the process.
It is very difficult when you have more than one mental health condition. Also, as mentioned, there is a huge lack of support for those who are moving towards recovery but still finding things difficult and need help. Including those with a normal BMI. I also believe that at points in my treatment, I felt threatened by the removal of support if I wasnt improving. This is unhelpful as it demonstrates the true importance of treatment. If it was easy to adhere to treatment, you likely wouldnt need it!
I've heard negative things about camhs, and I'm reluctant to reach out because I'm very nearly 18 so there's not much point
I've spoke about it and been ignored
Just the initial assessment(as previously mentioned) of my BMI not being low enough for treatment.
Lack of communication and very quick to turn people away.
Lack of easy accessibility
lack of funding for NHS - appointments too short and unpersonal
Lack of services. Lack of signposting.
Location of treatment centers, very long waiting lists no option of male/female therapist.
Long waiting list Desperately hoped for CAMHS and it never happened
Long waiting lists
Long waiting time
My weight was not critically low enough for an admission initially, and I was left unsupported for a while due to this. I was deteriorating and asking for help but did not get adequate support until my condition was life threatening. I have autism and this has also been a barrier for me when there was not any training provided to staff to support autism (I also was denied any support or adjustments to my care, which I now understand is illegal). I was incorrectly labelled by the eating disorder unit as having a personality disorder, despite specialist services providing evidence of myself not meeting the diagnostic criteria, and this was harmful to my recovery.
No care in the community No understanding of my problems I never got to a healthy weight, which meant it was [Redacted information]. Recovery was never possible under this 'care'.
None
None - the hardest part was recognising the problem and taking the first step to seeing my GP which my family supported me with. When I required inpatient treatment there were no NHS beds so I was very quickly put into a private unit funded by the NHS. I didn't have to wait for long at all.
None at all, apart from the year long waiting list.
Not being underweight enough or purging often enough to meet referral criteria, poor experience of inpatient and outpatient ED services outside of London have made me weary and unlikely to access services in London now I live here
Not enough mental health support. No support for my partner. No long term support
Quality of care When further disordered eating developed years later I avoids seeking any help based on previous experience
Seeing any medical professionals at all. Getting registered took 9 months at a GP. Isolation. Cost
Service don't really have experience of people who have diabullima and who have anorexia as a larger bodies person they are quite dismissive and don't have enough resources to help people who really need it. I had to get really sick before anyone would take notice.
Shame and lack of knowledge on how to get support

The community ED NHS team I found to be inexperienced and unprepared to deal with anorexia, making comments and doing absolutely nothing when my weight was dropping to dangerous levels.
The very long waiting list and hardly any support in the meantime. I was told "now you've been assessed you're in recovery", but had no idea what that meant or how to go about it. I felt I had laid my soul bare and asked for help and was left cold, empty and alone. This was so tough and overwhelming and made me feel that maybe I wasn't "sick enough" to deserve support. Ultimately it made my ED behaviours a lot worse as a coping mechanism
The wait times are so extremely long and allowed me to get so much worse.
There is no NHS provision for adults are not in a life threat if situation, at least that was the message I was given when I was assessed in 2022. My experience previously is that there is certainly no provision that is set up to support male patients.
Trying to do it away from home but couldn't move as all the ED units are seperate. Many appointments all at different hospitals
Wait list Feeling it's a weight disorder and that being taken into consideration- they suddenly sped things up when I lost a lot of weight Probably being autistic (which they told me) but can't assess for that Funding
Wait times via NHS
waiting list has been so long, availability of therapist- none are free in the evenings and as an NHS worker with several oncall shifts there are alot of barriers to have treatment
Waiting lists of years - sat in those with no support deteriorating and awful communication Medical staff have narrow definition of what an ED is and who experiences them I am a survivor of child abuse w/ c-ptsd and no joined up care in fact told support for that would stop if I got ED care despite two being linked and need holistic joined up care Precarious housing - as a private renter with limited resources (which ED costs impact) services do not appreciate that if lists are years we will often have moved so get shunted to bottom of a new list and never get care. I have stayed in non decent and abusive homes as I can't face the fight again but this makes my ED much worse   Dentists have no clue - but we know teeth can be a huge giveaway for EDs + cost of treatment.
Weight not being low enough therefore 'non urgent' which allowed me to become more unwell requiring more intensive support Long waiting lists for therapy (over a year) Little understanding from the GP surgery Poor understanding in general
When I first contacted my GP I was given details for external services to self refer myself to, however due to the fact that I was unwell and not really wanting to seek treatment I did not do the self referrals. My family members then had to do it for me in order to receive help. It delayed the process and made it harder for me to receive help. I feel like the referrals should be done by the GP
When I've relapsed before it can be really hard to say you need support and your can't pull yourself out so calling the gp and having to talking to the receptionist feels so humiliating. When I did manage it, the gp dismissed it despite long history requiring inpatient.   My greatest challenge has been the introduction of calorie content to restaurants and cafes. This isn't just on menus but on the walls. It's impossible to not see and there have been so many times that I have been too overwhelmed and had to leave or to ask for menus without calories where people give you horrible looks or say they don't have them. This has caused me so much harm

Q: Who have you supported with an eating disorder or disordered eating?

Base: respondents who have supported someone with an eating disorder (n=33)

My child, while they were under 16	11
My child, over 16 or as an adult	19

Another family member	5
A friend	7
A colleague	0
Other	1
None of the above	0

Q: What has been your experience of supporting someone with an eating disorder or disordered eating to access treatment or services in London?

Base: respondents who have supported someone with an eating disorder (n=33)

As I said we are in Bristol. I have had to fight so hard to get the support my daughter needs she was 13 at admission to general hospital. In my view the services are not good enough, well funded enough and there are times when I believed that she was not goi g to make it. She still doesn't have a formal diagnosis.
Challenging to access CAMHS initially, once in initial support good, but team were too quick to move us out of services and provided poor advice, significantly delaying real recovery.
Daughter at Uni in London , previously just diagnosed before leaving home town. Had to register with new GP In London - told BMI was probably too high to be seen. Referred to Maudsley, had to wait 8 months for treatment. Because of COVID, only had video call sessions with Clin Psychologist (no doctor or dietitian input). Originally promised 30 sessions, cut down to 20 sessions because "there are other people on waiting list who need help". [Redacted information]. Told to go back to GP for IAPT referral. We ended up paying privately to see a different Clin Psychologist to help with [Redacted information]/ mental health / eating disorder behaviours. Had very little input as a parent of >18 year old
Difficult to access treatment due to long wait times and inflexible criteria around weight
GP didn't refer even though I said she has a problem with eating, after a telephone appointment and inperson appointment two weeks after. Tried to seek help privately but was struggling to find anyone suitable and then a psychiatrist wouldn't see her as she said her weight was too low and suggested I take her to A&E, this was after a GP had seen her and done nothing! The only reason my daughter got the treatment she needed as she was admitted into the childrens ward as soon as I took her to A&E. support should've been available sooner and the GP should've listened to my concerns as she ate well prior to this. I explained her change in behaviour at the sight of food too and nothing was done.
I have supported friends from school to receive treatment, and supported friends through accessing care after relapsing.
If they don't want to get help they won't get beyter
Immensely grateful! From the start of realising that our daughter had an eating disorder, the GP took her concerns seriously and immediately referred her to SLAM. It was around 6 weeks before she was eventually seen which seemed like a lifetime as our daughter's weight was dropping rapidly.
In 2009 when I first moved to London it was very easy to be referred. However the treatment from once a week, to daycare then inpatient didn't address the underlying reasons why she developed one. The focus was food and gaining weight which didn't support her into recovery. Now she has had the illness for over 20 years. Her brain needs rewiring and she can't access the treatment she needs to make a full recovery. As a mother I fear they will turn her away due to her bmi being too high and then fear she will loose weight and then be sent to palliative care. She's on a waiting list to have an assessment and I fear the assessment could potentially harm her if they refuse to offer her treatment. She will interpret this as being "too fat" and not ill enough.

Initial referral to CAMHS and then onto specialist ED team was pretty fast. While my daughter was able to be treated as an OP the care was very good, the problem came when IP care was needed as there was no adolescent ED ip units and she ended up being sent , to Berkshire and Kent for it - not got given age and vulnerability. Once in adult services her ED was often forgotten about as at times she hid it well and her other issues took over ([Redacted information], depression.PTSD).
It was very stressful and often felt hopeless. The person became an adult a few years into their eating disorder which made getting access to treatment quite challenging, as well as the requirements to meet certain thresholds for intensive treatment. The person was very resistant to treatment and it felt like the system wasn't equipped to deal with someone who wouldn't cooperate as often they would be discharged early due to these issues. As a family member there was no support available other than that which we found ourselves and very little attempt to include us in the treatment process.
My daughter is over 18 so we are very excluded from her care and information by all parties - GP/ university/ mental health team unless she agrees to information sharing. Since the eating disorder made her lose insight it was very difficult to get her proper care until she had spontaneous foot fractures and her university stopped her going. She had a telephone assessment by an ED team. [Redacted information]. She lied. They did not see her in person. To get her quicker help to stop her deteriorating further and try to get her back to university we paid for private treatment who arranged emergency inpatient admission since she was losing weight rapidly.
My daughter's eating disorder was largely ignored while she was in London. She did receive separate services for her personality disorder
My sister struggled with an eating disorder and we really felt at a loss of where to get assistance for it while also not upsetting her as eating was a very sensitive subject at the time. We just didn't know where to start
Once they were admitted to an ED unit, I felt relieved that they were receiving support. To get them to that point was really hard - lack of understanding in GP services and general hospital.
Our GP took our concerns seriously and my daughter was referred to CAMHS. She was first seen by CAMHS around six weeks later. This may not seem like a long time but it felt like we were descending into hell. Whilst my daughter's weight was within the low but 'normal' range for most of this waiting period, her mental state declined very sharply. She seemed terrified of all foods and barely left her room. The team we saw for the diagnosis at CAMHS were very kind and professional, and the nurse we saw each week had an instant rapport with my daughter. Sadly, this format of one chat a week over zoom did not work for us and after 9 months my daughter had actually lost weight, with no signs of it going up. The illness had made her very controlling and aggressive towards me which was a barrier to me being able to help her recover. It also brought me close to a breakdown. We were told by CAMHS that what was happening was domestic abuse. Occasionally I would ask if we could try something different, perhaps have input from a dietician or psychologist, or try a therapy, but it became clear that the system of one session a week with a nurse was all that we would ever get. We were encouraged to use friends and family and possibly even call the police if I felt in danger. CAMHS were very clear that we should not take our daughter to see a private therapist outside of CAMHS, but they never offered any therapy - e.g. CBT-E or DBT. At one point we were told that my daughter didn't weigh enough to be able to mentally cope with therapy, and I accept that that was probably true, but when she did gain weight we were told that she would not qualify for DBT therapy because she wasn't turning up at A&E all the time ([Redacted information]). Things came to a head around the 9 month mark as my daughter developed new, intense stomach pains. Our CAMHS nurse told us to go to our GP, explaining that CAMHS don't deal with physical issues. But the GP refused to take action and told us we have a team at CAMHS, and we should go to them. I tried putting her right, but she was

convinced that we had a whole team to support us. As the pains continued and eating got more difficult, we tried A&E, often waiting 5 or more hours to be seen. I think perhaps they aren't set up for this sort of issue, as whilst my daughter's weight was low, she didn't, in their eyes, warrant an emergency stay. A complication was that my daughter would present as a relatively serene, calm patient. To me, it felt like an emergency, as I could see the pain my daughter was in and I felt like CAMHS had lost any sense of urgency. I contacted PALS and soon after our nurse at CAMHS booked an appointment for us to see their specialist paediatrician, who was the only person at CAMHS who could deal with physical issues. We were relieved that we would finally be seeing a specialist but the appointment would take 2 weeks to come through. In the meantime, we decided to pay to see a private gastroenterologist and to get a private abdominal scan. The results were frightening - my daughter was showing early stages of SMA syndrome which is the result of a lack of fat around internal organs and can result in parts of the gut dying off. When we finally saw the paediatrician she explained how serious SMA syndrome was and offered three clear options to my daughter in terms of upping her energy intake. This paediatrician, at [Redacted information], was amazing and I wished we had had this meeting months ago. We came very close to my daughter being admitted to hospital against her will and being fed by an NG tube, but at the eleventh hour she agreed to increase her food intake. After a disturbing spike in her aggressive behaviour, things gradually began to get better.
Out of London
Part of the problem with ED patients are lack of motivation to accept help and part is with access to treatment. London is no different to other parts of the country
Poor - just poor
They are non binary (assigned male at birth) and are invisible to services. Despite clearly being too thin their experience when they've sought support has been dehumanising and involved misgendering inc in official docs despite communicating pronouns. This led to increased restriction and they now won't go near services. So frustrating as it took over a year of cajoling to get them to speak about this and so my efforts are wasted, their health continues to be compromised owing to a proud failure to offer care
Treatment just makes things worse
Very hard and, as a parent, very upsetting to not be able to access profesional help. I've taken my child to the GP when very young and we felt we were not listened to our concerns and dismissed with 'It's just a phase! They going to grow out of it'. There is still a lack of understanding what difficult eating in a child encompasses and to what extent their continued health is affected. From our experience, as people who love to cook from scratch and love a great variety of food, we feel that a lot more should be done to raise awareness of eating dissorders from a very young age, and monitoring by qualified proffesionals should start in primary schools. A lot more support is aslo required so that families can give the best chances for their loved ones to overcome these issues.
Very poor. The services are hopelessly under-resourced even though there are dedicated individuals trying their best in a service not fit for purpose. Original GP we consulted seemed to lack knowledge so there was delay in referring to CAMHS eating disorder service. My daughter then spent more than 3 months on a general paediatric ward at [Redacted information} waiting for a specialist inpatient bed. In that time her eating deteriorated further being surrounded by several other anorexics who weren't being adequately supervised by the agency RMNs who were very poor compared to the excellent St George's paediatric nurses (but who were overworked and didn't have specific mental health care experience or training). As an inpatient subsequently at Springfield, we found the eating disorder ward there unable to cope with [Redacted information] when regaining weight (so they were keen to discharge her as soon as she started [Redacted information]) and the adolescent psych ward at Springfield she was consequently admitted to 3 times in 2022, said they couldn't support her eating as they're 'not an eating disorder ward' and let her skip meals so when she

returned home her eating was already in sharp decline again. Despite many anorexics I've met [Redacted information] the system isn't set up to cope with both occurring simultaneously even though they frequently do. We consulted a range of private facilities, but were told our daughter was too ill and risky for them. Our Young person's CEDS unit at Springfield is covering a huge area - the whole of South West London so they are unable to offer home visits, this is hopeless when trying to treat an illness which patients are generally resistant to having treatment for. My daughter now refuses to go to [Redacted information] so I have to weigh her myself each week and report the weight, her psychologist sessions each week are done virtually and she only agrees to do those because she is now under a CTO section and it's a condition that she engages with weekly weigh ins and psychologist sessions. Basically, by default, as a single mother of 3 children I've been left to care for my acutely ill and risky child on my own at home with no real practical help including from social services.
Waiting lists and inconsistency
We accessed the treatment through a self referral as our doctors were very unhelpful. We were very fortunate that we were picked up quickly by the Maudsley, and were put under their care. It did happen during lockdown so much of treatment was online.
We could only access online materials
We live in LB Richmond. Waiting lists were so long we had to remortgage the house to pay for private treatment. Had we been in the neighbouring Borough she would have received NHS support much quicker.
We were very let down by our GP and CAMHS in London. My daughter's symptoms were triviliased by our GP when we first got help in 2020 by telephone and early 2021 in person. I was told she was "not sick enough" for CAMHS. She was v unwell and very low weight at this point. We struggled alone with some private help over Zoom for 18 months. We managed partial weight restoration but after my daughter's GCSEs in 2022 she deteriorated rapidly. We were told there were no specialist beds in London and she was on the "amber list" for inpatient. We were concerned she would collapse and die and managed to secure private inpatient care in Birmingham. We paid Â£21K per month for the first few months and then the NHS took over. Since her discharge in July 2023 CAMHS were a little more proactive but the outpatient service is limited and interferes a great deal with her school so we chose to seek private support outside school hours instead.
While resident in London my loved one had no treatment for an eating disorder although they did access general mental health services

Q: What are the barriers or challenges for those seeking support for an eating disorder or disordered eating in London?

Base: Respondents who work with those experiencing eating disorders or disordered eating (n = 16)

Barriers are: getting the right support at the right time, in a swift manner. Patients I support still feel judged, misunderstood. Still a lot of myths out their in regards to eating disorders. Lacking of understanding generally about all eating disorders. Challenges of the geographical vastness of London, different boroughs being larger than others. Lack of service support in some boroughs vs others. Can be a postcode lottery.
Denial- not receptive to the help and support yet Family's denial- colluding with the patient Fear of judgement from peers and family if they were to seek support
Front door mental health teams may not feel equipped to assess or offer first line interventions for the range of eating disorders. Maybe through a lack of training and understanding that an eating disorder can be a 'serious mental illness' (SMI) , maybe they have their own bias of who develops an ED. For adult ED there is no 'self- referral' available , it is dependent on GP or CMHT referral, which maybe impacted on by referrer bias

Lack of knowledge around avaliable services Lack of understanding around eating disorders Long referral wait times for NHS Fear of being triggered by receiving support
Lack of recognition/ impaired motivation to change/ lack of joined up thinking ie liaison with GP/ place of education/ healthcare professionals ignorant of when to call in the troops / long waiting lists for NHS treatment, improperly trained mental health services/ lack of funding available for appropriate training, lack of sufficient properly trained clinical or counselling psychologists for local services / no support available for overeating disorders of various types, since these are deemed simply lack of willpower rather than a mental health problem
Not enough
Not enough resources, so waiting lists are long, treatment is limited (time limited or groups etc) and many people are told they do not meet criteria for treatment. I now with in the private sector, and even there demand outstrips supply. There is also not brought understanding/awareness if EDs so people don't get early support, feel they are not ill enough, and get iller before getting treatment. Despite improvements, still issues with those turning 18 or moving between areas (especially with uni). They still frequently fall through the gaps. Also problems with people not fitting into boxes and thus falling between services (eg ED services won't take because of Pd and PD service won't take because of ED).
Patients and families not understanding that sometimes the best treatment is no treatment. Hospital admissions particularly those under section can worsen some forms of illness. Some patients need to be discharged from services to recover. I have seen this happen.
Postcode lottery No dietary advice Waiting lists too long and no support No support for wider issues
Restrictions on BMI stopping people from accessing appropriate support, therefore people need to get 'worse' before they can get help Postcode lottery of where services are available
services are often not able to offer people the type of support that they are able to engage in if there is more than one diagnosis
Support that is available is often time limited and not able to be individualised, and eating disorder services struggle to make adaptations in line with the Equality act. The funding provided to eating disorder services by the government is wholly inadequate.
The substantial burden of oral diseases and barriers to accessing adequate dental care are one the main challenges reported by people with eating disorders. This burden has a profound impact on their quality of life including experiencing pain and difficulties in eating, speaking, smiling and sleeping; having meal interruptions, lower self-esteem and self-confidence and reduced social interaction; and experiencing discrimination and stigma related to poor dental appearance. Currently there are many barriers to maintaining good oral health and seeking appropriate dental care for people with eating disorders.   For a summary on evidence on the burden of oral diseases and barriers to dental care amongst people with eating disorders, please see: - Choi J, Price J, Ryder S, Siskind D, Solmi M, Kisely S. 2021. Prevalence of dental disorders among people with mental illness: An umbrella review. Aust N Z J Psychiatry. 48674211042239 (see the section on eating disorders) - A blog written by an eating disorder expert by experience regarding the challenges she faced when she was detained and needed dental care https://outdoorprescription.wordpress.com/2022/10/05/dental-care-and-mental-health/ - Mind Your Smile Twitter Chat: #MindYourSmile   - [Redacted information]
Think race stops people from considering certain things such as ED. For my young people, it's similar. And from my experience, these backgrounds don't typically acknowledge it so it's something foreign for us to consider.
Waiting lists in the NHS. Often people present to private services and struggle to pay but are desperate for help.

Q: What stigma or discrimination, if any, do you think people suffering from eating disorders or disordered eating experience?
Base: all respondents (n= 112)

- it's seen as a 'choice' and that 'just eating' will fix it - you have to be emaciated to have an eating disorder - if you have an eating disorder you didn't eat anything All of these are assumed and they're not true.
affects relationships at work, family and friends
All Psychiatric illness comes with stigma,society doesn't understand the complexity and is often scared of the unknown. ED's are considered by many to be associated with white middle class females and being about fashion/vanity. They are not seen as the deadly destructive disease that they are in some cases.
All sorts. This is an unhelpful question!
Although i feel stereotyping has moved on a lot in more recent years regarding Eating Disorders i still feel there is a lot to do regarding men struggling with Eating Disorders and the difficulties they may face, for example a GP not picking the Eating Disorder up so quickly, so potentially a delay in referring and the knock on affects this poses. Difficulties in accessing services if you have a higher BMI, due to not meeting criteria. The diet/healthy eating culture is something which is everywhere, on social media and in lots of aspects of day to day life. The introduction of calories on menus, and the struggles this poses.
As an allied health professional in the nhs, not even I talk about my eating disorder unless necessary. There is so much judgement from colleagues as well as the general public. Medical appointments are normally dismissive and rude particularly when I'm at a healthy weight. Calorie contents on menus and trying to avoid this is the worst bit with an already stressful situation made worse with increased judgement.
Attention seeking
Being a male.in his 30s it's seen as strange.
Being larger and suffering with eating disorders can lead to professionals not taking you seriously
Being made to feel they are not ill enough
Being seen as weak. I wasn't allowed to sit on a certain seat at a flight because I was told it was the emergency exit and I was not acceptable or strong enough to open the door. They didn't know of my disorder.
Bias from family members, community and professionals . As a serious mental illness with the highest mortality of any MH disorder, it does not have equity for example with psychosis, and adult ED does not have parity with CAMHS ED. Equal funding for adult ARFRID is not available ? The London ICB MH Strategies do not explicitly mention Adult Eating Disorders ? some mention of CYP and perinatal, but not Eating Disorders. The ICB need to be ringfencing funds for this cohort of patients as per Community Mental Health Transformation plans & commitments An appreciation that these funds will not provide sufficient provision for the demand. Acute hospitals under treat and can be dismissive of the physical deterioration a patient may experience. The Acute Hospitals need to take responsibility for the training of A&E staff (MEED guidance) ED cannot just sit in the domain of mental health services, it crosses over for some of the most unwell patients. While the focus over the last few years has been 'early intervention ' there is also a need for provision for 'life long' sometimes referred to as severe and enduring 'SEED' and a need in some cases for palliative care for the most unwell. There is a lack yet of appropriate physical health care clinics not just for monitoring but also for sensitive & specialised advice for comorbid physical health problems such as Diabetes and Menopause. The largest access to psychological treatments is provided via IAPT /Talking Therapies , Eating Disorders is largely 'excluded' from this offer. As a result service users and there families are discriminated and struggle to access suitable services once it is an eating disorder

Binge eating is not as serious as other disordered eating behaviour
BMI Weight Gender - men often told they cant have an ED
BMI/ weight having to be low in order to be taken seriously
Bullying- limited social networks of support Discrimination in the workplace- being hired for employment Dating- finding romantic connections Unhelpful comments from friends and family due to ignorance
Can be a very hidden condition with constant reinforcements surrounding people with eating disorders - 'you look good' if there's any weight loss, etc.
Children can be cruel to each other, and fat shaming is very much an issue, especially in secondary schools.
Criteria for treatment seem very narrow and unfortunately the provision of separate services can lead to ignoring other conditions
Depends on presentation   I note that those who are not thin white female fail to even register. That said I do not think they experience stellar treatment as I know through loved ones awful care
eating disorders are still treated by both the public and professionals as weight disorders. people assume the lower a patients weight, the worse their eating disorder is.
ED symptoms eg [Redacted information] or looking skeletal are distasteful, so these disorders are by their nature create stigma. Shame stops many from disclosing their symptoms and also people who want help often don't disclose because they lack faith that they will be understood / assisted.
Embarrassment, shame that the person has somehow deliberately 'done this to themselves'. This misunderstanding may be through lack of understandable information around what EDs are (until exposed to someone living with an ED it's quite hard to understand this serious mental health condition).. Over the years, realise that at least some of that may come from the person with the ED keeping it in the dark and not sharing their difficulties until they have lived with it for some time. For some people with an ED lack of understanding by HCP's (perceived or real) can reinforce their feelings of lack of worth, 'not being ill enough', embarrassment and shame.
Everyone is really underweight , if your a child its just a phase , its for attention, your lying
First, people think it's a choice, and therefore that you are attention-seeking. They also downplay your illness and question the extent to which you were actually struggling. Also, people do not consider your illness seriously unless you are thin. I was told my a student nurse that 'You are slim, but your weight doesn't concern me'. That made me feel invalidated and reinforced my internal beliefs that I wasn't worthy of help.
Huge stigma - lack of understanding of EDs, fear and mistrust.
I dealt/deal with mine very privately for reasons I'm not even sure of myself. But I've seen more severe/extreme cases of eating disorders and therefore i struggled to identify issues I had for years.   Perhaps the idea that only women struggle with it. Makes it seem like a weakness. Something of our own fault because we could "just eat normally".
I feel that those in higher weight bodies get less support or treatment options than those who are underweight. Also as an older woman I feel eating disorders are ignored more than in a younger person. Often we have been suffering for decades with little or no support
I have BED. Many people don't consider it a real eating disorder due to fatphobia and assume I am greedy, lazy or both
I have experienced a severe and life threatening eating disorder however I have never been underweight. Because of this fact I have not been believed, it has taken longer to receive treatment, I have been dismissed by healthcare professionals, I have been refused GP checkupsâ€¦. Eating disorders are not weight disorders
I know my daughter was dismissed by psychiatrists and her experiences framed in attention seeking and attachment disorder, which also placed some of the blame upon me, which I felt

was inappropriate and unprofessional. It took 9 months for them to medicate her for her adhd, and this then has helped with her [Redacted information} and other impulses but I felt very alone as a solo parent during the treatment and when I expressed potential autism, it was dismissed over and over again
I still hear professionals saying that it is a choice as if we have control over what we are doing to ourselves rather than acknowledging it as a mental illness that can't just be switched off without extensive support to weight restore. I find professionals tend to talk to the eating disorder and don't always recognise that there is a whole person in the room alongside the eating disorder. The focus on weight rather than symptoms of the eating disorder also remains a huge problem. Everything in treatment is focussed around your weight
I think from my experience, it's assumed only teenagers and young people suffer from eating disorders. Some treatment only seems to be granted when BMI is dangerously low, at which point it is very difficult to prevent further relapses.
I think if someone is a healthy weight then eating disorders remain stigmatised and untreated, leaving those affected unsupported and suffering in silence
I think it really depends on what type of eating disorder, as I do feel when I lost weight I was actually more complimented for it even thought it was disordered. I think speaking out is hard as it's defo still a tabo subject
I think it's really difficult for people with eating disorders to live in a world where the focus is on people losing weight when the majority of people with eating disorders are trying to avoid that. It makes it really difficult to progress and get better when the messaging from society feeds into the disordered thinking. There is stigma around eating disorders in that people don't like to talk about it because they don't know what to say or do. Combined with the behaviours of the person with the disorder this can lead to social isolation and allow the disorder to continue because people don't know what is happening or are unable to call it out / help.
I think people assume that it is about vanity and 'silly teenage girls' succumbing to the influences of social media. There is an assumption of choice.
I think people have a misconception of what eating disorders are, and how all consuming they can be. It can impact anyone, gender, ethnicity, weight and age which I think is widely misunderstood. People often think it's about issues with food but I found through therapy for most it's so much deeper than this and the ED is often a symptom of the issue
I was also told I had borderline personality disorder - an erroneous diagnosis - this diagnosis was hugely stigmatised (I was labelled as the 'BPD' patient, not the ED patient, or both of them) - it meant I could not access care for my eating disorder. Nobody understands EDs - especially in the medical community. They have no education about EDs in the medical degree. This leads to huge stigma and discrimination. We are ghosted.
I'd say that there is still a lot of stigma around eating disorders in the world which unfortunately many eating disorder sufferers have to deal with on a daily basis. I feel like a lot of people think eating disorders are a choice and associate them with vanity, not realising that they are life threatening mental illnesses. When I was in the midst of my eating disorder I felt extremely ashamed of it and really struggled to even say the name of my eating disorder out loud, due to the stigma surrounding these illnesses. It is also very important to add that there circulate plenty of stereotypes in terms of how an eating disorder sufferer 'looks' or behaves. For example, anorexia is associated with being severely underweight and individuals who suffer from it being young white women. Whereas in reality, eating disorders don't have a look and they do not discriminate, affecting people of all races, genders, sexual orientations and ages. I feel that then when an eating disorder sufferer does not align with these stereotypes, their experiences can often be trivialised and not taken seriously which is an enormously hurtful thing and one no one should have to go through because everyone's experiences of eating disorders are valid and deserve help. Also, in regards to discrimination, I would say that not all eating disorders are given the same acknowledgement in society, in

the way that everyone knows about bulimia and anorexia but there is much less conversation about binge eating disorder, ARFID, orthorexia and others which is truly harmful because it leads to less understanding about them and thus less aid to those suffering from these eating disorders. Nevertheless, I do have to say that there has been improvement in regards to stigma and discrimination surrounding eating disorders. As more people and charities are talking about them, the stigma is gradually being reduced which is amazing to see. There is still a lot of work to be done but I think that continuing challenging that stigma and talking about these issues will lead to a better understanding of these mental disorders.
If you do not look thin enough people don't believe there is anything wrong. People also think eating disorders are limited to starvation or bulimia and are not aware of all the other ways it can impact you
I'm not aware of my daughter suffering either. However, as someone who is overweight it wasmuch harderfor me to ask for help as I don't meet stereotypical impression of an ED sufferer and while in the waiting room for assessment and treatment I overheard comments discriminating against my size.
In eating disorder services I faced stigma (and arguably discrimination) for binge/purging and [Redacted information]
It can be seen as "not a real problem" and some people think of it as an illness only experienced by middle class white women when that's not the case at all
It can be very difficult to get restaurants to treat requests for calorie count free menus seriously. There is effectively no NHS provision compared to other conditions. As a 40 year old man living with anorexia I've had to justify my existence both within the NHS and other support services, and dealt with services not set up to deal with males (e.g. being told to manually adjust standard exchange lists and meal plans to reflect my extra dietary needs). My employers and colleagues have generally been supportive though, and I've rarely faced stigma just a lack of understanding. One the biggest sources of stigma in my experience are the many well meaning campaigns to "tackle it" which just end reinforcing the message that EDs and mental health conditions are stigmatised. I've also found a lot of workplace wellbeing interventions (e.g. mental health first aid) exclude serious mental health conditions and imply that all I needed to do was go for a walk and do a bit of mindfulness and I'd stop having any problems.
It is still thought of as a 'silly girls illness'. It is an illness of choice. Looking better ie weight restored means they are better. It's because she is a dancer. As a parent I have caused it or make it worse. She just needs to eat something. She doesn't look sick. No one understands the implications on behaviour, self worth, the manipulation, the lies, the depression and anxiety that comes with the behaviour. No one has any idea how hard it is to get treatment. How much the sufferer does not want to be like this. Or what it is like to live with someone- especially your own child - in the middle of recovery
It's all about vanity etc
Its hard to understand and no support , and huge stigma
Its misunderstood (even among mental health professionals who are not used to EDs), considered vain, a choice, attention seeking, a female disease, not as serious as other illnesses.
It's not a choice. It's often stigmatised as being a lifestyle choice or something that somebody has to "choose" to live with. I believe recovery is possible for all, with the right care and support (no matter how intensive, expensive, and time-consuming).
Lack of understanding is very obviously intrinsic in today's society
Lack of understanding of eating disorders including how much they vary and present themselves in different people
lots of stigma around this not being a real issue and that people can control the problem people are often seen as attention seeking men find it harder to be heard about the experience they have with regards to ED or related matters

Many people have a lack of understanding of it and do not see it as a thing
Many people, like myself, would not mention it to anyone
May not access services, may experience shame/blame/guilt; for those who cannot pay for therapeutic support (which may in turn help with making a referral to an eating disorder clinic) these people will go under the radar with no early help in place. People from minoritised communities already face barriers to accessing early help services and may not access GP as first port of call.
Misconceptions, especially with them being seen as people just wanting to be thin, like an extreme diet, whereas in reality it is, for many people, an eating disorder is so often mostly unrelated to weight and eating issues are caused by other struggles.
Misinformation (eg that all EDs are anorexia) Stigma
Misunderstanding of varying degrees of disordered eating - bulimia hidden and shameful, anorexia feared, BED ridiculed. Weights are still focused upon to get help. My weight is "healthy" but my thoughts, feelings or behaviour are not
Misunderstanding of what causes it/ triggers
Need to be severely underweight to have anorexia - you can be malnourished and underweight at any weight
No ED if you're not thin Not a real problem Don't look ill You can just stop it
Not sure about "stigma." My daughter expressed shame at her diagnosis. I'm not sure where that came from. Her symptoms were certainly trivialised. I think she was seen as a young middle class girl who somehow had chosen to starve herself. Our GP essentially told her off and told her that she had to eat more.
Once you're over 30 generally not recognised. Still thought of as a young persons illness.
Other people just think they want to be thin. How little do they no!
People assuming your a druggie
People believe it's self inflicted and indulgent.
People seem to associate all EDs with body image or just not trying hard enough
People think everyone with an ED is deathly thin and doesn't eat at all, which is harmful to those who aren't
People think we're the "healthy one" and if we gain weight or choose to eat a bit more than we normally would then we get shamed and focused on by people who are doing diets etc. People don't realise how triggering food is for those with ED and that being around food and diet talk is so so tough. Some people even ignore this and carry on when you've told them how tough it is for you. It can make it difficult to want to get better because you are surrounded by it all the time
Please see above.
Sadly I still see people experiencing a huge amount of stigma and discrimination. Judgement and sometimes outwardly being criticized for their difficulties. Misconceptions remain, that this is totally about vanity, People can stop doing ed behaviours if they wanted too. Stigma remains that people with an eating disorder are untreatable. I see a lot of judgement and lack of compassion sadly for clinicians. Must recently being in a general hospital.
shame that it is their fault or done for attention, that men can't have EDs, that only thin white women can have EDs,
Shame, a sense of being categorised, not understood
So, we experience a ton of barriers and stigma. We often are told that we aren't really sick when when we are literally dying. Or we will be forced impatient when we aren't really that sick..not a lot of standards and using methods that don't really generalize to everyone. Folks in larger bodies, people of color and trans folks are really marginalized as are Deaf and Autistic people.
Stigma that people with EDs just want attention or just want to 'be skinny'. Stigma that people want to be unwell (I believe that for anyone with an ED who does say that, it is their

illness talking). Discrimination - being pushed away from the GP / physical health services. Being blamed for one's struggle.
Strangers assume I am on drugs because I am low weight, even more so because I experience severe anxiety. I am seen sometimes as a child rather than the menopausal woman I am.
Terrible stigma; child still has never shared condition with friends. Limited understanding by schools make them I'll-equipped to support recovery. Rampant fat-phobia in NHS, including eating disorders is increasing incidence of eating disorders and perpetuating illness by not encouraging adequate weight restoration.
That everyone who experiences it, are similar. Young, white females who are underweight and want to look thin.
That it is purely a weight/intake disorder and only perceiving underweight people as struggling. That bingeing and purging is less serious or more embarrassing. That it is silly/a little girl's disease
That it's a choice, like a diet we want to be on, rather than a lack of control over your own brain. People think girls do it to look like models but sometimes that's not the case. It's a mental disorder and it's all in your brain. And boys have it too.
That it's just about the food. Underlining cause and mental health issues. People don't understand the effect is has on a person or carers.
That somehow the individual is to blame for their illness and has the power to 'choose' to become well. That they are 'difficult' patients to engage with and manage. That if they don't engage well or recover with treatment that it is a problem with them as a person rather than a problem with the treatment or access to treatment. That people are well once they are weight restored and don't need ongoing support. That people are sicker when they are at a lower BMI and hence can access to help....physically that is in most cases true but you can be mentally most unwell at a higher BMI. [Redacted information]
That the only symptom of an eating disorder is weight control
That they are just white teenage girls wanting to be skinny, vain, selfish. It has never been about the weight it is the control and the stigma only worsens the feelings
That they are only a physical disorder. In actual fact the mental strain is worse then the physical. They seemed to reduce the support offered once I'd received a healthy weight-ignoring that this is a mental illness.
That they expect you to just have an eating disorder and get scared when you have other mental health issues. It's still regarded as a weight disorder.
That you have to be skinny to have An eating disorder. Not everyone follows the typical eating disorder stereotypes
That you have to be underweight to get treatment
That you have to be underweight to have anorexia. I only got help when I was severely underweight, when I was only a little underweight the GP and crisis team didn't care.
That you have to look a certain way. You need to be very very sick for your ED to be valid.
The assumption that it was teenage rite of passage
The condition seems to come from a sense of low self esteem which is only exacerbated when you are told nobody will help you.
The idea that people with EDs are fatphobic
The stigma has been huge. My daughter has lost friends and family are now estranged because of stigma.
There is a lot of surrounding guilt, stigma and shame
There shouldn't be a necessity to be under a certain weight to qualify for treatment as this is very triggering and harmful. People shouldn't be discharged from eating disorder services as soon as they reach 'a healthy weight' as this is also very triggering and tends to cause a relapse. Amongst some there's a tendency to see an eating disorder as a choice and a

stereotype that this happens to privileged 'white kids'. Teaching in schools on 'healthy eating' can be very unhelpful and calories on menus in restaurants is a disaster.
They suffer a great deal. I am aware that staff in hospitals are bewildered or rejecting of this group of patients
Told they aren't "ill enough" for treatment (BMI not low enough) , told others need sessions more than they do because they are more sick than them
Unavailability of services for all but the sickest and use of other diagnoses (particularly those of Personality Disorders) as diagnoses of exclusion
We are told that it isn't an issue because we're not underweight. This is incredibly harmful as it reinforces the idea that we need to lose more weight in order to be valid which can cause so much damage to our mental and physical health. People suffering from eating disorders need to be taken seriously from the very beginning regardless of weight.
You have to fit a stereotype (really low weight etc) to get any help. There is a lot of fatphobia within ED services.

Q: What initiatives do you think would help better support people in London experiencing eating disorders or disordered eating?
Base: all respondents (n= 112)

Incorporating oral health within the care delivered by eating disorders services, please contact [Redacted information] for further information - Cross-referral and trauma informed care pathway between dental services and eating disorders services.
A greater emphasis on continued support, such as drop in sessions. The door shouldnt be closed after discharge and only opened if you experience a full relapse. Help and support around building life after a long illness, such as help with getting a job.
Access to care for people at any BMI, longer periods of care especially after weight restoration, better community care enabling intense support out of the hospital environment enabling a better quality of life. Education of GPs/acute medics/ all medics and students on eating disorders so that they are better understood, recognised and to help dispel stigma and discriminatory actions amongst healthcare professionals
Access to early intervention More skilled ED therapists/psychologists Life span services (no cut off at 18) More flexibility if you move bouroughs Services that see all ED so people with mild ED still get quality treatment and don't feel they're not I'll enough Gp training Review of IP services More flexibility in NHS day care services
Access to early support and intervention is key. DO NOT base qualification on low BMI - it becomes a badge of honour. On a practical day to day level showing the calories on menus etc. just makes it harder to try to recover. It is counter productive and dangerous. Having to ask for a menu without the info adds to stigma and is something a sufferer would never do.
Access to support groups Zoom access to support groups Easy and free access to counselling services GP lead eating disorder programmes to offer ongoing support
Access to treatment regardless of weight.
Access to treatment. Wider range of treatment. Better services. Better understanding of eating disorders that aren't typical anorexia Removal of calories on menues Early intervention
Adverts in tube / public about support More awareness of what a disorder is (not just anorexia presenting in girls) - change the stereotype that it can affect everyone
An ambition for adult self- referral, however the current system is unlikely to cope ? CAMHS experienced a 40% increase when they moved to self referral? KOOTH (a MH digital platform) offer a CAMHS/CYP ED offer which did exist for Adults under 'QWELL' - however in south London this was decommissioned for adults, I think it was underused because it was not integrated into primary care or front door MH services. Rebranding to ensure ED is known as a SMI and with that comes the same resources as psychosis, including a national

dashboard or NHSE target for 2nd appointment (commencement of treatment) . Generic Community Mental health teams (as per the current CMH MH Transformation aims) need to accept/assess & treat adult ED and co work with local ED specialist teams. The 'Living Well' hubs & MH Champions across London, need to provide a specific focus for ED , using links into certain community's who have a hesitancy to seek help via mental health.
Anything that makes people realise it's not about food and that it's incredibly complex to recover from. Better resources for older adults - group sessions that aren't full of young teens
Assessment in person. Early Education for families and carers Better information sharing. Peer support groups for sufferers and families Education for schools, colleges , universities Early intervention Move away from BMI
Being able to talk to someone who will not be judgmental and will understand why you have an eating disorder, depending on what kind of disorder it is
Better access to caring for someone with an eating disorder. When I had CAHMS support and regular weekly appointments with our family pychologist the techniques and suggestions they gave me were cery useful.
Better access to services and treatment, shorter waiting times, better awareness and support of how to support someone with an eating disorder or disordered eating in the workplace
Better treatment and new research to support recovery without so much focus on food and weight (eating disorders are not about food and weight). Dr Laura Hill's treatment programme in America resonates with a potential good recovery model. Trauma informed care.
CAMHS to offer more than one hour a week of support, to be more flexible, tailoring their protocols according to the needs of the patient and carer - perhaps with more intense interventions early on, with home visits and input from dieticians. Have cast iron communications between GP surgeries and specialist services so that they each know what their roles and responsibilities are, providing eating disorders training to staff at GP surgeries.
Coordinated services and more, knowledgeable, accessible GPs
Creating awareness of what an Eating Disorder is, and sharing what those who live with one go through. Psycho education at schools around Eating Disorders Family support and education on how best to manage their loved ones with an Eating Disorder
Cross London solution / joined up NHS
Definiety education and awareness campaigns - on the tube and in schools. People need to be aware of the impact of their words. Also, whatever we can do to remove calories from menus will improve the lives and recovery of people with eating disorders. This was introduced based on poor/no good evidence that this strategy prevents obesity, but it does harm people with eating disorders.
Disordered eating has no services and is never discussed . you have to have a stereotypical "eating disorder"
Earlier access to support - reducing waiting lists and making referral processes quicker and easier. Longer term and more comprehensive support - multidisciplinary and intensive support has been shown to be most effective. Psychology is vital at all stages. Dietetic support is vital at all stages and must be regularly reviewed. OT support is vital. Psychiatry is vital. Group support is vital. Peer support is vital. Support until someone is truly better - don't discharge at a 'just about ok' place as relapse is far too likely and too common. Help someone strive for full recovery not a partial recovery still driven by an eating disorder. Better support for families, siblings, partners, and friends of those who are struggling. Better education for schools and colleges and universities - what to look out for, how to help, how to talk to someone they are concerned about, how to foster a positive culture in their environment. And one more... stop any adverts / brands / companies that promote diet culture. Weight does not equal worth.

Early help access to counselling provision in school, community, family hub, youth work settings - access to counselling with GP practices. Initiatives to fund counselling provision delivered by registered members of a professional counselling body such as BACP, or UKCP. Funding should be allocated to schools to provide access to counselling provision before any medical interventions are ever needed. Eating disorders are coping mechanisms for trauma and other under-lying psychological conditions or experiences. The recent Children's Commissioners report highlighted waiting times as an issue for both urgent and routine referrals. The report found that the number of children and young people starting treatment for eating disorders has more than doubled since 2016-17. Around 11,800 children and young people began treatment for eating disorders in 2022-23, up from 5,240 in 2016-17. However, in nearly half (45%) of urgent cases, patients were waiting more than 12 weeks to begin treatment, almost three times more than 16% in 2016-17. For routine cases, this drops to 34% in 2022-23 and 20% for 2016-17 respectively. Only 78% of urgent cases and 81% of non-urgent cases are being seen within the target time frame of 1 and 4 weeks respectively in the third quarter of 2022-23. Although this data is England wide it will be reflective in patient experience in London. BACP stress in all of our campaign work the importance of early access to counselling provision as vital, delivered by a trained and competent children and young people specialist counsellors in schools and community settings. Eating disorders and disorderly eating are the tip of the iceberg, the 'behaviours' presented after unprocessed psychological distress, including childhood trauma, amongst other early adverse childhood experiences. We need to provide more preventative and early help services including Government funded (which could be awarded by devolved health care funding) access to counselling. Areas such as Norfolk and Waveney NHS Trust have developed a referral pathway via their Single Point of Access to mental health support to include commissioned out counselling to trained CYP counsellors (who are members of professional bodies) who have signed up to offer up to ten counselling sessions administered via a host organisation, in this case the Norwich YMCA (bids went out to tender). This model, based on a model set up in Bradford during covid, is easily replicated across other ICS areas. Please contact BACP for further details - [Redacted information]. BACP have also called for funding for community hubs, where children and young people up to the age of 25 can access counselling in the community. These hubs follow the YIACS model (youth, information, advice and counselling services) as developed by Youth Access. Longer term funding for third sector counselling providers is also needed to provide further choice and extend the reach of just having a school-based counselling model. Lastly, eating disorder referrals should build in access to counselling as part of the treatment package to compliment the medical model approach to current treatment.
Early intervention. Put money into this and people get treatment straight away and this much much reduces the length of illness. To wait until someone is severe means way more cost and suffering in the long term.
Early intervention/prevention Low level CBT for people with warning signs Beat charity offer really good services so more promotion in school
Eating disorders are expensive, with some patients being revolving door and actively hostile to change. Having worked in this field for over 40 years I dont know what will help. Prevention is important and this has to start young with strategies to boost emotional intelligence and to foster help-seeking actions. There are few PHSE programmes that make any difference at all. NICE guidelines have, I believe, failed to improve GP competency managing what are esentially mental health issues (albeit with physiological complications). There is evidence that catching restricting behaviours very early with 6-8 weeks of inpatient help have favourable outcomes but by their nature anorexia sufferers are competitive and being locked up together has unwanted consequences in terms of teaching each other harmful behaviours and competing for weight loss. It is tempting to provide a knee jerk answer here; more money etc but ED patients are resource heavy and many have other

comorbid mental issues like [Redacted information] and substance abuse or even autism in the case of morbid obesity or anorexia. In an ideal world, all GP practices in London would have a nurse practitioner properly trained to assess and monitor younger people who are of concern. They would know not to wait until they are thin enough to be regarded as a medical emergency because if that happens it is already too late. But there are far far more people with eating disorders than people with anorexia. And 95% of sufferers have no hope of being supported or identified such as the vast hidden numbers who are not bulimic but who eat compulsively. A good initiative would be to have a register of people in the private sector who are properly trained and who can show evidence via examination of skills from evidence based treatments of the whole range of eating disorders. The British Psychological Society had a go at defining suitable competencies but few people match these criteria and there are many people claiming to treat eating disorders including qualified counsellors or nutritionists who have no clue. As with substance addictions, support is often limited to managing emergencies or turning to charities and there are clinics for those who can pay. But we have heard many stories of people who have had a poor experience of treatment in a private sector which is largely unregulated. I do not think that addressing stigma is helpful. We risk normalising disordered eating or even promoting it (this is called the iatrogenic effect of poor eating disorder awareness strategies such as describing eating disorder symptoms to vulnerable teenagers. I am not minimising the issues here. Eating disorders main and kill and cause vast collateral damage. On top of that the sufferers themselves actively in many cases interfere with their own therapy. Finally while there are some good people working in CAMHS and adult services, I have had reports of poor service; the problem often being inadequate training
Education and raising awareness as to how these issues impact on the patient and the extent of the health issues they bring with them. More training and even having a designated specialised health professional station or visiting schools to monitor and better support pupils, parents and shcool staff.
Education for all front line staff Health Screening for all ED understanding at all levels from schools, to GPs to perinatal services Giving people hope that they can recover
Education for GPs, education and support systems for universities (mental health service at Uni told my daughter they couldn't help as her condition was too specialised)
Education in schools and workplaces on how to initiate conversations and help support with someone who they suspect to have an eating disorder. Making referral pathways clear, accessible and well advertised so that people may self refer or refer others
Explain that ED is deeper. Show it's an issue for all genders to consider. Show the links between mental health and food. But also as someone who used food to deal with [Redacted information] as a teen, by the end of 2018 I didn't even realise what a "normal" amount of food is. Even now I have to be really vigilant because I slip into missing meals with ease.
Far more funding and resources channelled into eating disorders. Home visits to support eating and mealtimes practically at home. Much more training in medical schools for students doctors, currently they only receive on average 2 hours in their whole training on eating disorders. Updated training to GPs on eating disorders, updated training in schools and rethinking of curriculum as quite a lot of it is unhelpful to those with eating disorder. Get rid of calories on menus.
Follow up after treatment to be extended, maybe a group. Care plan to be adhered to by GP.
FREED Take concerns seriously, early referral to ED services where staff are trained and knowledgeable in best ways of supporting people with EDs
Funding increases. More lived experience in eating disorder services, informing decisions from ward to board.
Get rid of calorie contents in cafes and restaurants.
Greater investment is psychological help - need earlier intervention

Having more community based services in all boroughs. -@ Having better GP and mental health communication. Drop in clinics based at GP practices for eating disorder patients. - Funding for more teaching, going into universities, schools, GP and health centres. -@ Having more funded support groups for people to come together and not feel alone in their difficulties. -@ more Funding for NHS services to expand our provisions and remit.
Helplines, support groups, nutritional awareness, no calorie counting on menus, social prescribing linked to gym membership. Health promotion around self-esteem and positive body image from an early age. Access to counselling (free or heavily subsidised) delivered by trained counsellors and psychotherapists (BACP/UKCP/NCPS) who can help work on 'self' - disorderly eating and eating disorders may be a result of unprocessed trauma/poor attachment styles - if treatment is just provided 'medically' those struggling will not get to the root cause of the issues. Access to psychological therapies needs to be part and parcel of any treatment programme (and professionals must be suitable competent and trained to work in this area)
I feel that those diagnosed with eating disorders should be able to self-refer to services, particularly given how difficult it is accessing GP appointments. This would also free up GP time. I recognise that services will still need blood results and ECG but I feel the eating disorders teams should do this as part of the assessment process rather than giving more work to the GP.
I personally feel that people should be able to self refer to eating disorders services, particularly as GPs are not specialists in this area and yet they are the gatekeepers. Plus it can be difficult accessing GP appointments. Given the seriousness of eating disorders and the impact on health I feel that access to treatment should be prioritised to prevent deterioration and death. I also feel that eating disorders services should be undertaking the tests they require, ie. Blood tests, ECGs as requiring GPs to do this is not only disjointed but causes delays. Another problem is only being able to access one mental health service at a time, some people need services to do more joined up working to support those with complex needs
I think fear, hearing personal stories, creating hope and practicing uniques forms of expressions.
I think focussing general public messaging around weight management to be around "healthy weight" rather than losing weight would help. I also think improved education on the curriculum about what being healthy means. Not just what you should eat but why it's important to be a healthy weight, and the consequences of being severely underweight, and why different types of food are necessary to be healthy (e.g. fats). I also think there needs to be a way to reduce the stigma against being overweight or making unhealthy food decisions and recognising that for most people an occasional unhealthy choice is totally okay - often people feel like if they eat a chocolate bar then that has to be justified or even hidden in order to avoid judgement. From the system perspective research shows that intensive early intervention results in better outcomes, reduced re-admission, and shorter admission periods. If there could be some sort of early intensive intervention that would avoid people having to get to a point from where it is hard to return before they can get treatment. I also think there needs to be a better understanding of the psychiatry behind eating disorders, and improving awareness of when eating disorders are symptoms of a different disorder rather than it always being seen as the underlying condition.
I think more boroughs should have the EDP service or similar to help people who need support that aren't classed as severe enough to need hospitalisation I also think there is more education needed amongst gp and healthcare professionals on the referral process and following up with people, it is a mental health issue at the end of the day and they should have a duty of care. Unless you reach out you can be forgotten about which is worrying

I think they need to do better with a lot of the marginalized communities. Autistic and trans people are often misunderstood and treated wrong. We don't have access to treatment as Deaf people. There's too many barriers for folks in larger bodies.
In terms of initiatives, I think that having some sort of a programme at schools to deliver informative lessons about eating disorders would be incredibly useful. Whether it be during PSHE or form time, having a space devoted to talking about eating disorders, in a non-triggering and sensitive way of course, would really help to not only widen the understanding and awareness of eating disorders, but also aid students struggling from eating disorders. In my school, I created with the student council an eating disorder awareness presentation for Eating disorder awareness week, which included interactive activities, dispelling myths about eating disorders, general important information as well as support resources and tools to assure positive mental wellbeing. From the responses I received, both teachers and students enjoyed the presentation and found it very worthwhile. Therefore, definitely introducing time to speak about eating disorders at schools would be a fantastic initiative in my opinion. Especially that eating disorders do greatly affect teenagers who commonly struggle with body image issues, pressures of social media etc. In addition, another initiative would certainly be removing calories from menus. I realise the goal of this has been to promote healthy eating habits in terms of making people aware of what and how much they consume. But I think that placing calories directly on menus is truly harmful to those suffering from eating disorders. I personally do find it triggering as do many eating disorder sufferers. Perhaps a better initiative/ solution would be to include some sort of qr code or app that allows those who wish to check calories of their meal in a restaurant. That way, ed sufferers do not have to see these calories and potentially avoid getting back into destructive eating disorder behaviours triggered by seeing these calories on the menus.
Knowledge around the signs people should look out for. More boundaries / rules when it comes to fads and toxic fitness advice.
Making some food and meals in supermarkets(as an example) less overwhelming. Lots of food can be hard sometimes
More awareness and more government funding to support everyone.
More awareness of the signs
More awareness on what it's like to experience an eating disorder, so sufferers can feel seen and validated and people who don't know what it's like can better understand what it feels like. I still feel like I don't have the vocabulary to describe what it was like at times
more awareness, increased support available for free
More check ins and more training so medical people/ first aiders/ paramedics see the warning signs such as passing out
More community/lived experience support groups. Finding a group has been the best thing for me because no one else understands like they do. But we support each other and get each other through the difficult days and remind each other why recovery is so important and worth it. I also think going back to menus without calories on would be good. There should be a push for health as a more rounded concept I.e. everything in moderation and balance, not a demonisation of food groups etc. in schools and that because it just fuels disordered eating. Also more support when on the waiting list! Don't just drop people off the cliff face when they've told you really personal things to be assessed and leave them for years without any hope or help!!!
More dietician support alongside psychology. Longer lasting follow up periods
More education about how you don't have to be underweight to have anorexia and try to do something about the really long wait times so people have less time to get worse
More education and support
More EMHP in schools More ELSAs in schools All to receive more specific training

More funding for NHS ED services, which would mean more eating disorders could be caught earlier, improving prognoses significantly
More funding for NHS services More funding for charities like BEAT Petition to remove calories on menus
More funding for treatment to reduce waiting lists, wider availability for treatment - not just for patients at their deepest lows. Lots of people are turned down as they are "not sick enough". More training within NHS on how to support staff with EDs, more campaigns, more teaching and support at schools
More GP awareness. Understanding the demographics regarding people struggling with Eating Disorders. i.e not just a british white female between the ages of 13-25. More support groups - both face to face and online. Shorter waiting lists for services, so earlier intervention.
More help from.gp
More informal support groups
More informal ways of seeking short term support or advice
More information about what EDs are.
More money - waiting lists are too long Clear and published reversal criteria with a focus on inclusion and not weight which incentivises escalating ED and ignores those who are not thin. Complaints are often dismissed so there is no cultural shift
More on offer in different settings
More open discussions, more advertising, making mental health overall less taboo. Educating people on how to talk to people that are in recovery/ finished recovery as people think that once people are a healthy weight they can discuss calories/ diets again
More research funding More PPIE education in schools about nutrition, food and mental health in general
More specialised help Early intervention
More specialist therapy and dieticians available on the NHS.
More support groups etc vua social media or an app
More understanding of the types (including newer ones) of EDs
More units that special in diabullima or joined up services that deal with other EDs and diabullima as this condition needs treating differently to other ED such as anorexia or bullima. More education about other EDs also and more representation of larger bodies in regards to eating disorders.
Not to just focus on weight & treat patients as individuals
Peer Support and more campaign work more ways for people to speak openly and share their experiences.
Peer support groups for parents, and also for YP who have overcome thier issues, better information sharing. Ensuring that camhs professionals and psychiatrists are fully trained on up to date research in the field
Peer support groups run by the services More support on the wait list Between transition from referral, assessment, treatment and discharge Health providers having a better understanding Being able to diagnose other issues that may be affecting the ED (ASD)
People just being listen to and not judged by professionals
Promotion of where to get help, better understanding by doctors, more information within schools
Public awareness, funding, more beds
Quicker services
Quicker times to access treatment NOT using BMI or weight to diagnose NOT using weight to determine mental state It is a MENTAL HEALTH DISORDER, NOT a weight disorder.
Removal of calories from menus Earlier intervention in schools around disordered eating Instigation of neutral language around food Shorter referral times for those seeking help

Removing the calories from menu's in restaurants
Self referral. Patient initiated referral when known to a service. Relapse prevention/support. Drop the scales,weight and BMI should not be indicators for treatment. Better training for medical staff not just working in Mental Health. Smaller hubs away from the main Psychiatric Hospitals which are more informal. Outreach and community support.
Services for those at a higher weight. Inclusive services
Step care - care in the community following discharge. Integrated CBTE - provides the whole package. Peer support groups/initiatives, from people who have fully recovered. A patient forum - for coproduction.
Stopping unhealthy interventions e.g. calories on menus; stopping having diet culture endorsed by those with influence; better education about EDs and spotting signs in self/others
Subsidised therapy
Support for different types of ED at different times. More support less central and on the outskirts of London boroughs. Drop in sessions for those with a diagnosis to get support while waiting for treatment. Specialised adolescent ED units
Support groups
Support networks
Talk about it more. Eating disorders are not just anorexia. Inform family members of how to best approach a loved one with an eating disorder
The Mantra group held at the Maudsley Hospital I attended was an excellent treatment and support for me. If these groups are held regularly, it would benefit so many people struggling with an eating disorder. Also assessment/treatment should not be based just on BMI.
Train GPS so they are more knowledgable about anorexia.
We need better early intervention. Training for school nurses, GPs and information sessions for parents to help identify symptoms very early on and to take co-ordinated community action to reestablish proper eating patterns very early on in the eating disorder. Supported eating at school for those struggling could be a life saver. For teenagers many begin by skipping lunch at school so prevention and intervention in schools could be highly effective. Good early intervention could stop symptoms from worsening and avoiding the need for more intensive treatment. For families supporting their loved ones we need better community support for refeeding and so on. The toll on families is very high with high levels of distress suffered by parents and siblings. Refeeding is often a lengthy and fraught process for which families are ill prepared. They need professional help with the process. They also need time out from caring. Many parents currently give up work to look after their children, This is not feasible for many families. All those that need inpatient care should be given beds in specialist units and should be fully supported until full weight restoration. Partial weight restoration does not relieve symptoms and means deterioration on discharge from hospital is very likely. We would not accept such a poor level of service for "physical" illnesses. It is a form of unspoken stigma that means that eating disorder sufferers are provided with so little care.
Well signposted services, advertised in non-online/social media spaces - eg: local authority free newspaper, library noticeboards, supermarket noticeboards. Many of us with eating disorders don't go out much, so free newspapers from local authorities are a great, and free, spot for promoting services, organisations, etc.
Widespread acceptance by ED clinical community of growing evidence for biological, metabolic, genetic mechanisms, and critical role of negative energy balance as critical causative factors. Removal of calories on menus; removal of triggering items from school curricula (health, PE, biology, maths); Education for GPS, all teaching staff , coaches on causes (see above) and provision of appropriate support.

Demographic questions

Q: How old are you?
Base: all respondents (n= 112)

Under 18	4
18-24	25
25-34	26
35-44	16
45-54	21
55+	15
Prefer not to say	1

Q: How old is the person you are supporting? We are aware that you may have supported multiple people with an eating disorder or disordered eating, if this is the case, please think about the main person you have supported.
Base: respondents who have supported someone with an eating disorder (n=33)

Under 18	9
18-24	12
25-34	6
35-44	5
45-54	0
55+	0
Prefer not to say	0

Q: What is your gender?
Base: all respondents (n= 112)

Male	5
Female	102
Non-binary	3
I identify in another way	0
Prefer not to say	0

Q: What is the gender of the person you are supporting?
Base: respondents who have supported someone with an eating disorder (n=33)

Male	0
Female	28
Non-binary	2
They identify in another way	1
Prefer not to say	2

Q: Is your gender identity the same as assigned at birth?
Base: all respondents (n= 112)

Yes	106
No	2
Prefer not to say	2

Q: Is the gender identity of the person you are supporting the same as assigned at birth?
Base: respondents who have supported someone with an eating disorder (n=33)

Yes	2
No	2
Prefer not to say	29

Q: Where do you live?
Base: all respondents (n= 112)

Barnet	3
Bexley	3
Brent	2
Bromley	5
Camden	2
City of London	4
Croydon	2
Ealing	2
Enfield	2
Greenwich	2
Hackney	3
Hammersmith and Fulham	4
Haringey	2
Harrow	3
Islington	3
Kingston upon Thames	3
Lambeth	5
Lewisham	2
Merton	4
Newham	1
Outside of London	23
Redbridge	1
Richmond upon Thames	4
Southwark	6
Sutton	3
Tower Hamlets	2

Waltham Forest	3
Wandsworth	8
Westminster	2

Q: Where does the person you are supporting live?
Base: respondents who have supported someone with an eating disorder (n=33)

Barking and Dagenham	1
Barnet	1
Croydon	2
Greenwich	1
Hackney	2
Haringey	1
Harrow	1
Islington	2
Lambeth	1
Lewisham	1
Newham	1
Outside of London	9
Redbridge	1
Richmond upon Thames	3
Southwark	2
Wandsworth	3
Westminster	1