



# Eating Disorders in London

Health Committee

**LONDONASSEMBLY**

## Health Committee



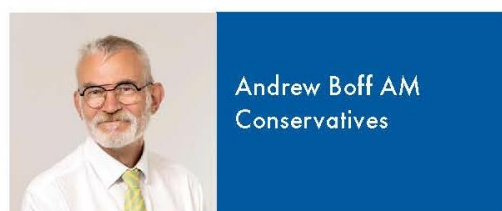
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## Foreword



**Dr Onkar Sahota AM**  
**Chair of the Health Committee**

Up to six per cent of the UK population may suffer from an eating disorder in their lifetime. In severe cases, eating disorders have devastating impacts on the lives of individuals and their loved ones.

Many people suffer in silence with an eating disorder for too long. Some may not recognise their symptoms at first, while others may feel reluctant to come forward and seek help due to the stigma associated with the condition. People who do not fit prevalent stereotypes of an eating disorder sufferer may find it even harder to reach out for support, particularly men, older people and people from certain minority ethnic groups.

Given that people may be initially reluctant to seek help, it is crucial that when they do, they are met by informed health practitioners supported by robust systems to deliver the specialist help required.

However, this is often not happening in London.

The London Assembly Health Committee has found that many people face significant barriers to access treatment amidst over-stretched services struggling to meet increased demand. As an experienced GP, I was particularly concerned to hear that some people in London have found their GP to be ill-informed and insensitive to their experiences. The Committee also heard that some GPs failed to make necessary referrals to specialist services.

Those that are able to secure referrals then face services that are facing significant capacity pressures. Referrals to specialist eating disorder services have more than doubled in London since 2016, for both children and adults. Simultaneously, the Committee was told that services in London do not have sufficient staff to safely deliver the care that is required.

It is in this context that we see inconsistent waiting times. Last year, 61 per cent of adults accessed services within four weeks of being referred but performance between trusts differed widely. Some adults have waited over three years to start treatment in London after being first referred.

Improvements to waiting times for children and young adults have also stuttered in the past two years and services in London are failing to meet national waiting time standards for children and young adults. For those stuck on waiting lists, the Committee was told there is almost no support provided. People told us how their condition deteriorated dangerously while waiting, unsupported, for treatment to begin.

The findings set out in this report highlight how over-stretched services are not able to provide the kind of tailored, long-term, integrated support that is required to address both the underlying causes, and health impacts, of eating disorders.

However, I am not without optimism. London is home to some of the most effective and innovative eating disorder services in the country, staffed by dedicated and expert professionals. The Committee makes several recommendations which it thinks can harness the assets present in London to deliver improvements to eating disorder services across London.

I would personally like to thank all those that provided evidence to the Committee. I am particularly grateful to the many people with direct experience of eating disorders who shared their views via public meetings, private meetings and the Committee's survey. This report is far richer for their contributions. I hope the powerful testimonies within this report, alongside the Committee's recommendations, can help spur action to ensure London leads the way in the delivery of accessible and effective treatment for eating disorders.



## Executive summary

In June 2023, the London Assembly Health Committee launched an investigation into eating disorders in London, following reports that referrals for eating disorder services have increased in recent years and performance against waiting time standards dropped during the COVID-19 pandemic. The aim of this investigation was to understand what is driving the increase in referrals, how services are responding to this additional demand and to explore people's access to, experiences of, and outcomes from treatment services.

The Committee held two formal meetings with expert guests, including clinicians, people with experience of living with an eating disorder, and representatives from the Greater London Authority and NHS England. It also held a private session with people with lived experience of being affected by an eating disorder and received 112 responses to its survey from those with experience of an eating disorder, supporting a family member or friend with an eating disorder or those working with those experiencing an eating disorder.

The Committee is grateful to all those who shared their expertise to inform this investigation. Many people shared their personal stories of having an eating disorder or supporting a loved one with an eating disorder, and this evidence has been hugely valuable to the Committee's work.

This report highlights several concerns around the increasing prevalence of eating disorders in London and the pressures faced by services to respond to this demand. Too many people and their families are not able to get the care and treatment they desperately need. This report identifies major issues related to barriers to securing referrals, waiting times for services, quality of care, management of discharges and the paucity of support in the community.

The key findings made in this report include:

- The demand for eating disorder services in London has increased in recent years and was accelerated by COVID-19. However, some GPs could benefit from updated training on eating disorders and many people struggle to access referrals to specialist services.
- Whilst NHS funding for eating disorder services is at its highest ever level<sup>1</sup>, services in London have struggled to cope with the demand. Performance on waiting times has worsened, with people stuck on long waiting lists, often with their symptoms getting worse and with little interim support.
- Some services are left to prioritise only the most severely ill people and are reportedly going against clinical guidance by using body mass index (BMI) as a threshold for determining who should and shouldn't have access to services.
- Excellent care is available in parts of London, but work is needed to provide consistent access to the best care possible for all Londoners.

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<sup>1</sup> NHS England, [Children and young people's eating disorders programme](#)

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- Resources of community groups and voluntary sector organisations are not currently being harnessed effectively to support those with mild to moderate symptoms.
  - The absence of positive support networks for young people leads some to engage in 'pro-eating disorder communities' online, which may encourage and accentuate existing eating disorders.
  - Eating disorders have a devastating impact on families and yet there is little support provided to families and carers of people with eating disorders.

The report makes 12 recommendations for change, which are detailed below. The Committee acknowledges that the ability to enact many of these recommendations falls outside the direct powers of the Mayor and the GLA. However, the Committee believes the Mayor can play a role in working with the NHS to help address the challenges that services face, improve standards of care and expand existing good practice to improve outcomes for people with eating disorders in London. We have therefore focused on how the Mayor could most fruitfully intervene and influence the services, in order to make a real difference to the lives of Londoners affected by eating disorders.



## Recommendations

### Recommendation 1

The Mayor should work with NHS England (London), including through the London Health Board, to advocate for the adoption of training on eating disorders across all GP practices in London.

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### Recommendation 2

The Mayor should request that NHS England (London) explores the feasibility of establishing self-referral routes for adult eating disorder services across London and the likely number of referrals that would be generated, so that the service set up can meet the needs of the patients self-referring.

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### Recommendation 3

The GLA Health team should work with NHS trusts across London to ensure that: all people on waiting lists for eating disorder services are provided with clear information and resources; and additional interim support is commissioned for those on waiting lists who are at higher risk.

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### Recommendation 4

The Mayor should lobby NHS England (London) to ensure that health services are not rejecting nor prioritising patients for treatment for an eating disorder on the sole basis of BMI, as stipulated in NICE guidelines.

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### Recommendation 5

The GLA Health team should work with NHS England (London) to conduct a London-wide audit of available eating disorder services, to identify and address any gaps in provision for particular eating disorders, such as binge-eating disorder and avoidant/restrictive food intake disorder.

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### Recommendation 6

The Mayor should request that NHS England (London) supports the roll-out of specialist care pathways across NHS trusts in London for people with autism suffering from an eating disorder.

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### Recommendation 7

The Mayor should request that NHS England (London) reviews how the Improving Access to Psychological Therapies workforce can be utilised across London to provide better access to talking therapies for people with eating disorders.

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### **Recommendation 8**

The Mayor and the GLA Public Health Unit should design and deliver a public awareness campaign on eating disorders across London, with the aim of addressing stigma and improving signposting to support services.

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### **Recommendation 9**

The Mayor should work with relevant partners to ensure that Thrive LDN and Good Thinking provide good, easily accessible and up-to-date information to help people with an eating disorder understand options for treatment and services available in London.

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### **Recommendation 10**

The Mayor should raise awareness of the existing legislation that exempts schools from including calories on menus, to support schools that may believe they are required to display calorie information.

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### **Recommendation 11**

The Mayor should take steps to support those experiencing eating disorders when using cafes and restaurants on GLA and TfL premises, ensuring that relevant exemptions to calorie labelling on menus are applied. This could include doing more to promote the option of providing a menu without calorie information.

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### **Recommendation 12**

The Mayor should bring together the GLA Health Team, NHS England (London) and Feast to review how NHS trusts engage with and support families impacted by eating disorders; and identify areas where additional support can be provided.

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## About eating disorders in London

### About eating disorders

According to the National Institute for Health and Care Excellence (NICE), “eating disorders are characterised by persistent disturbance of eating or eating-related behaviour which leads to altered intake or absorption of food and causes significant impairment to health and psychosocial functioning.”<sup>2</sup>

According to the NHS, examples of eating disorders include:

- Anorexia nervosa – trying to control your weight by not eating enough food, exercising too much, or doing both
- Bulimia – losing control over how much you eat and then taking drastic action to not put on weight
- Binge eating disorder – eating large portions of food until you feel uncomfortably full
- Avoidant/restrictive food intake disorder (ARFID) – avoiding certain foods or limiting how much you eat or both.<sup>3</sup>

The NHS states that people may develop eating disorders due to a combination of psychological, biological, genetic and social factors.<sup>4</sup> The Committee heard that there are a wide range of possible contributing factors, including genetic causes and environmental triggers. The Committee is not in a position to provide a comprehensive summary of the causes of eating disorders, although this report does discuss some potential causes or contributing factors that were raised by guests.

Some people with eating disorders may not have all the recognised symptoms from a particular disorder or may experience symptoms from more than one disorder, which can make it more complicated to get a formal diagnosis.<sup>5</sup> For example, atypical anorexia carries the same symptoms of anorexia nervosa but without being underweight.<sup>6</sup> According to the NHS, the most diagnosed eating disorder is “other specific feeding or eating disorder” – a diagnosis given in circumstances where an individual’s symptoms do not exactly fit those expected for any single eating disorder.<sup>7</sup>

Beat, a UK-based eating disorder charity, has estimated that 1.5 million people across the UK are suffering from an eating disorder at any one time, and that six per cent of the population suffer from an eating disorder in their lifetime.<sup>8</sup>

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<sup>2</sup> National Institute for Health and Care Excellence, [Eating disorders: What is it?](#), July 2019

<sup>3</sup> NHS, [Overview – Eating disorders](#) [Last accessed 09/02/24]

<sup>4</sup> NHS, [Overview – Eating disorders](#) [Last accessed 09/02/24]; Mind, [Eating problems](#) [Last accessed 26/05/23]

<sup>5</sup> Mind, [Eating problems](#) [Last accessed 01/06/2023]

<sup>6</sup> Beat, [Anorexia nervosa](#) [Last accessed 01/06/23]

<sup>7</sup> NHS, [Overview – Eating disorders](#) [Last accessed 26/05/23]

<sup>8</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.1

According to the NHS Health Survey for England 2019, four percent of all adults in England may have an eating disorder.<sup>9</sup>

### Treatment for eating disorders in London

NHS eating disorder services offer a range of treatment options. Care may involve any of the following:

- monitoring of weight, mental and physical health
- psychoeducation about the disorder
- cognitive behavioural therapy
- other forms of individual, group or family therapy
- dietary counselling
- guided self-help programmes
- involvement of family in care plans.<sup>10</sup>

Where there are concerns that someone is seriously unwell or underweight, that person may be admitted to a specialist clinic or mental health hospital and receive additional support and medication.<sup>11</sup> Admissions may be planned for the purpose of medical stabilisation, symptom interruption and weight restoration. Urgent or unplanned admissions may be made with the purpose of weight restoration.<sup>12</sup>

There are eight NHS trusts currently delivering specialist eating disorder services in London (see table one). Each of the five Integrated Care Boards in London have at least one child and adolescent service, and one adult service in their area.

**Table 1: Eating disorder services in London**

ICB	Provider	Children and adolescent/ adult
<b>North Central</b>	Central and North West London NHS Foundation Trust	Children and adolescent; and adults
	Royal Free London NHS Foundation Trust	Children and adolescent
	Barnet, Enfield and Haringey Mental Health NHS Trust (St Anne's Hospital)	Adults
<b>North East</b>	East London NHS Foundation Trust	Children and adolescent; and adults
	North East London NHS Foundation Trust	Children and adolescent; and adults

<sup>9</sup> NHS, [Health Survey for England, 2019](#), 15 December 2020. The SCOFF scale was used to determine whether someone had a possible eating disorder, but this does not provide definitive diagnosis. See notes included in dataset for further information on SCOFF.

<sup>10</sup> NICE, [Eating disorders: recognition and treatment](#), 16 December 2020

<sup>11</sup> Mind, [Eating problems](#) [Last accessed 01/06/2023]

<sup>12</sup> NICE, [Eating disorders: recognition and treatment](#), 16 December 2020

<b>North West</b>	West London NHS Trust	Children and adolescent; and adults
<b>South East</b>	South London and Maudsley NHS Foundation Trust	Children and adolescent; and adults
<b>South West</b>	South West London and St George’s Mental Health NHS Trust	Children and adolescent; and adults

Private providers also operate in London and will sometimes receive referrals from the NHS where it has insufficient inpatient capacity. Providers include Priory Group, Cygnet, Ellern Mede and Schoen Clinic.<sup>13</sup>

### Mayoral powers and the role of the GLA

The Mayor is required through the Greater London Authority Act 1999 to publish a health inequalities strategy that contains proposals and policies for the reduction of health inequalities in London.<sup>14</sup>

There is no reference to eating disorders in the Mayor’s Health Inequalities Strategy (HIS) or the HIS Implementation Plan 2021-24.<sup>15</sup> However, there are objectives within the strategy that the Committee believes have clear relevance to issues related to eating disorders, including:

- “Mental health becomes everybody’s business. Londoners act to maintain their mental wellbeing, and support their families, communities and colleagues to do the same
- No Londoners experience stigma linked to mental ill health, with awareness and understanding of mental health increasing city-wide.”<sup>16</sup>

Whilst the Mayor has no formal powers related to the delivery of health services, the GLA Act 1999 also states that the Mayor’s strategy must “describe the role to be performed by any relevant body or person for the purpose of implementing the strategy”. A relevant body includes any NHS trust or NHS foundation trust which delivers services within London.<sup>17</sup>

This report therefore identifies areas where we believe the Mayor and GLA can take action, both within their current powers and by using their role to influence and work alongside health delivery partners. The Committee also expects this report will be considered as evidence to inform the next Mayor’s Health Inequalities Strategy implementation plan.

<sup>13</sup> Written evidence – Royal College of Psychiatrists. Published alongside report.

<sup>14</sup> UK Government, [Greater London Authority Act 1999](#)

<sup>15</sup> GLA, [Health inequalities strategy](#), September 2018. GLA, [Health Inequalities Strategy Implementation Plan 2021-24](#), 9 December 2021

<sup>16</sup> GLA, [Health inequalities strategy](#), September 2018

<sup>17</sup> UK Government, [Greater London Authority Act 1999](#)

## About the investigation: evidence and methodology

### Meetings

This investigation sought to understand the prevalence of eating disorders in London, and people's access to, experiences of and outcomes from, treatment.

The Committee held three evidence sessions as part of this investigation. It held a formal session on 29 June 2023 to hear evidence on the causes and prevalence of eating disorders in London and how people could access treatment. The following guests attended:

- Hope Virgo, Author and Campaigner and person with lived experience
- Dr Karina Allen, Consultant Clinical Psychologist, Eating Disorders Outpatients Service - South London and Maudsley NHS Foundation Trust
- Andrew Radford, Chief Executive, Beat Eating Disorders
- Jazz Bhogal, Assistant Director, Health, Education and Youth, GLA

It held a second formal session on 21 September 2023 to hear evidence on people's access to, experiences of and outcomes from eating disorder services in London. The following guests attended:

- Emma Christie, Head of Mental Health, NHS London
- Dr Brian Sreenan, Consultant Psychological Lead for Disordered Eating, NHS East London Foundation Trust
- Dr Agnes Ayton, Consultant Psychiatrist, Oxford Health NHS Foundation Trust
- Dr Ashish Kumar, Clinical Director Child and Adolescent Mental Health Services (CAMHS) Mersey Care NHS Foundation Trust and Chair Faculty of Eating Disorders, Royal College of Psychiatrists
- Dr Victoria Chapman, Consultant Child and Adolescent Psychiatrist, Royal Free CAMHS
- Jessica Griffiths, National First Episode Rapid Early Intervention for Eating Disorders (FREED) Co-lead, South London and Maudsley NHS Foundation Trust, eating disorders therapist and person with lived experience.

Evidence gathered from these sessions has been used throughout this report and attributed to guests. Full transcripts and recordings of these sessions are publicly available.<sup>18</sup>

Finally, the Committee also held a third evidence session in private with three guests with lived experience on 21 September 2023. Two guests had experience of supporting their child to access eating disorder services in London, and one guest had direct experience of accessing treatment for an eating disorder in London.

Evidence gathered from this session is used throughout this report but is not attributed to guests, to ensure that they are not identifiable. The Committee has also not published a

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<sup>18</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023; London Assembly, [Health Committee – transcript](#), 21 September 2023.



transcript from this meeting and some quotes have been modified to remove any detail (such as specific areas in London, ages, BMI and NHS trusts) that could be used to identify guests.

The Committee is grateful to all those who provided oral evidence to its investigation.

## Written evidence

The Committee also received nine responses to its call for written evidence. The Committee refers to these responses throughout the report and has published all responses it received.<sup>19</sup> The questions asked in the call for written evidence are included in Appendix A of this report. The Committee is grateful to the following organisations who provided written evidence to its investigation:

- Autistica
- Beat
- Carney's Community
- Family Mental Wealth
- Goldsmiths, University of London
- Jessika Morgan-McNeil
- Local Dental Committee Confederation
- Marc Terry
- Royal College of Psychiatrists.

## Survey

The Committee was keen to hear from people with experience of eating disorders and eating disorder services in London. As part of this, the Committee launched a survey to allow Londoners to inform its work. The survey used mostly open text box questions to allow respondents to share as much or as little as they would like to, and in acknowledgement that the survey is not representative of all experiences of eating disorders in London. The Committee is grateful to staff at eating disorder charity Beat who advised on the phrasing of survey questions.

The Committee received 112 complete responses to its survey. The survey was open to anyone who wanted to respond; many respondents had personal experience of an eating disorder (75), experience supporting someone else with an eating disorder (33) or working with people with an eating disorder (16).

Most respondents' experiences related directly to London. 55 respondents had experience of adult eating disorder services in London and 24 had experience of Child and Adolescent Mental Health Services (CAMHS) in London. Other respondents had either not accessed eating disorder services or had accessed services outside of London.

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<sup>19</sup> Written evidence published alongside report.

Respondents with personal experience of eating disorders were predominantly female (69), with only small numbers of men (3) and non-binary people (2) responding. Most respondents with personal experience of eating disorders were between the ages of 18 and 34 (see table below).

Most respondents who were supporting someone with an eating disorder described the person they supported as being female (28), compared to male (0) and non-binary (2). Most people being supported were either children or young adults between the ages of 18-24 (table below).

	<b>Age of respondents with a direct experience of an eating disorder</b>	<b>Age of people being supported by respondents</b>
Under 18	4	9
18-24	22	12
25-34	23	6
35-44	10	5
45-54	10	0
55+	4	0

The Committee has published the survey questionnaire and responses alongside the report. Responses to the survey are used throughout this report. Please note responses have been edited to remove any information that may be used to identify respondents.

As the survey is not a representative sample, experiences described may not be representative of all Londoners with an eating disorder, their experience of services or of supporting or working with those with an eating disorder.

The Committee is grateful to all those who responded to the survey.

### **Freedom of information responses**

The Committee sent Freedom of Information (FOI) requests to NHS trusts that deliver specialist eating disorder services in London.

The Committee requested information on:

- referral numbers for adults and children since 2016-17, including rejected referrals
- demographic information of referrals for adults and children, including gender, age and ethnicity
- waiting times for adult referrals, including longest waiting times since 2016-17.

The Committee has published all information received by Trusts alongside this report.

## Chapter one: seeking support for an eating disorder

### Recognising symptoms and seeking treatment

Before seeking treatment for an eating disorder, people must first acknowledge that they are unwell. However, the Committee heard how many people suffer in silence with their eating disorder for some time before seeking treatment. For example, one respondent to the Committee's survey stated: "I have experienced disordered eating for 35 years but was only diagnosed with anorexia 8 years ago". Another stated: "I have been living with anorexia for almost ten years and only sought support this year".

The reasons why people may take some years to seek treatment are varied. One respondent to the Committee's survey suggested they simply did not know they had an eating disorder, as they had never been told what eating disorders were:

"I realise I struggled a while ago [...] 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?"

One survey respondent with personal experience of eating disorders described the "guilt, stigma and shame" that surround eating disorders. Other respondents suggested that they struggled to reach out for help for their eating disorders:

"Many people, like myself, would not mention it [eating disorder] to anyone."

"Fear of asking for help, I present well on the surface but continue to struggle with eating disorders behind closed doors."

A guest at the Committee's private meeting told the committee that they first developed an eating disorder when they were 17 years old but they were not diagnosed until they were 29. Beat has found that it takes adults on average almost two years to seek help after first recognising the signs of an eating disorder.<sup>20</sup> Beat says more advice and guidance is needed so that families, carers, schools and others can help to spot signs of eating disorders and help those affected to seek treatment earlier.<sup>21</sup>

The Committee also heard evidence that certain groups of people may face additional barriers in recognising their symptoms and seeking support. For example, respondents to the Committee's survey suggested there was an inaccurate but prevalent stereotype that eating

<sup>20</sup> Beat, [Delaying for years, denied for months](#)

<sup>21</sup> Beat, [Best practice in ensuring early intervention for eating disorders](#), September 2022

disorders only affected “young, white females”, “middle class white women”, or “silly teenage girls”.

Respondents said such stereotypes caused additional barriers for people such as men, people from ethnic minority groups and older people to access help. One respondent stated: “I strongly feel my race (black) means I am overlooked and not fitting in narrow definitions of who has an ED [eating disorder]”. Another respondent stated that it was considered strange to be a man in his 30s suffering from an eating disorder.

The NHS Health Survey for England 2019 suggests four per cent of all adults in England may have a possible eating disorder, and that prevalence is higher amongst women (five per cent) than men (three per cent). The survey indicates prevalence is highest amongst women aged 25-34 (9 per cent) and 35-44 (8 per cent), followed by girls and young women aged 16-24 (7 per cent).<sup>22</sup> In London, data provided to the Committee through FOI requests shows that the vast majority of adult referrals received by London eating disorder services in 2022-23 were for women (6,180 compared to 626 men).<sup>23</sup>

However, guests stressed that men, minority ethnic groups and LGBTQ+ people may be underrepresented in both treatment figures and prevalence estimates.<sup>24</sup> Dr Agnes Ayton, Consultant Psychiatrist, Oxford Health NHS Foundation Trust, described “a significant gap of accessing services for men, ethnic minorities and other minority groups”.<sup>25</sup> Dr Ashish Kumar, Clinical Director CAMHS Mersey Care NHS Foundation Trust and Chair Faculty of Eating Disorders, Royal College of Psychiatrists, said:

“There are estimated 1.25 million people with eating disorders in the population. We are reaching out to only a fraction of them. As a result, there is a huge number of people with eating disorders in the community who are not accessing our services. Among the people who try to access our services, are we catering to males, are we catering to ethnic minorities, and are we building our team to cater to their needs? Is there capacity? Is there training? I do not think so”.<sup>26</sup>

The Committee also heard that people who have different types of eating disorders, or atypical symptoms, face additional barriers in accessing support. One respondent described the “misunderstanding of varying degrees of disordered eating”. Other respondents stated that particular eating disorders were poorly understood – including binge eating disorder, ARFID and

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<sup>22</sup> NHS, [Health Survey for England, 2019](#), 15 December 2020. The SCOFF scale was used to determine whether someone had a possible eating disorder, but this does not provide definitive diagnosis. See notes included in dataset for further information on SCOFF.

<sup>23</sup> London Assembly Health Committee analysis of Freedom of Information request data received from Trusts. Published alongside report.

<sup>24</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 pp.3 – 4, 26 and 29

<sup>25</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.17

<sup>26</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.17

orthorexia.<sup>27</sup> One respondent with experience of supporting someone else with an eating disorder cited a lack of understanding of how much eating disorders “vary and present themselves in different people.”

The Committee is concerned that this lack of understanding of different types of eating disorders makes it less likely some people will recognise their symptoms as an eating disorder or receive an appropriate response from services. One respondent suggested such misunderstanding “is truly harmful because it leads to less understanding about them and thus less aid to those suffering from these eating disorders.”

## **Approaching GPs for support**

When people do reach out for support for an eating disorder, they are likely to first approach their GP. The Committee heard some positive examples of GPs responding to people presenting with eating disorders. A respondent to the Committee’s survey said that their GP “reacted without judgement and with compassion and urgency, making a referral to specialists quickly”. Another stated that “they were very supportive and helped me to access support/go on a waiting list very quickly”.

Unfortunately, much of the evidence received by the Committee suggests respondents feel that many GPs are not providing an appropriate response to patients presenting with eating disorders and failing to make referrals to specialist services. For example, a guest at the Committee’s private session said their GP would not take their concerns for their daughter seriously: “I had been going privately because the GP kept on saying, ‘Oh, it is a phase’, or, ‘Yes, she is a little bit underweight but she will grow out of it’.”

A respondent to the Committee’s survey, who had also sought support for their child’s eating disorder, reported a similar response from their GP: “I’ve taken my child to the GP when [they were] very young and we felt we were not listened to and our concerns were dismissed with ‘It’s just a phase! They’re going to grow out of it’.” Other respondents with direct experiences of seeking support reported dismissive responses from GPs:

“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 nine months later I was taken straight to A&E for a week long admission.”

“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.”

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<sup>27</sup> [Beat](#) describes orthorexia as: an unhealthy obsession with eating “pure” food. It notes that this is not currently recognised in a clinical setting as a separate eating disorder, so someone who visited the doctor with the symptoms would not be officially diagnosed with “orthorexia”,

The Committee heard that some GPs may simply lack knowledge or training around eating disorders. For example, a guest at the Committee's private session found GPs to be poorly trained in relation to eating disorders, when they had sought support for their child:

"I think a lot of the issues that we have with eating disorders is that the GP is the first point of contact and in my experience, where I have been going through this nightmare now for nearly seven years, I would say the large proportion of the ones that I have met are very inexperienced and say very unhelpful things to the patients".

Some respondents to the Committee's survey suggested their GP was well-meaning but lacked appropriate training:

"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."

"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."

The evidence reflects the findings of both the Parliamentary and Health Service Ombudsman (PHSO) in 2017, and the Public Administration and Constitutional Affairs Committee (PACAC) in 2019, that GPs and other medical professionals need to be better trained to ensure they are responding to eating disorders appropriately.<sup>28,29</sup> In 2023, the PHSO said there were still issues with training for medical professionals on eating disorders.<sup>30</sup>

Andrew Radford, Chief Executive, Beat said that "retraining in GPs once they have qualified is incredibly difficult because they are so busy and there are so many of them". He suggested that the most effective way to address this is "by equipping the ill person with the information that they need and the assertiveness" to push for a referral when they go to their GP.<sup>31</sup>

Jessica Griffiths is the national FREED Co-lead, and also co-chaired the PHSO's Delivery Group in response to the 'ignoring the alarms' report. She said efforts had been made to improve education of doctors but that "it has been so difficult to cause change in that area because there is no mandate" and training remains optional for medical schools.<sup>32</sup> She suggested there was a role for the Mayor's London Health Board to push for adoption of available training across London:

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<sup>28</sup> PHSO, [Ignoring the alarms: How NHS eating disorder services are failing patients](#), 6 December 2017. N.b 'Ignoring the alarms' was published by the PHSO following its investigation into the death of Averil Hart from anorexia. It found that Averil's death would have been avoided if the NHS had cared for her appropriately. The report expressed significant concern with the national provision of eating disorder services.

<sup>29</sup> PACAC, [Ignoring the alarms follow up](#), 18 June 2019. N.b PACAC published a report to examine what progress had been made against the PHSO's 'Ignoring the alarms' recommendations.

<sup>30</sup> PHSO, [Urgent action needed to prevent eating disorder deaths](#), 27 February 2023

<sup>31</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.20

<sup>32</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.3



“There is excellent GP training, medical training, training for whole teams, but actually unless someone takes responsibility for implementing that in the boroughs of London, how do we know? That training is not going to be taken up. I would call up, once again, the [London] Health Board to present and say, ‘How can we hold our primary care colleagues and our trusts to account and encourage that eating disorder training and make it widely available and accessible and give the clinicians the time they need to complete it?’ That is absolutely vital. We need accountability”.<sup>33</sup>

The Committee heard that other healthcare professionals also lacked training to identify and respond to eating disorders effectively. Dr Agnes Ayton told the Committee that “the assessment of knowledge during undergraduate and postgraduate training for doctors is still very limited [...]. I would say it is still an ongoing issue in terms of training of primary care staff”.<sup>34</sup> Dr Ashish Kumar told the Committee that “There has been a lack of a coherent approach to training the medical workforce and other workforces like nursing colleagues and also psychologists, psychotherapists, trained CBT therapists and so on. That needs to improve”.<sup>35</sup>

In response to the Committee’s call for evidence, Nick Pollard, co-founder and Director of Family Mental Wealth, a social enterprise working to improve mental health provision for young people through family-based support, discussed the need for all healthcare professionals and allied health professionals to be aware of eating disorders:

“It is not just specialist clinicians who can, and should, contribute to the prevention and management of eating disorders. ALL healthcare professionals and allied health professionals will come across people with eating disorders in their day-to-day clinical work, and have the opportunity to contribute to the NHS aspiration to ‘make every contact count’. For example, the early symptoms of an eating disorder may first be identified by a dentist, pharmacist, or physiotherapist – if they have the vital knowledge to spot the signs.”<sup>36</sup>

In written evidence to the Committee, the Local Dental Committee Confederation, a group representing NHS dentists, stated that “the effect of eating disorders on oral health is clear and dentists and their team will be ideally placed to recognise the signs of eating disorders when providing dental care”. It recommended that “training needs to be provided to dentists and their team to ensure every contact counts with referral pathways from dentists to eating disorder support put in place through local training hubs”.<sup>37</sup>

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<sup>33</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p. 13

<sup>34</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.6

<sup>35</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.13

<sup>36</sup> Written evidence – Family Mental Wealth. Published alongside report.

<sup>37</sup> Written evidence – Local Dental Committee. Published alongside report.

## Recommendation 1

The Mayor should work with NHS England (London), including through the London Health Board, to advocate for the adoption of training on eating disorders across all GP practices in London.

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## Options for self-referral

Given the challenges presented to people in accessing referrals to specialist services through their GP, it may be necessary for people to make self-referrals. People can make self-referrals to Child and Adolescent Mental Health Services (CAMHS) in London. A guest at the Committee's meeting described making a self-referral for their child following "horrendous" experiences with GPs, and a respondent to the Committee's survey also stated that they accessed treatment for their child through "self-referral as our doctors were very unhelpful".

The Committee also received a survey response from an individual who had referred themselves to adult services. However, the Committee understands that self-referral is not an option for most adult eating disorder services in London. Some respondents to the Committee's survey with personal experience of an eating disorder, specifically called for self-referral options to be made available for adult eating disorder services:

"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."

"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."

"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."

The Committee is concerned that the lack of self-referral for adult services may mean some people are not able to access the treatment they require, particularly in cases where GPs may not be making appropriate referrals.

Dr Karina Allen, Consultant Clinical Psychologist, Eating Disorders Outpatients Service – South London and Maudsley NHS Foundation Trust, told the Committee that:

"Self-referral would be something to be thinking about and how much we can promote this as a way for people to access the support they need. Hope [Virgo] talked about GPs, who are overworked and overrun anyway, that may not be in a position to spot an eating disorder and promote early referral. Children and young people's eating disorder services allow self-referral and family-referral. At the moment, however, almost no

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eating disorder services are set up that way. It would be something that might facilitate greater access.”<sup>38</sup>

## **Recommendation 2**

The Mayor should request that NHS England (London) explores the feasibility of establishing self-referral routes for adult eating disorder services across London and the likely number of referrals that would be generated, so that the service set up can meet the needs of the patients self-referring.

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<sup>38</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.20

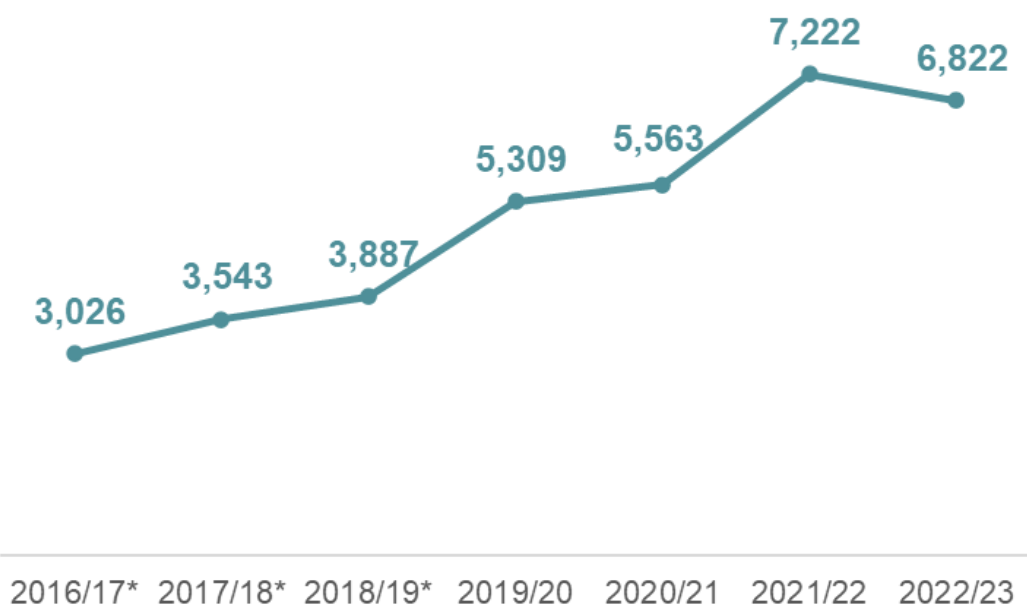
## Chapter two: accessing treatment in London

### Referrals to specialist services

Referrals to specialist eating disorder services in London have increased significantly amongst both children and adults in recent years.

In 2022-23, Freedom of Information (FOI) data obtained by the Committee from seven NHS mental health trusts shows that adult services in London received 6,822 referrals. Among the six trusts that provided information for each year requested, there was a 56 per cent increase in referrals between 2016-17 and 2022-23. This increase varied significantly among Trusts, for example North East London NHS Foundation Trust saw the highest increase of 227 per cent. A breakdown of the information by Trust is provided below.

### Adult eating disorder referrals

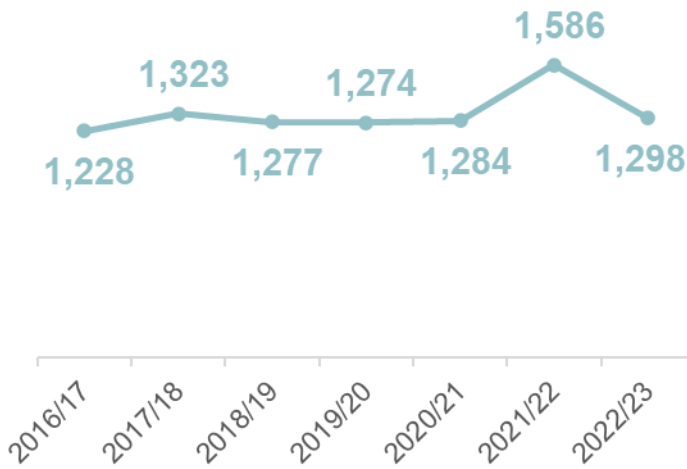


Source: London Assembly Health Committee analysis of Freedom of Information data from Trusts

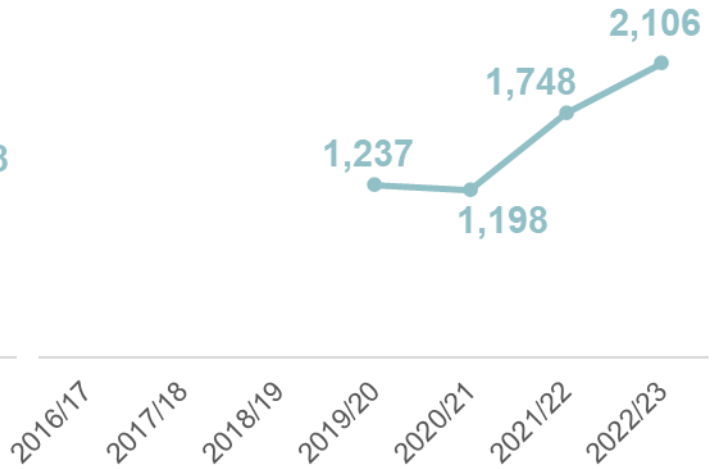
\*One trust was not able to provide information between 2016/17 and 2018/19, therefore numbers for these years may be higher, and any percentage increases calculated have excluded figures from this trust for accuracy.

Please note the Committee is aware of a cyber incident for the most recent year of information in relation to reporting of children and young people waiting times that impacted the reliability of some data. While it is not clear what impact this may have on this information, the Committee is cautious about commenting on a decrease in referrals in the last year as a result. One trust provided information for adults in calendar rather than financial years, which is reflected in the breakdowns below.

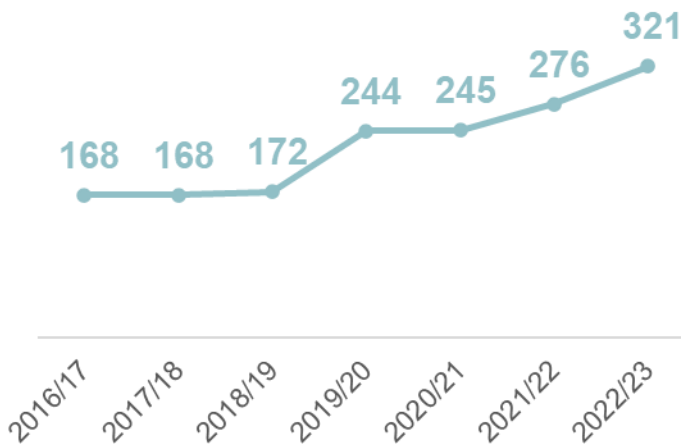
**Barnet, Enfield and Haringey  
Mental Health NHS Trust**



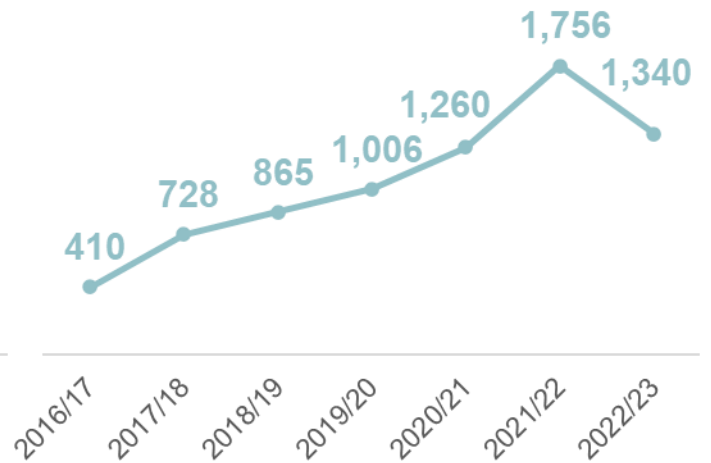
**Central and North West  
London NHS Foundation Trust**



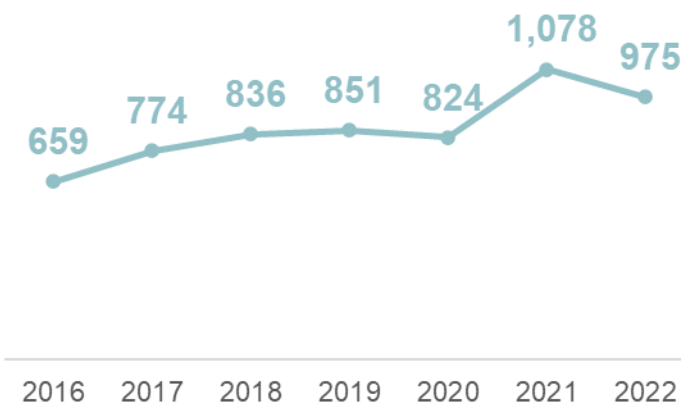
**East London NHS Foundation  
Trust**



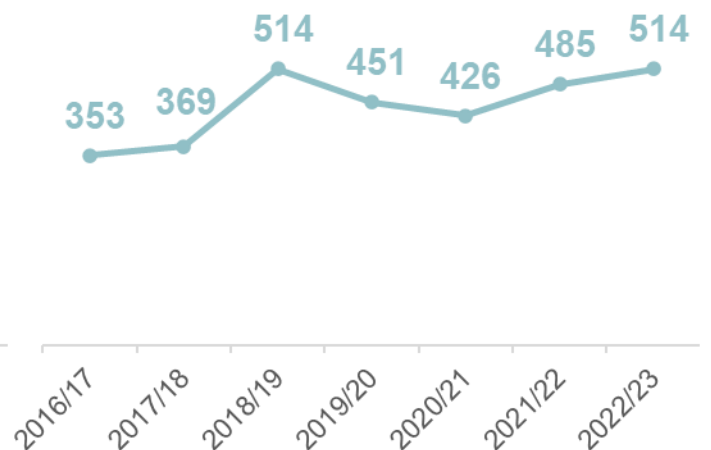
**North East London NHS  
Foundation Trust**



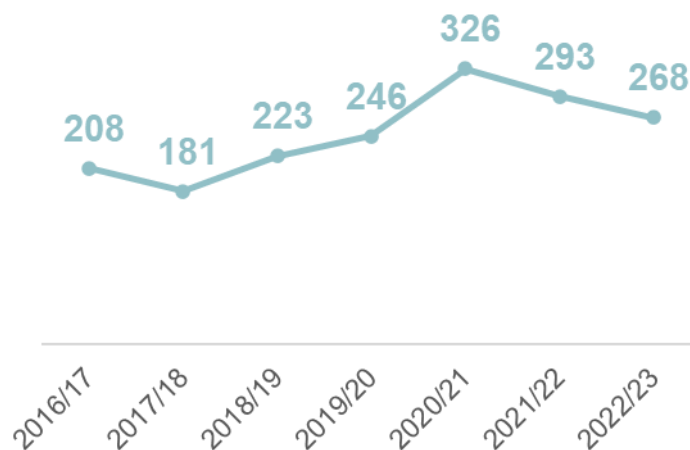
**South London and Maudsley  
NHS Foundation Trust**



**South West London and St  
George's Mental Health NHS  
Trust**



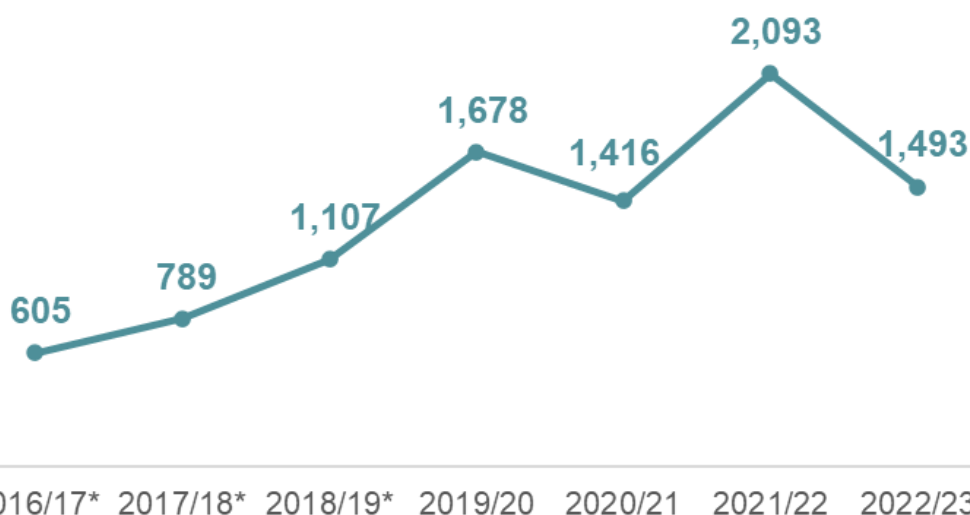
West London NHS Trust



Source: Freedom of Information data received from Trusts by the London Assembly Health Committee

Six of seven Trusts were able to provide information related to the number of rejected referrals for at least some of the years requested. In 2022/23, there were 1,493 rejected referrals. Trusts noted various potential reasons for rejected referrals, including capacity, administration error, duplicate or inappropriate referrals. Among Trusts that provided information for each year since 2016/17, there was an 88 per cent increase in rejected referrals.

Adult eating disorder rejected referrals



Source: London Assembly Health Committee analysis of Freedom of Information data from Trusts

\*One trust was not able to provide information between 2016/17 and 2018/19, therefore numbers for these years may be higher, and any percentage increases calculated have excluded figures from this trust for accuracy.

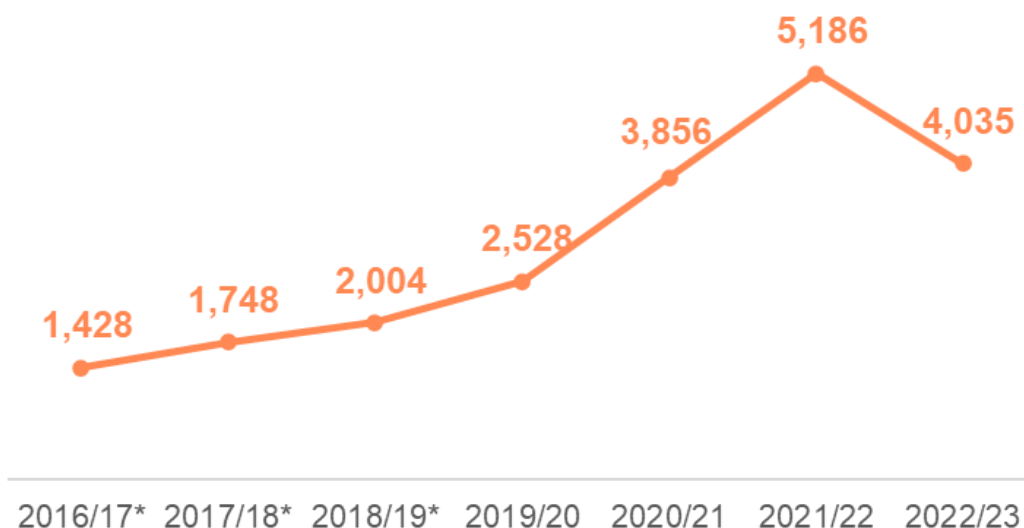


**Eating disorder referrals to child and adolescent services in London**

In 2022-23, child and adolescent services in London received 4,035 referrals. Among the seven trusts that provided information for each year requested, there was a 158 per cent increase in referrals between 2016-17 and 2022-23.

All trusts that provided information for each year requested reported an increase in referrals for children and adolescents between 2016-17 and 2022-23. North East London NHS again saw the highest increase in referrals, of 377 per cent. Royal Free London NHS Foundation Trust, East London NHS Foundation Trust and South London and Maudsley NHS Foundation Trust all saw referrals to child and adolescent services more than double.

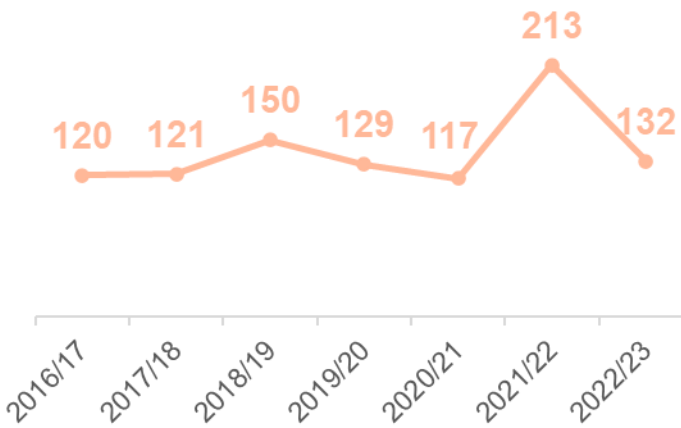
**Child and adolescent eating disorder referrals**



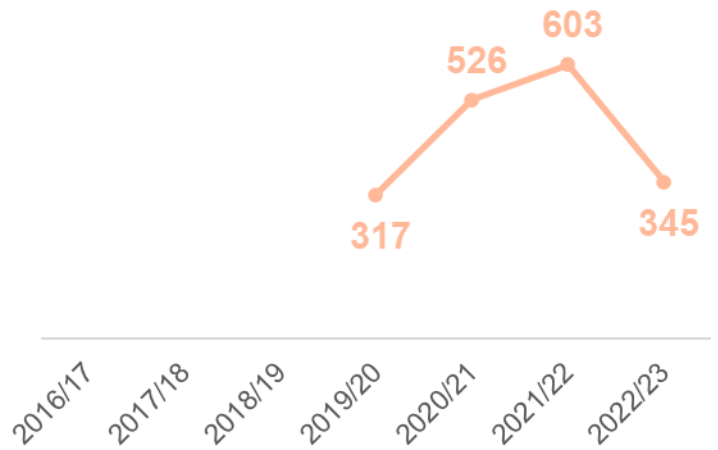
Source: London Assembly Health Committee analysis of Freedom of Information data from Trusts

\*One trust was not able to provide information between 2016/17 and 2018/19, therefore numbers for these years may be higher, and any percentage increases calculated have excluded figures from this trust for accuracy. Please note the Committee is aware of a cyber incident for the most recent year of information in relation to reporting of children and young people waiting times that impacted the reliability of some data. While it is not clear what impact this may have on this information, the Committee is cautious about commenting on a decrease in referrals in the last year as a result.

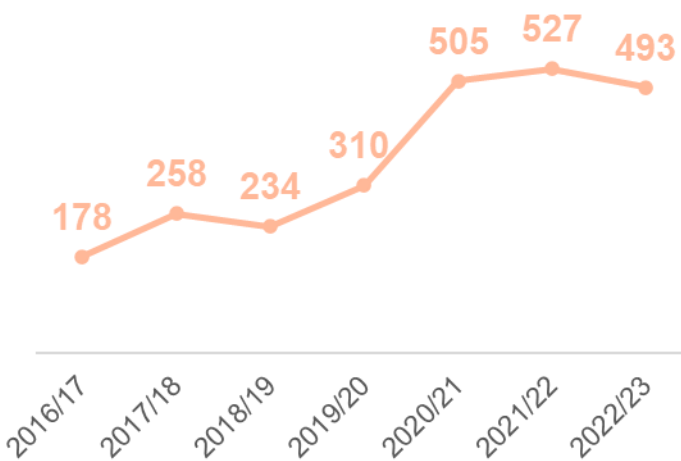
**Barnet, Enfield and Haringey  
Mental Health NHS Trust**



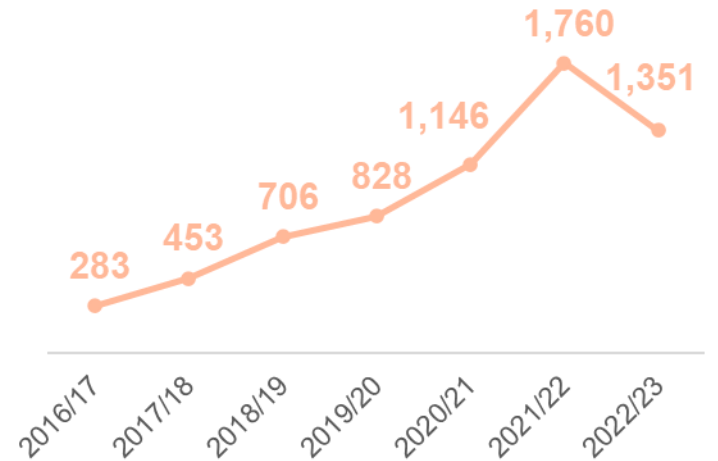
**Central and North West  
London NHS Foundation Trust**



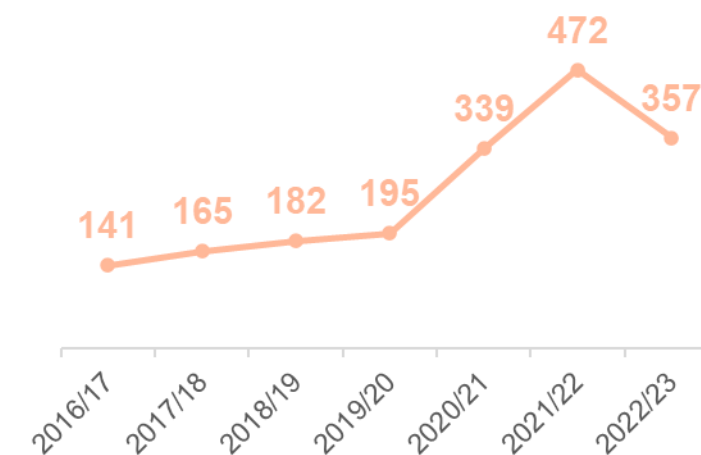
**East London NHS Foundation  
Trust**



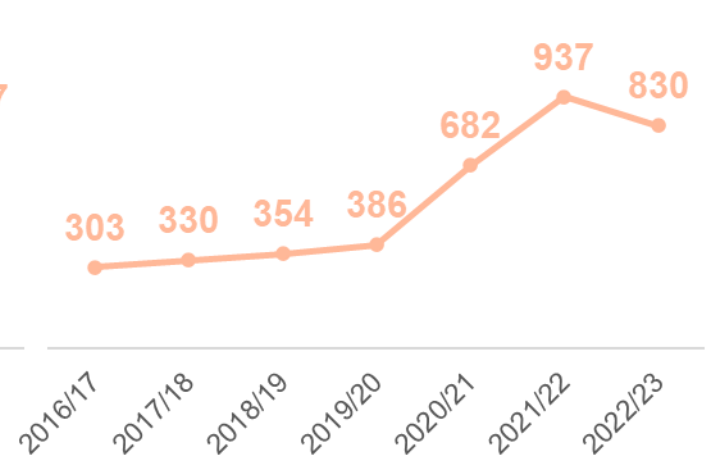
**North East London NHS  
Foundation Trust**



**Royal Free London NHS  
Foundation Trust**

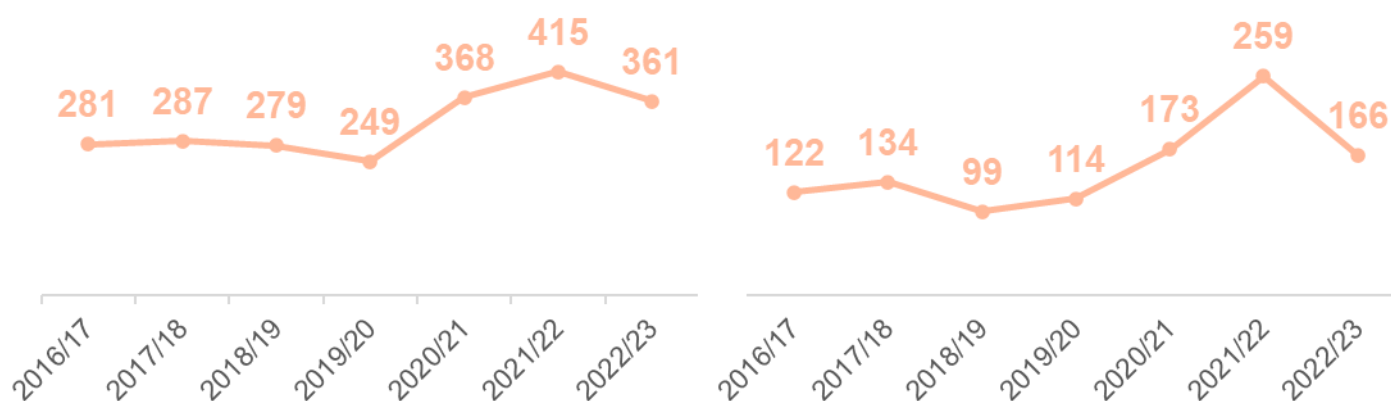


**South London and Maudsley  
NHS Foundation Trust**



### South West London and St George's Mental Health NHS Trust

### West London NHS Trust



Source: Freedom of Information data received from Trusts by the London Assembly Health Committee

The Committee notes this worrying increase in referral figures. However, as detailed in the previous section, it has also received compelling evidence that people are struggling to receive referrals to services at all. The Committee is therefore concerned that these referral figures represent just the tip of the iceberg, with many people in London struggling with eating disorders but not currently in treatment or unable to access treatment.

### NHS waiting times

Since 2014, efforts have been made by the Government and the NHS to improve the speed at which children and young people referred to services can access treatment. Alongside an investment of £150 million into eating disorder services nationally, new waiting time standards were established stating that children and young people should receive treatment within four weeks from their first contact with a designated healthcare professional for routine cases, and within one week for urgent cases.

The Government set a target of waiting time standards being met in 95 per cent of all cases by 2020.<sup>39</sup> Further investment was committed in the 2019 NHS Long Term Plan to allow the NHS to “maintain delivery of the 95 per cent standard beyond 2020/21”.<sup>40</sup>

Improvements in waiting times for children and young people were achieved across England and in London between April 2016 and March 2020 (see graphs below), where on average across the quarters London hit the target of 95 per cent of urgent cases starting treatment

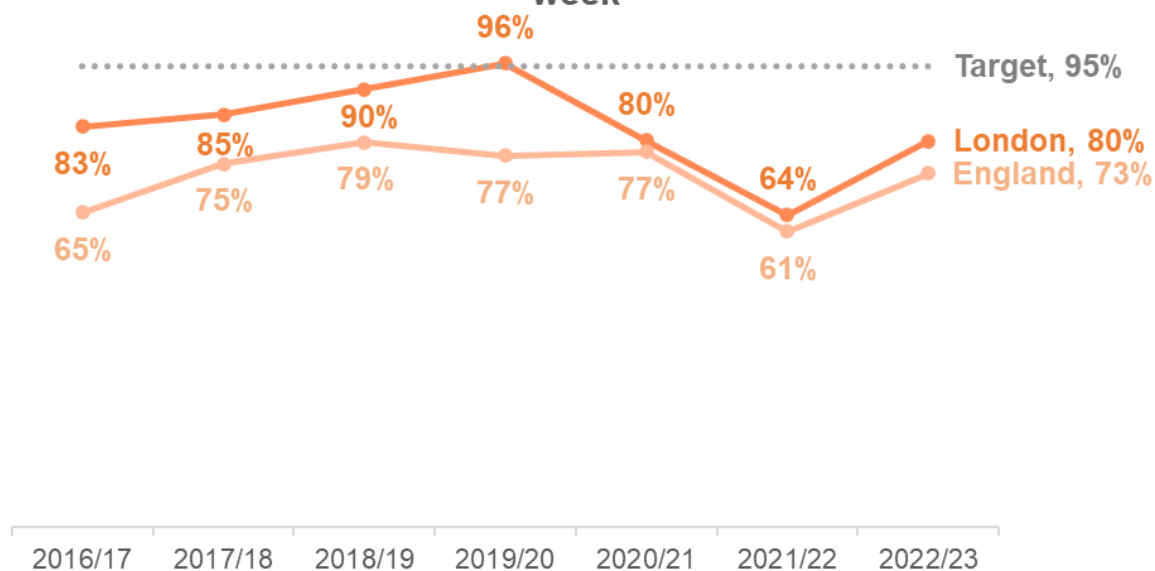
<sup>39</sup> NHS England, [Access and Waiting Time Standard for Children and Young People with an Eating Disorder](#), July 2015

<sup>40</sup> NHS England, [Long Term Plan](#), January 2019

within one week.<sup>41</sup> Of those children and young people who started treatment following an urgent referral in London in 2016-17, 83 per cent started their treatment within a week of first making contact with a healthcare professional. This increased to 96 per cent in 2019-20. Similar improvements were seen in routine cases. London has generally performed better than England as a whole.

However, this improvement was not sustained from 2020-21. In 2021-22 of those children and young people who started treatment following an urgent referral only 64 per cent started treatment within a week. Guests told the Committee that performance against waiting time standards was impacted by the COVID-19 pandemic. This is discussed further in chapter 3. Performance appears to have improved in 2022-23, though this data should be treated with caution due to a cyber-attack which impacted reporting for this year.<sup>42</sup>

**Proportion of urgent children and young people eating disorder cases starting treatment within one week**



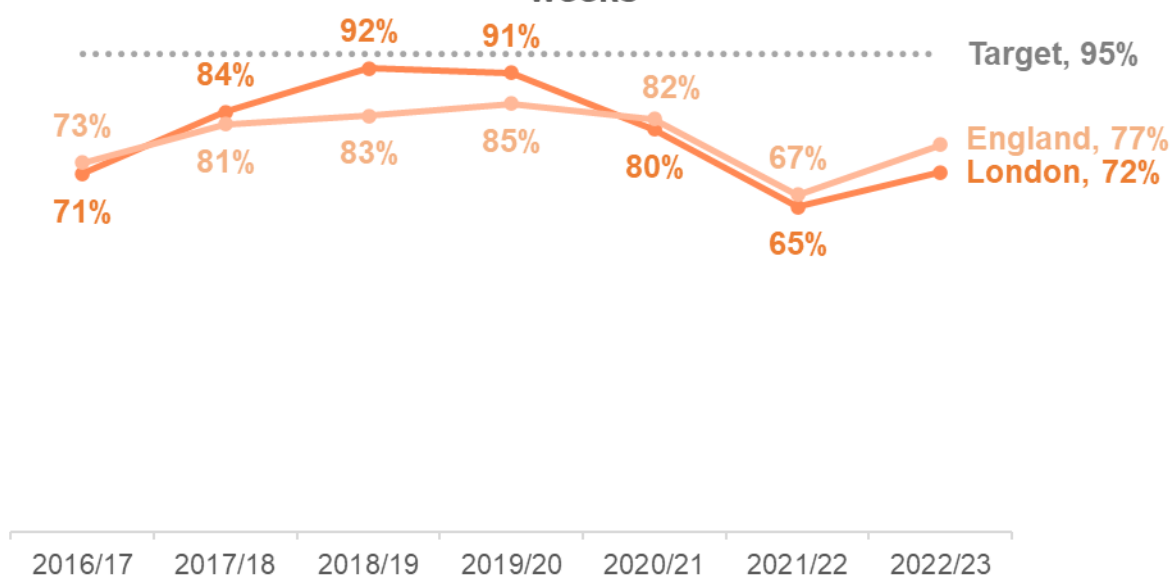
Source: London Assembly Health Committee analysis of NHS England, Children and Young People with an Eating Disorder Waiting Times<sup>43</sup>

<sup>41</sup> NHS England, [Children and Young People with an Eating Disorder Waiting Times](#)

<sup>42</sup> NHS England, [Children and Young People with an Eating Disorder Waiting Times](#)

<sup>43</sup> NHS England, [Children and Young People with an Eating Disorder Waiting Times](#)

### Proportion of routine children and young people eating disorder cases starting treatment within four weeks



Source: London Assembly Health Committee analysis of NHS England, *Children and Young People with an Eating Disorder Waiting Times*<sup>44</sup>

Waiting time standards have not been implemented for adult services. Therefore, trusts have not been required to report on waiting times for adults to access services following referrals.

However, the Committee has received data on waiting times for adults from NHS trusts in London through FOI requests. Six of seven trusts were able to provide data in response.

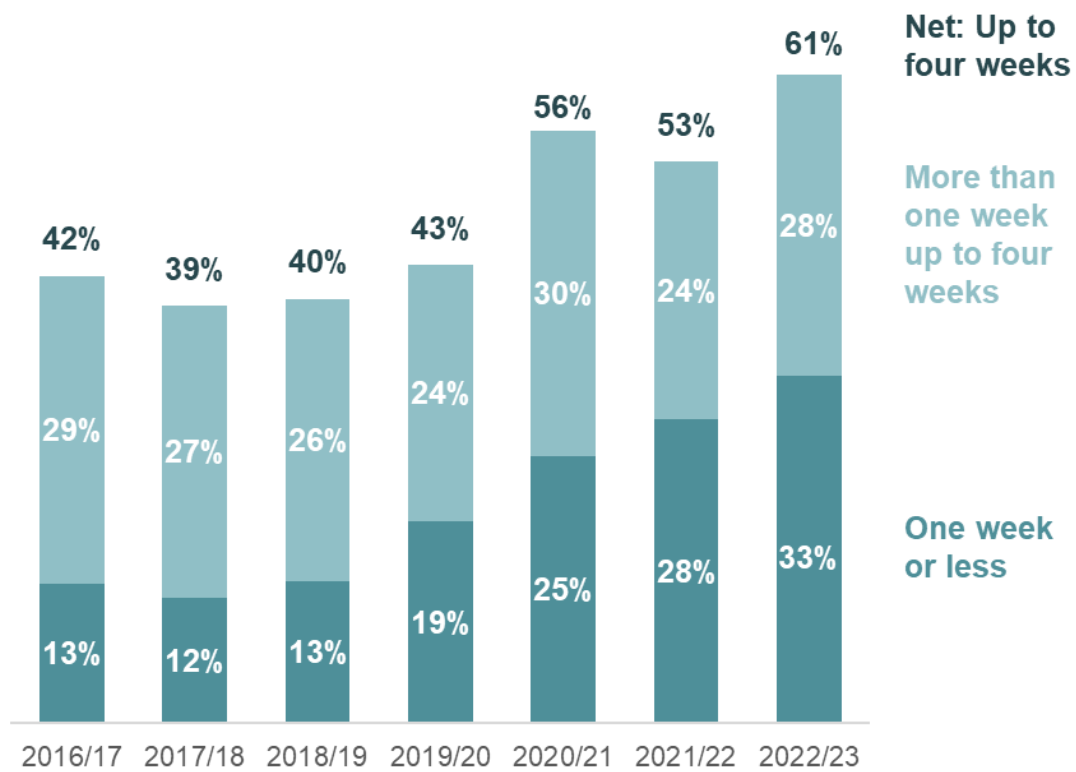
The Committee's analysis found that, in 2022-23, 61 per cent of adults referred for treatment started it in four weeks or less, including 33 per cent who started treatment within one week. This shows an improvement in waiting times since 2016-17, when around 42 per cent of patients started treatment within four weeks, and only 13 per cent of people started treatment within a week. This improved access to treatment has been achieved despite an increase in the number of patients being referred.

The Committee's analysis of information, provided by Trusts and published by the NHS, suggests that the proportion of adults waiting 12 weeks or more has not decreased in recent years in the same way it has for children and young people. In 2022-23, 18 per cent of adults waited 12 weeks or more, compared to approximately 4 per cent for children and young people across both urgent and routine cases.<sup>45</sup>

<sup>44</sup> NHS England, [Children and Young People with an Eating Disorder Waiting Times](#)

<sup>45</sup> The Committee notes that this data was affected by a cyber incident in 2022-23

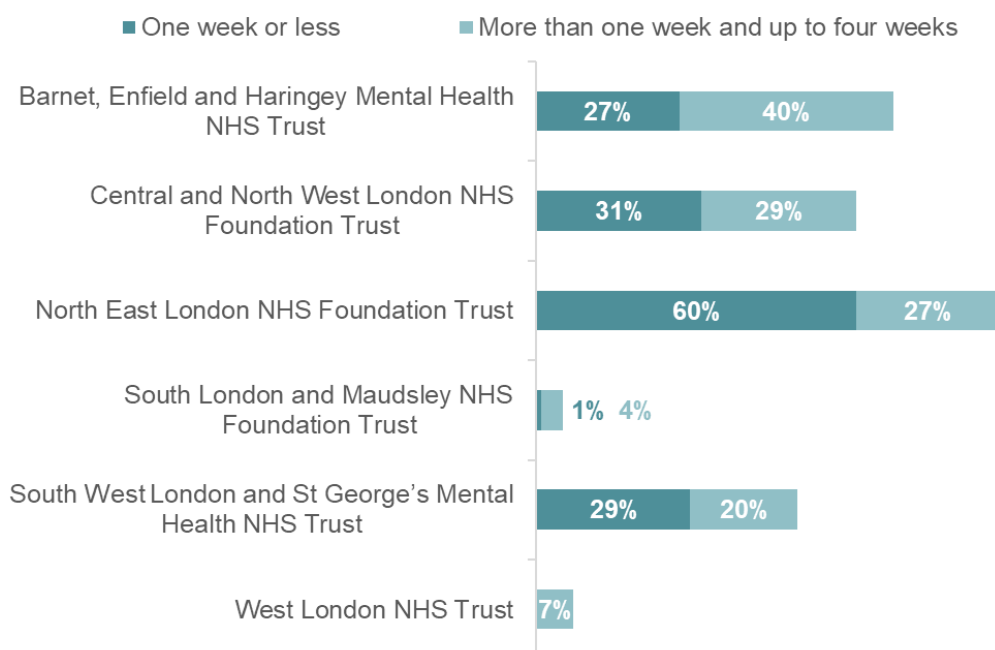
Proportion of adults waiting up to four weeks for treatment in London



Source: London Assembly Health Committee analysis of Freedom of Information data received from Trusts. One Trust was not able to provide information before 2019-20.

Source:

**Proportion of adults waiting up to four weeks for treatment in London by Trust, 2022/23**

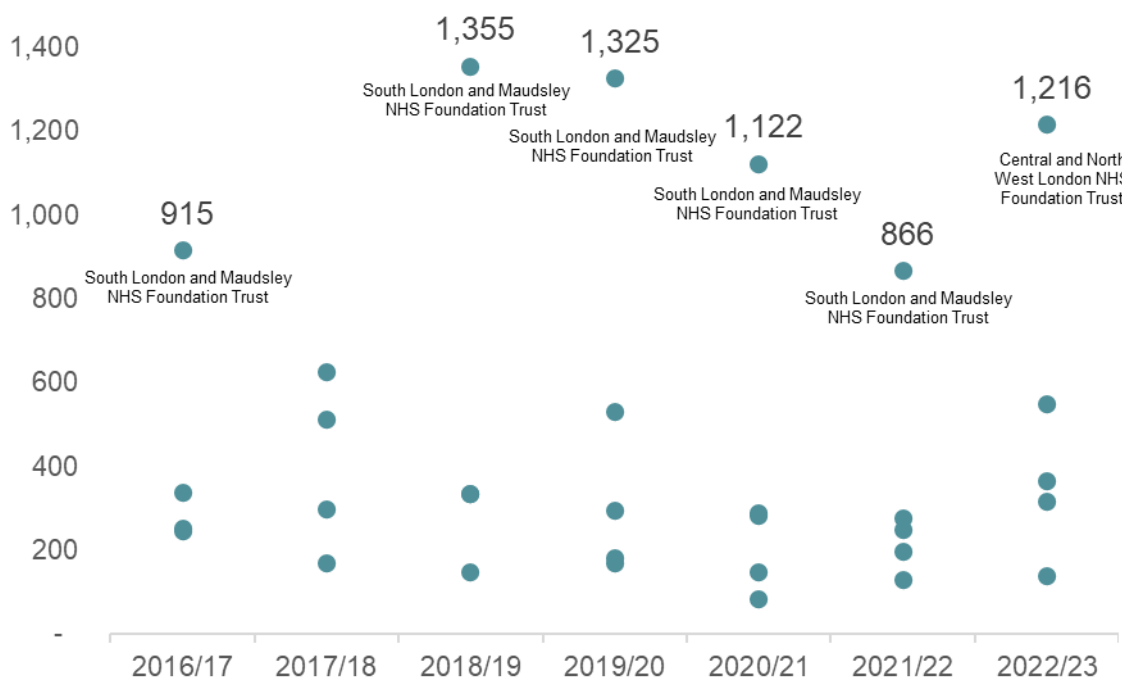


*Freedom of Information data received from Trusts by the London Assembly Health Committee*

Additionally, there was significant variation between Trusts. Last year, 60 per cent of adult patients in one trust started treatment within a week of referral, significantly higher than the average across trusts, with the second highest being 31 per cent.

The Committee also asked Trusts about the longest number of days that an adult patient has waited for eating disorder treatment for each year since 2016-17, and found significant variation (as outlined in the graph below). The longest number of days waited by adult eating disorder patients amounted to over three years in total, with four of five Trusts providing information having a patient waiting over a year for treatment. One Trust reported a wait of 1,355 days for a patient starting treatment in 2018-19, and another reported a wait of 1,216 days for a patient before starting treatment just last year. The Committee notes that there may be a range of reasons for variation among Trusts. It also notes that the longest wait times are not necessarily reflective of the average wait times, which are considerably lower. In 2022-23, the lowest average waiting time for a Trust was 65 days and the highest was 198 days.

**Longest number of days an adult patient has waited for treatment across Trusts**  
*each dot represents a Trust's longest number of days per year*



Source: Freedom of Information data received from Trusts

**Impact of waiting times**

Some respondents to the Committee’s survey, including both people with experience of CAMHS and adult services, said the process from referral to assessment and treatment was fast and effective:

“Fast referral, assessment, diagnosis, treatments and intervention. All staff were very caring and supportive.”

“I received a lot of support during my diagnosis and was able to access inpatient treatment promptly.”

“Once I was referred to CAEDS [child and adolescent eating disorder services], 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.”



However, many other respondents had waited significant periods of time to access treatment, including some waiting over a year. Some respondents said they had opted to pay for private treatment due to challenges in accessing NHS treatment, with one stating that “waiting lists were so long we had to re-mortgage the house to pay for private treatment.”

Several respondents to the Committee’s survey stated that their health deteriorated whilst waiting to access care, including some who described the perverse incentive to get more unwell to access services faster:

“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.”

“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 Committee heard that even short waits for services can be extremely challenging for people, particularly if people have come forward to seek support for the first time. One respondent described how they felt: “You've opened the wounds but don't have a plan, which can worsen the anxiety.” Another respondent who waited two months following diagnosis to start treatment said: “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.”

One respondent, who supported their child to access services, described the challenges they and their child faced waiting six weeks to access CAMHS after their first assessment:

“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.”

Dr Brian Sreenan, Consultant Psychological Lead for Disordered Eating, NHS East London Foundation Trust said that being placed on a long waiting list could also impact someone’s outcomes from treatment. He said that services can miss opportunities to support people while they have the motivation to get better, and that “people stay on waiting lists for months, if not years, and that motivation to change can dwindle, so people are caught in the trap for even longer”.<sup>46</sup>

Dr Ashish Kumar described how long waiting lists can worsen physical health and make it more challenging for patients to engage in therapy. He said, “As a result of this waiting, what

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<sup>46</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.20

happens is that these patients become worse and worse [...] if your brain is starved and if you are offering them therapy, they are not going to engage as they would engage if they were properly nourished".<sup>47</sup>

At the Committee's private meeting with people with lived experience, guests described experiencing waits of between five to eight months to access services in London after the initial referral. One guest described how this wait negatively impacted their mental health:

"From being referred in January to being properly diagnosed in May, it was then early October when I started the sessions. That period between May and October, I felt completely suicidal the whole time. That was one of the reasons why anorexia has the highest mortality rate."

The same guest went on to say that they received no support while they were on the waiting list:

"There was absolutely nothing [in the way of support]. My GP, nothing, and I just felt like I have never felt so mentally unwell in my entire life as I did. When I finally got in, there was such a sense of relief and my therapist was great, I cannot fault her. I think I was very lucky. But that period between May and October, I look back and I think I am really quite surprised that I did not do something to really hurt myself then. It was just too much."

Dr Brian Sreenan confirmed that little support was provided to people on waiting lists: "The reality is not a lot is given when it comes to an eating disorder perspective". He added:

"There are handouts and psychoeducation given to people. In terms of people turning to other ways of regulating their emotions, through self-harm or other things like that, there are other services that people can access whilst waiting, like home treatment teams or crisis services across NHS trusts. There are some initiatives in other areas of the country where there are podcasts being made for people who are on waiting lists and some educational videos and books that people can be supported to read through. The staffing level is that chronic that people cannot be supported."<sup>48</sup>

Some respondents to the Committee's survey also noted the lack of support for people on waiting lists, including one respondent who said the lack of support provided whilst on waiting lists ultimately undermined the effectiveness of the treatment they eventually received:

"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."

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<sup>47</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.4

<sup>48</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p. 20

Another respondent urged for there to be “more support when on the waiting list”. They stated that services should not “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.”

### **Recommendation 3**

The GLA Health team should work with NHS trusts across London to ensure that: all people on waiting lists for eating disorder services are provided with clear information and resources; and additional interim support is commissioned for those on waiting lists who are at higher risk.

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### **BMI thresholds for accessing services**

National Institute for Health and Care Excellence (NICE) guidance on the recognition and treatment of eating disorders states that “unusually low or high BMI or body weight” should be taken into account when deciding to refer people for assessment. However, it states that these factors should not be used on their own to determine whether people are offered treatment or whether people should be admitted to day patient or inpatient care. Instead, the guidance states that BMI or body weight must be considered alongside a range of other physical and mental health indicators.<sup>49</sup>

London clinical experts also told the Committee that BMI alone is not an appropriate measure to assess someone’s need for treatment, since it does not take into account the severity of mental ill health of each patient. Dr Brian Sreenan said that “somebody can have a normal BMI, but be psychologically extremely unwell and vice-versa as well”.<sup>50</sup> Dr Karina Allen, Consultant Clinical Psychologist, Eating Disorders Outpatients Service - South London and Maudsley NHS Foundation Trust, told the Committee that to determine access to services, clinicians required “a whole picture of someone’s mental health and someone’s physical health”.<sup>51</sup>

However, it is not clear that NICE guidance is always followed in London. For example, several respondents to the Committee’s survey stated that they had been turned away from treatment due to their BMI or body weight not being deemed low enough to require treatment:

“I was refused treatment because my weight wasn't low enough.”

“the biggest barrier for early treatment was weight/BMI not being low enough to access treatment.”

“my BMI not being low enough for treatment.”

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<sup>49</sup> NICE, [Eating disorders: recognition and treatment](#), 16 December 2020

<sup>50</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.20

<sup>51</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.19

Hope Virgo, author and campaigner and person with lived experience, also told the Committee that she knew of cases – both nationally and in London – of people being turned away from services if their BMI was not deemed low enough to require urgent care.<sup>52</sup>

The Committee heard a range of evidence to suggest that significant capacity pressures within eating disorder services in London are creating pressures whereby BMI or body weight is used as an indicator of immediate risk to determine who should have priority access to services.

For example, Dr Brian Sreenan stated that “people with certain BMIs jump the queue and get seen exceptionally fast compared to their fellow residents”.<sup>53</sup> This is reflected in the experience of some survey respondents, who suggested they were essentially fast tracked after losing a significant amount of weight:

“I only got help when I was severely underweight, when I was only a little underweight the GP and crisis team didn't care.”

“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.”

“they suddenly sped things up when I lost a lot of weight.”

Dr Brian Sreenan described the “perverse incentive” this creates for people seeking referrals or on waiting lists “to become more and more unwell in order to get treatment”.<sup>54</sup> A guest with experience of supporting their daughter also suggested that this was the case, stating that “we are all standing around waiting for this patient to become so chronically ill”. They described how their child reacted to being turned away from services:

“When they are then told that, ‘We cannot give you a place at the moment’, those words mean, ‘You are not ill enough’, and therefore my daughter would come out of those meetings going, ‘You see, I am not ill’, and then go completely down the pan. But why are we waiting for that to happen?”

One guest told the Committee that “throughout the country, you have to get to a certain weight, which is wrong, because if you get to that certain weight it is just that much harder to get them back”. Another guest told the Committee of the limitations of using weight or BMI to determine access to services:

“the first time I went for my weigh-in at [London NHS eating disorder service] I was just marginally below the healthy BMI, just within the underweight category, then for five weeks I was hugging the bottom line of the weight, therefore technically I was fine. I was not fine at all [...] I think the whole thing around weight is unhelpful. But BMI just possibly needs to be scrapped”.

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<sup>52</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.18

<sup>53</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.20

<sup>54</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.20

Whilst the Committee acknowledges the capacity pressures facing eating disorder services in London, we are concerned that the use of BMI or body weight to prioritise patients' access to services can lead to further deterioration of physical and mental health amongst highly vulnerable people. This deterioration will only create further pressures for services downstream, leading to more patients with increasingly severe and complex issues needing treatment.

In January 2022, the Mayor stated that he was "deeply concerned by reports that Londoners are being turned away from care or treatment" and said that "NHS England and Improvement and Healthy London Partnership<sup>55</sup> are working with adult eating disorder services to ensure that AED pathways remove any barriers to access such as weight or BMI."<sup>56</sup>

Emma Christie, Head of Mental Health, NHS London said that "the BMI threshold should never be the sole basis for a decision about access to services" but said that "there will be scenarios where, to all intents and purposes, from a service user's experience, they do feel like they are being excluded".<sup>57</sup> Dr Karina Allen told the Committee that some services in London may use BMI as a criterion when they have been specifically commissioned only to treat moderate to severe eating disorders. However, she said: "The fact that we have patients being stratified off based on BMI or other somewhat arbitrary criteria around severity is far from best practice".<sup>58</sup>

The Committee is also concerned about the wider impact that the use of BMI and body weight on determining access to treatment can have in reinforcing the stigma and misunderstanding experienced by many people who have an eating disorder but are not underweight. Several respondents cited this stigma in their responses:

"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 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 checkups. Eating disorders are not weight disorders."

"I think if someone is a healthy weight then eating disorders remain stigmatised and untreated, leaving those affected unsupported and suffering in silence."

"You have to fit a stereotype (really low weight etc) to get any help. There is a lot of fatphobia within ED services."

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<sup>55</sup> Healthy London Partnership was established by the NHS in 2015 and is now known as Transformation Partners in Health and Care. It provides consultancy support to NHS London agencies to assist with transformation programmes.

<sup>56</sup> London Assembly, [MQT – Eating disorders in London \(2\)](#), 24 January 2022

<sup>57</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.21

<sup>58</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.19

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One respondent, who was caring for their child with an eating disorder, expressed their fear that BMI or weight measurements could prove a barrier to their child accessing services:

“As a mother I fear they will turn her away due to her BMI being too high and then fear she will lose 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.”

Several survey respondents called for BMI and weight to be scrapped as measure to determine access to treatment. For example, one respondent stated that “weight and BMI should not be indicators for treatment.” Another urged that services “DO NOT base qualification on low BMI” and another stated that “BMI should NOT be a criteria for entering treatment.” One respondent, who stated that BMI and weight should not be used to determine access to treatment, also stressed that an eating disorder “is a MENTAL HEALTH DISORDER, NOT a weight disorder.”

#### **Recommendation 4**

The Mayor should lobby NHS England (London) to ensure that health services are not rejecting nor prioritising patients for treatment for an eating disorder on the sole basis of BMI, as stipulated in NICE guidelines.

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## Chapter three: capacity pressures facing services in London

### Workforce challenges

The Committee heard concerning evidence that there are significant workforce challenges within eating disorder services in London. While guests stressed that capacity pressures were felt nationally, Dr Karina Allen suggested some pressures may be heightened in London:

“There are some areas of the country that are faring worse than London, but London has a large population, so that is where London is more vulnerable. When demand goes up, the services really struggle to keep up so that is where London is perhaps facing a particular pinch point in recent years as the demand has increased and services have not been able to respond to meet that”.<sup>59</sup>

Andrew Radford told the Committee that the single biggest issue impacting eating disorder services nationally is workforce challenges.<sup>60</sup> Dr Allen told the Committee that “almost all of the eating disorder services in London do not have the staffing levels available to safely provide the care required”.<sup>61</sup> She said staffing services in London has become “extremely difficult”:

“Historically, London did better than some areas of the country at recruiting and retaining clinicians in NHS services, but that has changed over recent years both in terms of the cost-of-living crisis but also with patterns of hybrid and remote working. People are no longer needing to be based in London in the way they once were and this is contributing to more geographical diversity in where people are choosing to base themselves. London has been particularly hard-hit by recruiting and retaining clinicians in the eating disorder services that need them”.<sup>62</sup>

Dr Victoria Chapman, Consultant Child and Adolescent Psychiatrist, Royal Free CAMHS, described the challenge of staff retention in London CAMHS:

“There is a limited number of trained staff within the workforce for children and adolescents and they tend to just move from one team to another. What results is that teams get left without enough staff and then cannot meet the needs of their patients.

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<sup>59</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.28

<sup>60</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.26

<sup>61</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.2

<sup>62</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.25

Training and thinking about a sustainable workforce is really important in eating disorders.”<sup>63</sup>

Dr Brian Sreenan described similar challenges faced by adult services in London:

“In adult services we are robbing Peter to pay Paul all over the place. People just go from one service to another but there is no new blood coming into the system that will actually help us reach the targets and the huge demand that is placed on the system.”<sup>64</sup>

A respondent to the Committee’s call for evidence, who currently works with the Eating Disorders Day Unit at South West London & St. George’s Mental Health NHS Trust, wrote:

“Capacity to accept patients can be limited due to there not being enough staff for the referral rate. There is also not enough occupational therapists in eating disorder services [...]. As an Occupational Therapist myself working on a day unit I often cannot do half the things I would like to do, simply because I am the only OT and have to split my time between other generic tasks”.

In written evidence, the Royal College of Psychiatrists said that there were 78 eating disorder consultant psychiatrists in post in England in 2021, of which 16 were in London. This was the same number of consultants as reported in 2019. The evidence stated that there were three vacant substantive consultant posts in London in 2021.<sup>65</sup>

The Committee is concerned that workforce challenges are negatively impacting experience of and outcomes from treatment. We heard evidence that workforce pressures were being exacerbated by a high turnover of staff, and leading to an overreliance on inexperienced or temporary healthcare staff.

For example, one survey respondent shared that they had felt their community eating disorder team to be “inexperienced and unprepared to deal with anorexia, making comments and doing absolutely nothing when my weight was dropping to dangerous levels.” Another respondent described their care as “a mixture of good and terrible both in the same establishment” and stated that agency staff were inexperienced and held unkind attitudes. Another respondent described their experience of seeing an inexperienced dietitian:

“Initially I saw a dietitian 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”.

A guest at the Committee’s private meeting said their child had not received good care from “bank and contracted staff”:

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<sup>63</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.5

<sup>64</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.15

<sup>65</sup> Written evidence - Royal College of Psychiatrists. Published alongside report.



“I want to say that there are fantastic people in the NHS. But there is a lot of bank and contracted staff who should not be working within the health service and it is very dangerous. As far as I am concerned, they are not qualified - maybe on paper - but they are not the right people to be in that vicinity and they should not be anywhere near the patients”.

The same guest suggested the reliance on temporary staff was related to the high turnover of staff, which they attributed in part to poor working conditions:

“This is a massive issue and when you talk to a lot of people, which I did at the unit, about why they wanted to go, it was not because they did not like their job, it was because of the logistical nightmare of being underpaid, which we keep hearing all the time in the NHS, and also all the red tape that came with the job. It was not the job that they first took on”.

The Royal College of Psychiatrists, in written evidence, stated:

“The workforce is experiencing burnout, high turnover, and leaving for the private sector as take-home pay is higher and the risk and workload are at a lower risk. This has a negative impact on training and research, as well as on the stability of NHS services”.<sup>66</sup>

## **Funding of services**

Several respondents to the Committee’s survey argued that eating disorder services in London did not receive sufficient funding. One respondent who has supported someone with an eating disorder perceived services to be “hopelessly under-resourced even though there are dedicated individuals trying their best in a service not fit for purpose.” One respondent with experience of accessing adult services in London stated that “the funding provided to eating disorder services by the government is wholly inadequate.”

Some respondents said that additional funding for services could help to improve access to, and outcomes from, services. For example, a respondent to the survey who works with those with eating disorders called for “more funding for NHS services to expand our provisions and remit”. Other respondents with personal experience of accessing services in London said there should be:

“More funding for treatment to reduce waiting lists, wider availability for treatment - not just for patients at their deepest lows.”

“More funding for NHS ED services, which would mean more eating disorders could be caught earlier, improving prognoses significantly.”

NHS England has received additional funding for child and adolescent eating disorder services in recent years. Following new waiting time standards introduced from 2014, £150 million was invested in children and adolescent eating disorder services nationally. Further investment was

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<sup>66</sup> Written evidence - Royal College of Psychiatrists. Published alongside report.

committed in the 2019 NHS Long Term Plan to allow the NHS to “maintain delivery of the 95 per cent standard beyond 2020/21”.<sup>67</sup>

Guests welcomed this additional investment in child and adolescent services. However, Dr Ashish Kumar expressed concern that “sometimes the money which was intended for children’s eating disorder services has not reached the front line”.<sup>68</sup> He referred to work conducted by Beat, on behalf of the All Party Parliamentary Group on Eating Disorders, which found that in 2019-20 only a small proportion of the additional funding for eating disorder services was actually spent. Beat estimated that in London, only 17 per cent of additional funding allocated for 2019-20 was actually spent.<sup>69</sup> Beat suggests that challenges in recruiting staff to eating disorder services may have contributed to the underspend.

Guests also suggested that while child and adolescent services had received significant additional investment in recent years, adult services had not benefitted from investment. Dr Brian Sreenan told the Committee “there is a huge gap in the amount of funding that adult services get compared to children services”.<sup>70</sup> Dr Ashish Kumar said additional funding was needed in adult eating disorder services: “On one hand, we have a very good example of improved care in children’s eating disorders, but there is a disparity in adult eating disorder services”.<sup>71</sup>

Dr Agnes Ayton told the Committee that the additional funding placed into children and adolescent services was partly intended to ensure early interventions and “reduce the number of people who will have an eating disorder in adulthood”. However, she said that this has created a “a two-tier system when a 17-year-old can wait a week for an urgent assessment and then an 18-year-old has six months to a year of waiting time”.<sup>72</sup>

Emma Christie told the Committee that alongside additional investment for children and adult services, “there has been significant additional investment in eating disorder specialist pathways for adults through our Community [Mental Health] Transformation Programme”.<sup>73</sup>

## Availability of services across London

Some responses to the Committee’s survey indicated inconsistent service provision across London, which led to some people travelling long distances to access care:

“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.”

“distance from eating disorder clinic to where I live [was a barrier to accessing services]. Had to travel from Walthamstow to Barking minimum twice a week for months on end.”

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<sup>67</sup> NHS England, [Long Term Plan](#), January 2019

<sup>68</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.4

<sup>69</sup> Beat and APPG on Eating Disorders, [Short-changed: Funding for children and young people's community eating disorder services in England in 2019/20](#), May 2021

<sup>70</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.15

<sup>71</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.4

<sup>72</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.5

<sup>73</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.2

Another respondent described a “postcode lottery” of available services in London. Another respondent, who works with people with an eating disorder, noted that there were: “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.”

The Committee also heard that some people lost access to services when they moved away from London, for example to attend university. One respondent said that, “despite improvements”, people accessing eating disorder services when they turn 18 or move between areas “frequently fall through gaps.” They said there should be more flexibility when people move between London boroughs. Another respondent suggested there should be a “cross London solution” or that NHS services should be better joined up.

This was similarly highlighted in written evidence from Goldsmiths, University of London, which included views from members of the Central London Self Help Support Group for Adults with an Eating Disorder:

“The lived experiences of people with an ED in London reveals that where they are located is often contingent as to whether they receive the support they need. In some cases, there are lengthy waiting lists with wait times of over a year for adult services. This can be compounded if someone moves to a new borough. This has meant that some people have lost their place on the waiting list as they need to be referred to a service within their new borough. This could mean a further delay in receiving treatment”.<sup>74</sup>

Guests also told the Committee that provision of support for different types of eating disorder services across London was inconsistent.<sup>75</sup> For example, Andrew Radford told the Committee that some trusts do not commission services for binge eating disorders, and Dr Brian Sreenan said that not all trusts in London accepted referrals for avoidant/ restrictive food intake disorder (ARFID).<sup>76</sup>

### Recommendation 5

The GLA Health team should work with NHS England (London) to conduct a London-wide audit of available eating disorder services, to identify and address any gaps in provision for particular eating disorders, such as binge-eating disorder and avoidant/restrictive food intake disorder.

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## The impact of COVID-19

The Committee heard how COVID-19 has been associated with a significant increase in demand for eating disorder services. Dr Karina Allen told the Committee how consequences of the COVID-19 pandemic could have caused triggers for people who were already vulnerable to an

<sup>74</sup> Written evidence - Goldsmiths, University of London. Published alongside report.

<sup>75</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.28

<sup>76</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.26; London Assembly, [Health Committee – transcript](#), 21 September 2023, p.7

eating disorder, including the stress of the pandemic itself, people losing structure in their day, uncertainty and loss of control, lack of social support, and food shortages.<sup>77</sup>

A guest at the Committee's private session said: "I think a lot of people had an eating disorder were really experiencing hell [during COVID-19 lockdowns]. I was really noticing in my own behaviours a lot of stuff I was struggling with".<sup>78</sup>

Dr Karina Allen also said that fewer people sought support for eating disorders under a time of great pressure for the NHS, effectively creating a backlog of demand: "We were all being told to protect the NHS, so there was a drop in referrals or people seeking help for an eating disorder initially. There was an avalanche later on, with services opening up again, which we have still not caught up on".<sup>79</sup>

Andrew Radford said Beat helped four times as many people each month during the height of COVID-19 than it had before the pandemic.<sup>80</sup> Jessica Griffiths said: "The general consensus is that eating disorder rates have increased across the pandemic generally across the age range."<sup>81</sup>

Dr Victoria Chapman told the Committee of the additional pressures CAMHS experienced during COVID-19: "In CAMHS eating disorder services in London, towards the end of the pandemic, there was a two-and-a-half times increase in the number of referrals to some services across London in our service".<sup>82</sup> She said that this heightened demand increased pressure on services and negatively impacted performance against waiting time standards for children and adolescents: "the pandemic has had a huge impact and some of the Access and Waiting Time Directive key performance indicators have not been met".<sup>83</sup>

Emma Christie said: "Coming out of the COVID period, the most obviously impacted service line seems to be children's and young people's eating disorders with really significant increases in demand. We could see that in the access standard data, which had been holding steady at 95 per cent across both routine and urgent cases for a number of years and suddenly, as colleagues reflected it dropped."<sup>84</sup>

The Committee also heard that services saw an increase in severity of cases during and following the pandemic. Dr Victoria Chapman said that CAMHS services saw an "increase in very unwell young people who needed a lot of support and admissions to paediatric wards".<sup>85</sup> Emma Christie also observed an "ongoing trend" of children and young people becoming sicker and needing more intensive support. She suggested this increase in severity negatively impacted routine referral times, as sicker patients were prioritised.<sup>86</sup>

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<sup>77</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023

<sup>78</sup> Health Committee private meeting with people with lived experience

<sup>79</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.15

<sup>80</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.15

<sup>81</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.9

<sup>82</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.8

<sup>83</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.5

<sup>84</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.8

<sup>85</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.4

<sup>86</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.8

Both Dr Victoria Chapman and Emma Christie said additional funding and investment has gone into children's services to support the response post-COVID, and that this has improved response times. However, Dr Victoria Chapman warned that demand "is still above pre-pandemic levels", which she suggests may stem from "a gradual year on year increase in presentations for eating disorders that has been going on longer than the pandemic".<sup>87</sup>

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<sup>87</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.8

## Chapter four: improving quality of care

### Positive and negative experiences of treatment in London

The Committee heard varied accounts of people's experiences in accessing eating disorder services in London, including inpatient and outpatient care across both CAMHS and adult services.

Some respondents described very negative experiences. Respondents variously described their experience of treatment as "poor – just poor"; "poor therapists, poor care/ treatment, poor therapy, poor access to support. overall, a bad experience"; "Diabolical. 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".

Other respondents to the survey indicated that they felt services to be impersonal and to have lacked compassion. One respondent described their treatment as "one size fits all rather than focusing on individual needs". Other respondents suggested that they lacked input into the treatment they received:

"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".

"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".

"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."

The same respondent described their overall experience of treatment in NHS services as "disjointed, traumatic, and bewildering" and said that:

"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".

Other respondents described receiving interrupted treatment due to services not being joined up within the NHS, transitions being poorly managed between services or other issues such as high staff turnover. One respondent stated that "I have found treatment fragmented and mostly ineffective", while another described it as "a long and confusing process". One respondent gave a detailed description of their experience of supporting their child through CAMHS in London, highlighting in particular the challenges they faced in accessing support for

physical health complications associated with their child's eating disorder through CAMHS. The respondent called for changes to how CAMHS supports children:

"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".

The Committee heard from several other people with very positive experiences of treatment. For example, one respondent described treatment as "difficult and daunting... But the service also saved my life so I am grateful". Another respondent, who described their experience of treatment as "very good", reported having a great deal of agency in their treatment:

"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".

Other respondents praised various aspects of the care they received in London:

"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".

"I speak very highly of the care I received as an inpatient, day patient and outpatient".

"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".

Some respondents to the Committee's survey described positive experiences of being supported by excellent and caring healthcare staff in the NHS. One respondent described a nurse supporting them as "empathetic, experienced, encouraging and supportive". Other respondents also spoke highly of healthcare staff:

"the staff I've seen so far have all been really nice and haven't said anything triggering to me [...] ED services actually kind of make me want to get better".

"I felt very comfortable and able to open up as the lady I spoke to was lovely".

"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".

A guest at the Committee's private meeting described their NHS therapist as "amazing". They said: "It is a massive challenge, recovering as an adult because no one can force you to be there. Therefore, it is really delicate the way they approach it. I was referred for 12 weeks of cognitive behavioural therapy and I found it really effective".

The Committee notes that London has hosted some examples of excellent practice, such as the First Episode Rapid Early Intervention for Eating Disorders model (FREED) which was founded at the South London and Maudsley Trust (see below). The current challenges faced in London are also not unique to other parts of the UK.

### Good practice: FREED

The First Episode Rapid Early Intervention for Eating Disorders model (FREED) was developed by the eating disorders unit at South London and Maudsley Trust and King's College London in 2014.<sup>88</sup> FREED aims to improve services to young people aged between 16 and 25 who have had an eating disorder for less than three years.<sup>89</sup> FREED has improved treatment outcomes, including reductions in waiting times for accessing treatment and improving outcomes from treatment.<sup>90</sup> Subsequent studies appear to support the findings from the initial trial.<sup>91</sup> FREED has since been rolled out to several eating disorder services across England.<sup>92</sup>

Dr Ashish Kumar described FREED as a “fantastic model”. A respondent to the survey with experience of supporting their child stated that “FREED take concerns seriously” and praised the quick referral and expertise of the staff. Dr Ashish Kumar said access to the FREED intervention “has been quite patchy across London services” and recommended for greater investment to provide more consistent access to FREED.<sup>93</sup>

The 2017 ‘Ignoring the alarms’ report by PHSO identified several failings in how NHS eating disorder services were working nationally, including around the management of referrals between services; the management of hospital discharge; and the level of support offered by specialist adult eating disorder services.<sup>94</sup>

In February 2023, the PHSO again raised concerns about eating disorder services nationally, stating: “People with eating disorders are being repeatedly failed by the system and radical changes need to be made to prevent further tragedies”. It said little progress had been made since the publication of its 2017 report, and added that it had received 234 complaints related to eating disorders since April 2019.<sup>95</sup>

Guests also told the Committee that there were national challenges. Andrew Radford told the Committee that there is nowhere in the UK that is “meeting the need and doing it in a way that gets people into and through treatment quickly”.<sup>96</sup> Dr Allen said “I do not think again there are many areas in England where you could say that there is an eating disorder service that is

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<sup>88</sup> FREED, [The Maudsley Story](#)

<sup>89</sup> [FREED](#)

<sup>90</sup> FREED, [What is FREED](#)

<sup>91</sup> [Early intervention in psychiatry](#), The First Episode Rapid Early Intervention for Eating Disorders - Upscaled study: Clinical outcomes, 29 March 2021

<sup>92</sup> FREED, [The Maudsley Story](#)

<sup>93</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.18

<sup>94</sup> PACAC, [Ignoring the alarms follow up](#), 18 June 2019

<sup>95</sup> PHSO, [Urgent action needed to prevent eating disorder deaths](#), 27 February 2023

<sup>96</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.28



perfectly matching the needs of the local community".<sup>97</sup> Dr Ashish Kumar said: "Many of the recommendations of the PHSO report, which came out in 2017, have not been implemented, unfortunately".<sup>98</sup>

## Care for the most unwell patients

The Committee also heard examples of eating disorder services in London struggling to provide care for the most seriously ill patients, for example children and young people who do not necessarily want to cooperate with treatment. One respondent described their experience of supporting someone else through treatment as "very stressful and often felt hopeless". They said: "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."

A respondent to the survey who supports their child with an eating disorder also highlighted how eating disorder services were not set up to provide treatment for patients who self-harmed or were at risk of making attempts to take their own life. They stated: "We found the eating disorder ward unable to cope with my daughter's suicide attempts when regaining weight". They said that when their child was then transferred to an "adolescent psych ward" the parents were told the ward "couldn't support her eating as they're 'not an eating disorder ward' and let her skip meals". The respondent also said they had "consulted a range of private facilities, but were told our daughter was too ill and risky for them".

Another respondent stated: "I was told that bingeing and self harm meant I could not be treated as an inpatient". [Following an incident of self harm] I was not allowed on the ward for a week. Leaving me with no support when I was most at risk". They said that their experience of services had left them with trauma and that when they developed further disordered eating in later years, they avoided seeking any help due to their previous experience.

## Length of care and managing discharges

Some survey respondents shared experiences of being discharged from services when they felt the underlying causes of their eating disorder had not been addressed. They suggested that the focus of services was primarily on weight restoration and there was not enough support provided to address the underlying causes of the condition, which increased the likelihood of people being readmitted:

"My daughter was discharged from services before making a full recovery".

"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".

"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".

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<sup>97</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.28

<sup>98</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.7

“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”.

Other respondents shared positive experience of their treatment but said the support was simply not provided for long enough, and with very limited step-down support offered for people who are discharged from services: “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”.

Some respondents called for services to better support people towards longer term recovery. One respondent stated that services should aim to “Help someone strive for full recovery not a partial recovery still driven by an eating disorder” and another stated that “the door shouldn’t 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”. The Committee heard how integrated care models could be adopted more widely across London to achieve better care pathways (see below).

### Good practice: integrated care models

The integrated cognitive behaviour treatment (I-CBTE) model, trialled by Oxford and Marlborough NHS Trust, combines a planned 13-week admission to hospital with the goal of full weight restoration; seven weeks of ‘stepped down’ day treatment; and a further outpatient treatment over a total period of 40 weeks.<sup>99</sup> Dr Agnes Ayton told the Committee that “people who received I-CBTE Model had 70 per cent recovery rate as opposed to five per cent in treatment as usual. The readmission rates were 15 per cent instead of about 50 per cent with treatment as usual”.<sup>100</sup> The Royal College of Psychiatrists has encouraged commissioners and NHS mental health providers to consider implementing this model in their areas.<sup>101</sup>

Emma Christie said that while she was not aware that the specific ICBT-E model had been adopted anywhere in London, there was a focus on providing strong integration across inpatient and community settings in London.<sup>102</sup> Jessica Griffiths also told the Committee that “many of the eating disorder services within London” are “implementing an integrated care model”, including two integrated care models for treating anorexia nervosa: Maudsley Anorexia Nervosa Treatment for Adults (MANTRA); and Specialist Supportive Clinical Management (SSCM).<sup>103</sup>

<sup>99</sup> Journal of Eating Disorders, [Integrated enhanced cognitive behavioural \(I-CBTE\) therapy significantly improves effectiveness of inpatient treatment of anorexia nervosa in real life settings](#), 8 July 2022

<sup>100</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.16

<sup>101</sup> Oxford Health NHS Foundation Trust, [New integrated treatment could transform the lives of adults with life-threatening anorexia nervosa](#), 1 March 2022

<sup>102</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.16

<sup>103</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.14

### **Experience of people with autism accessing eating disorder services**

The Committee also heard that there is particular concern around unmet need amongst people in London with autism. In response to its call for evidence to support this investigation, Autistica – an autism research and campaigning charity – highlighted that those with autism are more likely to be impacted by eating disorders but many people will not have been identified as autistic when accessing services:

“Eating disorders are especially prevalent amongst autistic people, with as many as one in five women in anorexia services meeting diagnostic criteria for autism. In many cases, this group are not identified as autistic until long after eating disorders take hold, often involving an admission to inpatient services. In July 2022, there were almost 8,000 people on the waiting list for an autism assessment in London, the vast majority of whom were much longer than the recommended 13 weeks, and the backlog is rising fast”.<sup>104</sup>

Guests told the Committee that prevalence of eating disorders may be high amongst autistic people, but services do not always know how to effectively support people with autism. Dr Victoria Chapman told the Committee:

“The patients that sometimes become extremely ill and need admission to specialist eating disorder units often with children and young people have undiagnosed autism spectrum disorder (ASD). They have not had the assessment. Maybe they are still on the waiting list. They need a specific treatment pathway. As a result, quite often they get stuck in inpatient units without having the diagnosis and are very complex to treat. There is a gap there and it is very important that you mention the fact that the diagnosis and treatment of ASD is very important for these patients. I personally see the patients that maybe get detained under section, who spend maybe up to a year or more in inpatient units, often have that diagnosis but have not been treated”.<sup>105</sup>

One respondent to the Committee’s survey with personal experience of accessing treatment in London stated that they were told by services that they were “probably autistic” but could not access an autism assessment through the NHS. Another respondent stated that they had “difficulties getting autism diagnosis/assessment within the NHS” and that they felt this impacted their treatment outcomes, “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”.

The Committee also heard that even for people who have had an autism assessment, eating disorder services in London can be inflexible to their additional needs. One respondent to the survey stated that “autism was not considered during treatment”. Jessica Griffiths said:

“I was speaking to someone with lived experience last week who has autism and had so many hospital admissions. Because the inpatient ward was not appropriate for her needs and her accessibility needs and treatment adaptations, it really developed into a place where she lost trust in her treatment team and it became traumatic to go to the very place where she needed that support and treatment. There is a lot more we need to

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<sup>104</sup> Written evidence – Autistica. Published alongside report.

<sup>105</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.6

learn about autism and eating disorders. We know there is a huge crossover and there is a lot more we could do to support people better.”<sup>106</sup>

Jessica Griffiths praised the work of the Pathway for Eating Disorders and Autism (PEACE), a specialist pathway for people with eating disorders who also have autism, based at the South London and Maudsley Trust. She said: “There has been new research conducted that I believe is coming out in the next couple of years but we are trying to replicate that model in other trusts in London to ensure that actually there are specialised pathways for people who are autistic”.<sup>107</sup> In its written evidence, Autistica also called for more tailored interventions for eating disorders in autistic people.<sup>108</sup>

## Recommendation 6

The Mayor should request that NHS England (London) supports the roll-out of specialist care pathways across NHS trusts in London for people with autism suffering from an eating disorder.

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### Improving access to psychological therapies

Dr Brian Sreenan told the Committee that funding tends to be channelled into specialist services to support people with more severe symptoms, but that people who are at the mild to moderate end of the spectrum can be neglected or struggle to access treatment.<sup>109</sup> He said there was potential for eating disorder services to work more closely with the Improving Access to Psychological Therapies (IAPT) workforce, to provide access to talking therapies for people at the mild to moderate end of the spectrum.

One respondent to the survey, who works with adults with eating disorders in London, stated that: “The largest access to psychological treatments is provided via IAPT /Talking Therapies”, but that “Eating Disorders is largely 'excluded' from this offer”. Dr Brian Sreenan said that in East London, work had taken place to better integrate IAPT capacity with eating disorder services and suggested this should be rolled out more widely:

“The results coming out of our IAPT or talking therapies services in primary care are really excellent not only in terms of recovery rates for eating disorders but also in terms of the measures that their KPIs are based on and so the depression and anxiety measures, too. It seems to be killing two birds with one stone. I would really like to see that - maybe with the convening powers that this Assembly has - to really think more deeply with the talking therapies services as to why they cannot extend their provision for people with eating disorders”.<sup>110</sup>

Emma Christie expressed interest in following this up. She said there is work ongoing in London to integrate talking therapies with community services more effectively. She said: “We are aware that there will be people at a milder, earlier stage in their experience of an eating disorder that would definitely benefit from being able to access our talking therapy services”.<sup>111</sup>

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<sup>106</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.7

<sup>107</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.6

<sup>108</sup> Written evidence – Autistica. Published alongside report.

<sup>109</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.10

<sup>110</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.10

<sup>111</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.11

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### **Recommendation 7**

The Mayor should request that NHS England (London) reviews how the Improving Access to Psychological Therapies workforce can be utilised across London to provide better access to talking therapies for people with eating disorders.

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## Chapter five: improving support in the community

### Prevention and education

The Committee heard that improved education around eating disorders could help more people to spot the signs of an eating disorder and recognise their own symptoms, or symptoms in loved ones. Jessica Griffiths said “there are so many people whom people with eating disorders come into contact with, so many clinicians, school, workplace. All of those people need to have an awareness of how to talk to someone with an eating disorder and how to spot them and the treatment pathway, too”.<sup>112</sup>

Several respondents to the survey called for greater efforts to raise awareness in schools, colleges and universities to help identify and address eating disorders at an earlier stage:

“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”.

“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”.<sup>113</sup>

One respondent said “having some sort of a programme at schools to deliver informative lessons about eating disorders would be incredibly useful [...] 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”. Emma Christie said NHS London had supported the rollout of mental health support teams in schools, and providing them with the resources to spot early signs of eating disorders.<sup>114</sup>

Other respondents highlighted the importance of public education in specifically addressing the common misunderstandings about eating disorders, for example that “the only symptom of an eating disorder is weight control” or that you “have to be underweight to have anorexia”. Others suggested there should be efforts to promote where people can seek help if they have an eating disorder, including in offline spaces such as transport networks, local newspapers and library noticeboards.

In written evidence, Carney’s Community, a South London youth charity, said there should be “more discussions about eating disorders at school and in the media (including social media).

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<sup>112</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.14

<sup>113</sup> See also R53, R98 and R54

<sup>114</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.11

There should be more safe spaces where people can speak to trusted adults about things like eating disorders”.<sup>115</sup>

Some respondents also suggested there should be training provided in workplaces to support people to identify eating disorders amongst loved ones, and know how to approach them to discuss their condition:

“Inform family members of how to best approach a loved one with an eating disorder”.

“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”.

“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”.

The Mayor’s HIS sets out an objective that “No Londoners experience stigma linked to mental ill health, with awareness and understanding of mental health increasing city-wide”. This is a welcome goal, but it is clear that many people with eating disorders in London do face stigma and that there is widespread misunderstanding and lack of awareness surrounding eating disorders.

## **Recommendation 8**

The Mayor and the GLA Public Health Unit should design and deliver a public awareness campaign on eating disorders across London, with the aim of addressing stigma and improving signposting to support services.

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The Mayor’s HIS also sets out an objective that “Mental health becomes everybody’s business. Londoners act to maintain their mental wellbeing, and support their families, communities and colleagues to do the same”. The Mayor’s HIS commits to action towards this objective through Thrive LDN and the Good Thinking website. Jessica Griffiths told the Committee that information on eating disorders should be more prominently available through Thrive LDN.<sup>116</sup>

## **Recommendation 9**

The Mayor should work with relevant partners to ensure that Thrive LDN and Good Thinking provide good, easily accessible and up-to-date information to help people with an eating disorder understand options for treatment and services available in London.

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<sup>115</sup> Written evidence – Carney’s Community. Written evidence published alongside report.

<sup>116</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.10

## Calorie labelling on menus

The Committee also heard how some other efforts to promote healthy eating could have the unintended consequence of triggering or worsening people's eating disorders. In particular, the Committee heard opposition to the introduction of legislation in April 2022 that requires large food businesses, such as restaurants, cafes and takeaways to add calorie labels to the food they sell.<sup>117</sup>

The Government's stated aim of the legislation was to "ensure people can make more informed, healthier choices when it comes to eating food out or ordering takeaways".<sup>118</sup> A Public Health England survey from 2018 found that 79 per cent of people agreed with the statement that "menus should include the number of calories in food and drinks".<sup>119</sup>

However, guests at both formal meetings and several survey respondents highlighted the negative impact experienced by people with eating disorders from legislation requiring certain restaurants and cafes to include calories on menus. Andrew Radford, Dr Karina Allen and Hope Virgo all criticised the evidential basis for using calories as a metric of healthy eating.<sup>120</sup> Guests also said that detailing calories on menus was harmful to people with eating disorders. Hope Virgo described the impact it had on her:

"When the calories came out on the menus, while I was in a good space in my recovery, I did find it triggering and difficult to go out for dinner. It meant that a lot of the conversations that were happening with your friends and around the restaurants were around the lowest calorie option, what they were going to have, people saying things like, "I can have this, it has got 1,000 but I went to the gym today", or something like that, which is not helpful if you have had an eating disorder or you are in recovery or if you are in the grips of it as well."<sup>121</sup>

Some respondents to the Committee's survey described the harm they experience from seeing calories on menus:

"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".

Dr Karina Allen suggested restaurants could work within the current legislation to have two menus available – one with calorie labelling and one without. She also suggested that calorie

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<sup>117</sup> DHSC, [Tackling obesity: empowering adults and children to live healthier lives](#), 27 July 2020

<sup>118</sup> DHSC, [New calorie labelling rules come into force to improve nation's health](#), 6 April 2022

<sup>119</sup> Public Health England, [Calorie reduction: The scope and ambition for action](#), March 2018, p.70

<sup>120</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.17

<sup>121</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.17



labelled menus should not be the default option.<sup>122</sup> Andrew Radford agreed that people should have to opt-in for a calorie labelled menu, rather than it being the default option.<sup>123</sup>

Andrew Radford expressed concern that schools use calorie labelling on menus, despite being exempt from doing so in the legislation.<sup>124</sup> Hope Virgo also suggested that some schools use calorie labelling on their menus.<sup>125</sup>

We note in this context that at London's City Hall itself, calorie labelling is used on some menus at the public café, despite it being potentially exempt under the legislation as dishes are on the menu for less than 30 consecutive days.<sup>126</sup> In response to a question in July 2022, The Mayor stated that he was "pleased to note that the regulations include a provision which allows businesses to provide a menu without calorie information at the request of the customer".<sup>127</sup> The Committee believes there is scope for the Mayor to do more to promote this option in cafes and restaurants on GLA and TfL premises.

The Committee believes that further evidence gathering is needed nationally to determine the extent to which calorie labelling has helped the wider population to make more informed decisions about their calorie intake when eating out, and whether any changes to the legislation should be made in light of this.

## Recommendation 10

The Mayor should raise awareness of the existing legislation that exempts schools from including calories on menus, to support schools that may believe they are required to display calorie information.

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## Recommendation 11

The Mayor should take steps to support those experiencing eating disorders when using cafes and restaurants on GLA and TfL premises, ensuring that relevant exemptions to calorie labelling on menus are applied. This could include doing more to promote the option of providing a menu without calorie information.

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## Community support services

The Committee was informed of opportunities to improve the provision of lower-intensity support in the community for those people with less severe symptoms. For example, Andrew Radford said that people at the earliest stages of their eating disorder may benefit from support from peer workers or from guided self-help support delivered by people who are not clinicians. He said this could be more effective and cheaper, and could help to prevent people from

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<sup>122</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.14

<sup>123</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.17

<sup>124</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.16

<sup>125</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.7

<sup>126</sup> UK Government, [The Calorie Labelling \(Out of Home Sector\) \(England\) Regulations 2021](#)

<sup>127</sup> Mayor of London, [MQT 2022/2306: No Calorie Menu Options](#), 21 July 2022

presenting to specialist services down the line, when they have more complex and serious symptoms.<sup>128</sup>

Dr Karina Allen said there is an “enormous gap” in available support for people dropping down from NHS care and that there needed to be more support like “recovery groups and recovery spaces” in the community for people discharged from NHS treatment.<sup>129</sup> Andrew Radford also described an “enormous dropdown from what you receive on an NHS service when perhaps you are acutely unwell to what is available in the community” and said there needed to be more “stepdown options from NHS Care”.<sup>130</sup>

The Committee heard that a lack of options for engaging in positive communities both online and offline could also be contributing to the existence of more dangerous eating disorder ‘communities’ online. For example, many young people are exposed to content on social media that advocates an eating disorder as a desirable lifestyle choice, rather than a symptom of an illness.<sup>131</sup> The Committee was encouraged to consider the reasons why young people engage with online ‘communities’ of pro-ana (content advocating anorexia nervosa symptoms) and pro-mia (content advocating bulimia symptoms) content. Andrew Radford explained:

“The Pro-Ana and Pro-Mia sites, the environments where people are then encouraged to be better at having anorexia or better at having bulimia, are horrible environments. However, often they are also places where people will go to those environments and then they will go to a safe space as well and then they will come to Beat’s online groups and they move around between those things. They are getting something out of it.”<sup>132</sup>

In September 2023, the Government passed the Online Safety Act, which is designed to protect young people and vulnerable adults from harmful content online. Whilst Ofcom will ultimately be responsible for regulating this content, it is hoped that this will have a positive impact on reducing the extent to which young people can access pro-ana or pro-mia content.

Respondents to the Committee’s survey also highlighted the lack of community-based options for care, particularly for those who are looking to step down from specialist treatment but may need continued informal support. One respondent with experience of accessing services in London said that “finding appropriate support outlets, outreach, support groups and general service access is very poor to none”.

Another respondent said: “there is a huge lack of support for those who are moving towards recovery but still finding things difficult and need help”. They said that “the door shouldn’t be closed after discharge and only opened if you experience a full relapse”.

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<sup>128</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.25

<sup>129</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.8

<sup>130</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.33

<sup>131</sup> Internet Matters, [In their own words: the digital lives of schoolchildren](#), 2019; Centre for Countering Digital Hate, [Deadly by design](#), 15 December 2022; BBC, [Instagram eating disorder content ‘out of control’](#), 20 March 2019

<sup>132</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023, p.8

Other respondents, with experiences of accessing services and/or caring for others or working with people with eating disorders, said there should be more “community-based services in all boroughs” and “more informal ways of seeking short term support or advice”.

Andrew Radford also said there is an opportunity for the NHS to take better advantage of voluntary sector resource and support, and that England was lagging behind Scotland in how it engages with the voluntary sector to provide nonclinical support. He pointed to an example of how Beat had helped provide a cost-effective peer-led NICE-compliant treatment for people with binge eating disorders in Scotland.<sup>133</sup>

Emma Christie said there have been good examples of the NHS commissioning voluntary sector support, including support for parents and carers in relation to eating disorders.<sup>134</sup>

Dr Victoria Chapman said she does not refer patients to voluntary sector services often, partly because the severity of risk of people being supported is difficult to delegate out. However, she suggested the voluntary sector could play a role in helping to educate people, for example outreach into schools and “supporting schools understanding how to manage their whole health policy with eating and nutrition”.<sup>135</sup> Jessica Griffiths suggested voluntary sector support could be better harnessed to provide “community support for those from different cultural backgrounds”.<sup>136</sup>

Dr Brian Sreenan said that “involving third sector organisations is fantastic and there is massive resource there and massive skills and intelligence there. However, he said voluntary sector organisations should not be relied upon to deliver eating disorder treatment, and any support provided by external organisations “needs to be an adjunct to NHS provided NICE evidenced based care”.<sup>137</sup>

## Working with families

The Committee heard that it was important that where possible, clinicians should involve carers and families in the care plan for someone with an eating disorder. Dr Ashish Kumar said:

“Who is around the patient, who could listen to them and their inner feelings? Who could take them to a variety of appointments or help? This illness thrives on secrecy. [...] That is quite an important part, which has not been tapped very well – how to train and educate parents and carers about eating disorders and engage them in the treatment we offer. They are a vital resource of the whole picture”.<sup>138</sup>

Dr Karina Allen told the Committee that “involving families, carers or close others in the support of someone with an eating disorder is best practice and really important for the individual with

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<sup>133</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.31

<sup>134</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.22

<sup>135</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.23

<sup>136</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.25

<sup>137</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.23

<sup>138</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.24

an eating disorder and also for the family members being supported as well”.<sup>139</sup> Andrew Radford stated that families “can be incredibly powerful at understanding the illness, supporting the treatment, encouraging their loved one to get in, to stay on the course, stay in treatment and stay healthy afterwards”.<sup>140</sup>

Dr Ashish Kumar said there were examples of initiatives that sought to bring families into treatment, including family therapy models and ‘triangle’, which involves bringing parents and carers into treatment plans.<sup>141</sup>

Jessica Griffiths said more needed to be done to support and upskill people in the community to be able to support those with eating disorders:

“We need to look after them. We need to skill them up. We need to provide them support. We need to work together. None of us can do this on our own. We are a partnership, supporting our carers, supporting those people who are in treatment themselves, understanding that we are better together. There are lots of resources that we can provide for our family members in the community, such as in schools. You could do a carers workshop, understanding eating disorders. There are lots of things you can do in community groups and youth clubs to raise awareness and skill up our community”.<sup>142</sup>

Hope Virgo praised the service provided by Feast, a charity set up to support people caring for those with an eating disorder. She said there needed to be “wider education for parents and carers within schools, within our communities”.<sup>143</sup>

Guests also told the Committee that carers and families themselves experience a great deal of pressure when supporting loved ones with an eating disorder. Jessica Griffiths said that “carers and family members are likely to develop their own mental health issue; 50 per cent of them from supporting someone with an eating disorder”.<sup>144</sup>

Andrew Radford said that “eating disorders tear families apart in so many different ways” and endorsed NICE guidelines that state that families “should be offered an assessment of their own wellbeing and offered support if they need it”.<sup>145</sup> Research published by Cambridge University in March 2022 found that the experiences of family members of those with eating disorders did not meet the published guidance.<sup>146</sup>

Respondents to the Committee’s survey with experience of supporting someone with an eating disorder in London said there was a lack of support for families:

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<sup>139</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.15

<sup>140</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.8

<sup>141</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.23

<sup>142</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p.22

<sup>143</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.19

<sup>144</sup> London Assembly, [Health Committee – transcript](#), 21 September 2023, p. 21

<sup>145</sup> London Assembly, [Health Committee – transcript](#), 29 June 2023 p.33

<sup>146</sup> Cambridge University Press, [The experiential perspectives of siblings and partners caring for a loved one with an eating disorder in the UK](#), 24 March 2022

“A lot more support is also required so that families can give the best chances for their loved ones to overcome these issues.”

“Basically, by default, as a single mother of three 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.”

It is apparent that friends, families and carers play an essential role in supporting people impacted by eating disorders and it is widely acknowledged that families should be involved in treatment plans. However, it appears families themselves currently do not receive the level of support they need, in order for them to be able to best help their loved ones.

### **Recommendation 12**

The Mayor should bring together the GLA Health Team, NHS England (London) and Feast to review how NHS trusts engage with and support families impacted by eating disorders; and identify areas where additional support can be provided.

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## Other formats and languages

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### Chinese

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### Vietnamese

Nếu ông (bà) muốn nội dung văn bản này được dịch sang tiếng Việt, xin vui lòng liên hệ với chúng tôi bằng điện thoại, thư hoặc thư điện tử theo địa chỉ ở trên.

### Greek

*Εάν επιθυμείτε περίληψη αυτού του κειμένου στην γλώσσα σας, παρακαλώ καλέστε τον αριθμό ή επικοινωνήστε μαζί μας στην ανωτέρω ταχυδρομική ή την ηλεκτρονική διεύθυνση.*

### Turkish

Bu belgenin kendi dilinize çevrilmiş bir özetini okumak isterseniz, lütfen yukarıdaki telefon numarasını arayın, veya posta ya da e-posta adresi aracılığıyla bizimle temasa geçin.

### Punjabi

ਜੇ ਤੁਸੀਂ ਇਸ ਦਸਤਾਵੇਜ਼ ਦਾ ਸੰਖੇਪ ਆਪਣੀ ਭਾਸ਼ਾ ਵਿਚ ਲੈਣਾ ਚਾਹੋ, ਤਾਂ ਕਿਰਪਾ ਕਰਕੇ ਇਸ ਨੰਬਰ 'ਤੇ ਫੋਨ ਕਰੋ ਜਾਂ ਉਪਰ ਦਿੱਤੇ ਡਾਕ ਜਾਂ ਈਮੇਲ ਪਤੇ 'ਤੇ ਸਾਨੂੰ ਸੰਪਰਕ ਕਰੋ।

### Hindi

यदि आपको इस दस्तावेज का सारांश अपनी भाषा में चाहिए तो उपर दिये हुए नंबर पर फोन करें या उपर दिये गये डाक पते या ई मेल पते पर हम से संपर्क करें।

### Bengali

আপনি যদি এই দলিলের একটা সারাংশ নিজের ভাষায় পেতে চান, তাহলে দয়া করে ফো করবেন অথবা উল্লেখিত ডাক ঠিকানায় বা ই-মেইল ঠিকানায় আমাদের সাথে যোগাযোগ করবেন।

### Urdu

اگر آپ کو اس دستاویز کا خلاصہ اپنی زبان میں درکار ہو تو، براہ کرم نمبر پر فون کریں یا منکورہ بالا ڈاک کے پتے یا ای میل پتے پر ہم سے رابطہ کریں۔

### Arabic

الحصول على ملخص لهذا المستند بلغتك،  
فارجاء الاتصال برقم الهاتف أو الاتصال على  
العنوان البريدي العادي أو عنوان البريدي  
الإلكتروني أعلاه.

### Gujarati

જો તમારે આ દસ્તાવેજનો સાર તમારી ભાષામાં જોઈતો હોય તો ઉપર આપેલ નંબર પર ફોન કરો અથવા ઉપર આપેલ ટપાલ અથવા ઇ-મેઇલ સરનામા પર અમારો સંપર્ક કરો.



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