The alarms should no longer be ignored: A Survey of the Demand, Capacity and Provision of Adult Community Eating Disorder Services in England and Scotland before COVID-19

**Authors:** David Viljoen<sup>1,2</sup>, Emily King<sup>1</sup>, Sophie Harris<sup>1</sup>, Jonathan Hollyman <sup>1,3</sup>, Kate Costello <sup>1,4</sup>, Eimear Galvin <sup>1,5</sup>, Melissa Stock <sup>5,6</sup>, Ulrike Schmidt <sup>7</sup>, James Downs <sup>8</sup>, Murali Sekar <sup>6,9</sup>, Ciaran Newell <sup>10,11</sup>, Sam Clark-Stone <sup>12</sup>, Amy Wicksteed <sup>13</sup>, Caroline Foster <sup>14</sup>, Francesca Battisti <sup>15</sup>, Laura Williams <sup>14,4</sup>, Roshan Jones <sup>1,16</sup>, Sarah Beglin <sup>17</sup>, Stephen Anderson <sup>18</sup>, Thuthirna Jebarsan <sup>19,20</sup>, Viviane Ghuys <sup>19</sup>, Agnes Ayton <sup>1</sup>

<sup>1</sup> Adult Community Eating Disorder Service Oxford, Oxford Health NHS Foundation Trust (OHFT), UK; <sup>2</sup> Ellern Mede Ridgeway and Ellern Mede Barnet, London, UK; <sup>3</sup> Salomons Institute for Applied Psychology, Canterbury Christ Church University; UK; <sup>4</sup> University of Edinburgh, Lothian NHS, UK; <sup>5</sup> Oxford University, Oxford Health NHS Foundation Trust, UK; <sup>6</sup> Hertfordshire Community Eating Disorders Service, Hertfordshire Partnership University NHS Foundation Trust, UK; <sup>7</sup> King's College London, Institute of Psychiatry, Psychology and Neuroscience, London, UK; <sup>8</sup> The Royal College of Psychiatrists, UK; <sup>9</sup> Priory Group, Chelmsford, UK; <sup>10</sup> Dorset Eating Disorders Service, Dorset Healthcare University NHS Foundation Trust, UK; <sup>11</sup> Bournemouth University, UK; <sup>12</sup> Eating Disorder Service, Gloucestershire Health and Care NHS Foundation Trust, UK; <sup>13</sup> Sheffield Eating Disorder Service, Sheffield Health and Social Care NHS Foundation Trust, UK; <sup>14</sup> Adult Eating Disorder Service, Surrey and Borders Partnership NHS Foundation Trust, UK; <sup>15</sup> Wiltshire Community Eating Disorders Service, OHFT, UK; <sup>16</sup> Oxford Child and Adolescent Eating Disorder Service, Oxford Health NHS Foundation Trust, UK; <sup>17</sup> Adult Eating Disorder Service, UK; <sup>19</sup> Berkshire Eating Disorders Service, Berkshire Healthcare NHS, UK; <sup>20</sup> Talking Therapies, Berkshire Healthcare NHS, UK.

Corresponding author: David Viljoen

#### **About the authors**

David Viljoen was a Consultant Clinical Psychologist with Cotswold House, Adult Community Eating Disorder Service Oxford, Oxford Health NHS Foundation Trust (OHFT), UK and is now a Consultant Clinical Psychologist at Ellern Mede, London, UK. Emily King is an Assistant Psychologist with Adult Community Eating Disorder Service Oxford, OHFT, UK. Sophie Harris is an Assistant Psychologist with Adult Community Eating Disorder Service Oxford, OHFT, UK. Jonathan Hollyman was an Assistant Psychologist with Adult Community Eating Disorder Service Oxford, OHFT, UK and is now a Trainee Clinical Psychologist with Salomons Institute for Applied Psychology, Canterbury Christ Church University. Kate Costello was an Assistant Psychologist with Adult Community Eating Disorder Service Oxford, OHFT, UK and is now a Trainee Clinical Psychologist at the University of Edinburgh. Eimear Galvin was an Assistant Psychologist with OHFT, UK and is now a Trainee Clinical Psychologist with Oxford University, OHFT, UK. Melissa Stock was an Assistant Psychologist with Hertfordshire Community Eating Disorder Service, Hertfordshire Partnership University NHS Foundation Trust, UK and is now a Trainee Clinical Psychologist with Oxford University, OHFT, UK. Ulrike Schmidt is a Professor of Eating Disorders, King's College London, Institute of Psychiatry, Psychology and Neuroscience, London, UK. James Downs is a Patient Representative with The Royal College of Psychiatrists, UK. Murali Sekar is a Medical Director and Consultant Psychiatrist in Eating Disorders with Priory Hospital Chelmsford, UK. Ciaran Newell was a Nurse Consultant with the Dorset Eating Disorders Service, Dorset Healthcare University NHS Foundation Trust and

is now an Independent Nurse Consultant and visiting fellow at Bournemouth University, UK. Sam Clark-Stone is a Lead Clinician with the Eating Disorders Service, Gloucestershire Health and Care NHS Foundation Trust, UK. Amy Wicksteed is a Lead Clinical Psychologist with Sheffield Eating Disorder Service, Sheffield Health and Social Care NHS Foundation Trust, UK. Caroline Foster is a Consultant Clinical Psychologist with Surrey and Borders Adult Eating Disorder Service, Surrey and Borders Partnership NHS Foundation Trust, UK. Francesca Battisti is a consultant psychiatrist with the Wiltshire Community Eating Disorders Service, OHFT, UK. Laura Williams was an Assistant Psychologist with Surrey and Borders Adult Eating Disorder Service, Surrey and Borders Partnership NHS Foundation Trust, UK and is now a Trainee Clinical Psychologist with University of Edinburgh, Lothian NHS, UK. Roshan Jones was a Clinical Psychologist with Oxford Adult Community Eating Disorder Service, OHFT, UK and is now a Clinical Psychologist with Oxford Child and Adolescent Eating Disorder Service, OHFT, UK. Sarah Beglin is a Consultant Clinical Psychologist with Adult Eating Disorder Service Cambridgeshire and Peterborough, Cambridgeshire and Peterborough NHS Foundation Trust, UK. Stephen Anderson, is a consultant psychiatrist with NHS Forth Valley Eating Disorder Service. Thuthirna Jebarsan was an Assistant Psychologist with Berkshire Eating Disorders Service, Berkshire Healthcare NHS Foundation trust (BHFT) and is now a Psychological Wellbeing Practitioner with Talking Therapies at BHFT, UK. Viviane Ghuys is a Principle Clinical Psychologist with Berkshire Eating Disorders Service, BHFT, UK. Agnes Ayton is a Consultant Psychiatrist with Cotswold House, Oxford, OHFT, UK.

## **Supplementary material**

Supplementary material is available online

## **Data availability**

The anonymised data that support the findings of this study are available from the corresponding author, D.V., upon reasonable request.

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#### **Author contributions**

The initial idea was developed by D.V. and A.A. Data were collected by D.V., E.G. and A.A. Preliminary analysis was conducted by J.H. and K.C. with further analysis completed by E.K., S.H. and M.S. DV, AA, EK, & SH wrote the first draft and all authors contributed to the final draft.

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## **Declaration of interest**

None.

#### **ABSTRACT**

Aims/Methods: This national survey compared demand and capacity of adult community eating disorder services (ACEDS) to NHSE Commissioning guidance.

Results: Of 21 services approached in England and Scotland 13 responded (10.7 million population). Between 2016/17 and 2019/20 average referral rates increased by 18.8%, from 378 to 449/million population. 3.7% of referrals were from child and adolescent eating disorder services (CEDS-CYP), yet 46% of referrals were aged 18-25.

Most ACEDS had waiting lists and rationed access. Less than half of services could provide full medical monitoring, adapt treatment for co-morbidities, offer assertive outreach or provide seamless transitions across care pathways.

ACEDS were 15% funded to meet demand and to achieve parity with the CEDS-CYP would require an estimated £7 million/million population.

Clinical Implications: Even pre-pandemic ACEDS experienced a growing demand that exceeded capacity. Given the increase in eating disorders since, substantial investment is required for ensuring safe and effective NHS services.

## **Background**

Eating disorders are increasing in the UK. According to the 2019 Health Survey for England, 16% of adults screened positive for an eating disorder, and 4% reported significant impairment in their functioning.<sup>1</sup> This represents a nearly threefold increase since the Adult Psychiatric Morbidity Survey of 2007.<sup>2</sup>

Historically, Adult Community Eating Disorder Services (ACEDS) in the UK have been under resourced. The Parliamentary and Health Service Ombudsman (PHSO) highlighted this in a report titled 'Ignoring the Alarms: How NHS Eating Disorders Services are failing patients'.<sup>3</sup> <sup>4</sup> The PHSO called for parity of investment for ACEDS, to match the expansion of community services for children and young people with eating disorders (CEDS-CYP) and the NHS England (NHSE) access and waiting time standards for community CEDS-CYP treatment.<sup>5</sup> Subsequently, in 2019, NHSE published commissioning guidance for adult community, day and inpatient services.<sup>6</sup> As part of the long-term plan, this remains an aspirational document with no specific assessment of implementation costs.<sup>7</sup> The Welsh Government published a review of eating disorder services in 2018,<sup>8</sup> and the Scottish Government in 2021.<sup>9</sup> These included important recommendations that are yet to be implemented.

In contrast to CEDS-CYP, there is no systematic data collection at the national level regarding access and waiting times for adults with eating disorders, and there are no reliable baseline data on the size of the demand (e.g. number of referrals) and capacity (number of staff needed) for ACEDS to deliver the NHSE commissioning guidance for adults with eating disorders.<sup>6</sup>

## Aims and objectives

The aim of this survey was to establish a baseline of ACEDS demand and capacity (prior to the pandemic and prior to investment), as well as whether services could comply with NHSE Commissioning guidance.<sup>6</sup> This information will help guide future commissioning and improve timely access to evidence-based treatment for adults.

## Method

This is a survey of ACEDs regarding demand and capacity in comparison to NHSE Commissioning guidance standards.<sup>6</sup>

We asked participating services to report referral patterns and staffing levels for total budgeted full-time-equivalent (FTE) and total actual FTE staff in post on 31 March 2020. We compared existing staffing levels to recommended staffing levels using the NHSE CEDS-CYP workforce calculator and Personal Social Services Research Unit (PSSRU) costs for health and social care in 2013-14, as recommended for adult commissioners.<sup>5</sup>

The survey included 41 questions, the majority of which asked respondents to select 'yes', 'partially', or 'not at all' as to whether services could comply with the guidance, with prompts to elaborate using an open text box. The questionnaires are included in the supplementary files.

## **Analysis**

Data were analysed with Microsoft Excel. Individual service statistics were converted to a million population to facilitate comparisons of demand (e.g., range and average number of referrals) and capacity (e.g., range and average Total Budgeted FTE and Total Actual FTE personnel) per million population.

Two members of the research team classified qualitative data separately for each question, and common concepts were deductively classified into a coding scheme (see Supplementary Table).

#### Setting

There was no information available at the time of the study on the number of ACEDS in the UK. The first and last authors approached 21 services using their professional networks (Faculties of Eating Disorders, British Psychological Society Division of Clinical Psychology, and The Royal College of Psychiatrists). In Wales and Northern Ireland, there were no specialised services. Thirteen ACEDS (12 from England and 1 from Scotland) with a combined population of 10.7 million completed the online survey. Given that the survey was concluded on 31 March 2020 (i.e. a week after the first Covid-19 lockdown), the response rate (62%) was satisfactory. In addition, eight of thirteen services (7.3 million population) supplied further information on referral patterns and staffing levels.

## The participating services were:

- 1. Berkshire Eating Disorder Service
- 2. Buckinghamshire Eating Disorder Service
- 3. Cambridgeshire and Peterborough Adult Eating Disorder Service
- 4. 'Community Eating Disorder Service' (Location not specified in service name)
- 5. Dorset Eating Disorders Service
- 6. Gloucestershire Eating Disorders Service
- 7. Hertfordshire Community Eating Disorder Service
- 8. NHS Forth Valley Eating Disorder Service
- 9. Oxford Community Eating Disorders Service
- 10. Sheffield Eating Disorders Service
- 11. South London & Maudsley NHS Foundation Trust Adult Eating Disorders Outpatient Service
- 12. Surrey and Borders Partnership NHS Foundation Trust Adult Eating Disorders Service
- 13. Wiltshire Eating Disorders Service

Services represented a variety of demographics, including rural, urban, and university populations. Sixty-two percent of Trusts provided inpatient care, while 85% offered intensive day therapy. We provide anonymous data in this paper.

#### **Ethics**

Individual patient consent was not needed. Each participating service registered a clinical audit with their respective Quality and Audit teams. The Oxford Health NHS Foundation Trust Audit Department approved the overall study.

#### **Results**

## **Demand: annual referral patterns**

Seven services (total population: 6.54 million) provided annual referral data for four consecutive financial years. The average number of referrals received increased by 18.8% between 2016/2017 and 2019/2020, from 378 (SD=106) to 449 (SD=111) per million population. The rate of accepted referrals dropped from 94%, 87%, 88%, to 84% over the four years.

Table 1 below represents a breakdown (mean, SD, median, range, mean %) per million population of the sources, age and gender of referrals for 2019/2020 for six services (total population 6 million).

Table 1: Demand: Break down of sources, age and gender of referrals in 2019/2020 per million population

Demand data (2019/2020)		Number of Referrals:	Mean %
		Mean (SD)	
		Median (range)	
Source of Referrals	General Practitioner (GP)	293 (114)	68.3
		294 (136-467)	
	Adult Community Mental Health	57 (60)	13.3
	Team (CMHT)	22 (18-160)	
	Child and Adolescent Mental	16 (22)	3.7
	Health Services	6 (0-54)	
	Self	7 (16)	1.6
		0 (0-36)	
	Acute Mental Health Inpatient	2 (3)	0.5
	units	0(0-6)	

	Other	54 (46) 59 (1-99)	12.6
Age range (years)	18-25	210 (67) 210 (157-341)	46.3
	25 and older	244 (68) 244 (163-340)	53.7
Gender	Male	37 (12) 37 (25-59)	8.2
	Female	416 (113) 416 (300-584)	91.7
	Other	0.3 (0) 0.3 (0-1)	0.1

GPs and Adult Community Mental Health Teams (CMHTs) were the most common referral sources. Less than half of the referrals were under the age of 25. Ninety-two percent were female.

## Capacity: staffing levels on 31st March 2020

Table 2 compares the NHSE CEDS-CYP workforce calculator<sup>5</sup> recommendations and associated staffing mix costs (based on PRSSU unit costs for health and social care in 2013-14) to the mean, SD, median, and range of budgeted and occupied FTE staffing roles per million population for 449 referrals/year for ACEDS on 31 March 31 2020.

The recommended staffing for CEDS-CYP for 100 referrals per year was 21.5 FTE at a cost of £1,559,061. $^5$  After adjusting for 449 referrals/year, the total budgeted FTE posts for ACEDS were on average 15% of NHSE recommendations for CEDS-CYP, with 14% of the necessary staff in post to meet patients' needs.

Table 2: Snapshot of the mean and standard deviation (SD), median and range of budgeted and filled FTE staffing roles per million population on 31 March 2020 in comparison to NHSE CEDS-CYP workforce calculator recommendations for staffing mix and costs adjusted to 449 referrals/year.

Role (Band)	Total Budgeted FTE posts per million population: Mean (±SD) Median (range)	Total Actual FTE occupied posts per million population Mean (±SD) Median (range)	NHSE CEDS- CYP workforce calculator estimates of 21.5 FTE staff/100 referrals adjusted to 449 referrals/year	% Total Budgeted mean FTE/NHSE CEDS-CYP workforce calculator staffing mix recommendations
Consultant Psychiatrist	0.9 (0.6) 0.7 (0.3- 2.2)	0.8 (0.5)	5.4	22%
Consultant Psychologist	0.3 (0.4) 0.1 (0-1)	0.3 (0.3)		
Psychiatrists (e.g. specialty doctors, trainees)	0.2 (0.3) 0 (0-0.7)	0.3 (0.4)	7.2	3%
Medical professionals (GP or physician)	0	0	0.9	0%
Psychologists (8B)	No data	No data	1.3	-
Operational/Team Manager (8A)	0.8 (0.6) 0.6 (0-1.9)	0.8 (0.5)	-	-
Psychologists/ Psychological Therapists (7/8A)	3.2 (1.8) 2.5 (1.4-7.1)	3.2 (1.8)	35.9	10%
(Systemic) Family Therapists (7/8A)	0.3 (0.2) 0.3 (0-0.6)	0.3 (0.2)		
Nursing Staff (6)	3.4 (2.8)	2.8 (2.6)	11.2	30%

	2.2 (1.4-8.4)			
Social Workers (6)	0.1 (0.4) 0 (0-1)	0.1 (0.3)	-	-
Occupational Therapists (6)	0.9 (0.7) 1 (0-1.9)	0.8 (0.6)	-	-
Dietitians (6)	0.8 (0.4) 0.9 (0.3-1.6)	0.8 (0.3)	6.7	12%
Assistant Psychologists	0.9 (0.7) 0.7 (0-2.3)	0.8 (0.7)	8.1	12%
Assistant Psychologists/Data Analysts/Research Assistants (4)	0.1 (0.1) 0 (0-0.3)	0.1 (0.3)		
Support Workers (4)	0.9 (1) 0.6 (0-2.2)	0.8 (1)	-	-
Peer Support Workers (4)	0	0 0	-	-
Office managers (4)	No data	No data	3.6	16%
Administrative Staff (4)	1.9 (0.4) 1.9 (1.4-2.5)	1.7 (0.6)	8.1	
Other	0.2 (0.4) 0 (0-1)	0.2 (0.4)	8.1	2%
Total:	14.8 (3.9) 14.7 (10.3- 20.8)	13.9 (2.5)	96.5	15%
PRSSU cost of recommended staffing mix of recommended service (based on unit costs for health and			£7,000,183	

social care for 2013- 14)				
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<sup>\*</sup>FTE = Full time equivalent posts

# Capacity of ACEDS to deliver the NHSE AED commissioning guidance for commissioners and providers

Table 3 summarises survey responses on whether the 13 ACEDS had the capacity to meet the NHSE AED commissioning guidance.

Table 3: Survey responses on whether 13 ACEDS met the NHSE's AED commissioning guidance

ABILITY TO MEET NHSE AED COMMISSIONING GUIDANCE	Able to meet standard	
Statement	Yes	Partially
Referrals of all presentations of eating disorders are accepted, regardless of length of illness, severity or BMI	31%	0%
Evidence-based treatment, care and support is offered for all eating disorders, including binge-eating disorder, avoidant restrictive food intake disorder (ARFID) and other specified feeding or eating disorder (OSFED)	54%	0%
The service has capacity for managing risks safely	62%	38%
The service has capacity to follow-up patients (e.g. who are not engaging, not attending appointments) and avoids inappropriate discharge	46%	54%
The prevalence of eating disorders, and demand for services in the local area has been assessed using e.g. the Public Health Fingertips Tool	15%	15%
The service/Trust offers intensive day patient treatment for patients with eating disorders	85%	0%
The service received an increase in annual recurring investment over the last 5 years since 2014/2015	38%	0%
Access to care is equal regardless of whether a person presents for first time or with a long-term eating disorder	77%	23%
Individuals can self-refer to access the service including when re-presenting at first sign of relapse	23%	8%
The service has a waiting list for treatment	92%	8%

Commissioners develop and implement local plans in collaboration with people with experience, service providers and partner agencies	54%	15%
The ACEDS has the capacity to take responsibility for outreach, follow-up and engaging with people who are reluctant to receive treatment	46%	8%
If a patient is reluctant to engage, and there is evidence of recent deterioration or severe risk, support is offered indirectly by engaging patients' families, partners, carers or members of their support network	77%	8%
The service provides full medical monitoring (including blood tests and ECGs with same-day results)	38%	31%
The service has an agreed protocol with primary care services to ensure physical assessment and monitoring of patients	23%	62%
The service has support from acute medical care including emergency admissions.	54%	46%
The ACEDS remains the lead in providing care, working closely with inpatient staff from the start of the admission to discharge, to ensure persons receive appropriate levels of treatment	54%	46%
Intensive community treatment is offered as an alternative to inpatient treatment	38%	46%
For age-based transitions, the service works with the relevant CEDS-CYP team for a minimum of 6 months before planned transitions	38%	39%
The service has sufficient capacity to ensure seamless transition for people needing inpatient and day treatment, including admission and discharge planning i.e. with psychological therapy and social components included	38%	46%
For geographical transitions, the service has capacity to work closely with primary care providers, ACEDS in other areas, and university mental health services to ensure seamless transitions and avoid gaps and delays in handovers of ongoing care and treatment including for students during holiday times	38%	31%
Staff have specific training and skills to support patients with diabetes and diabulimia	23%	54%

Treatment is available and can be adapted for those who experience comorbid	38%	62%
conditions, such as autism, substance misuse or personality disorders		

Ninety-two percent of services had a treatment waiting list. More than half (7/13) of services utilised a variety of criteria for prioritising patients on the waiting list (i.e., physical or psychiatric risks; severity of the eating disorder; pregnancy; discharges from day or inpatient services; geographical transitions, see Supplementary Table). Some services reported up to two years waiting times for treatment.

Thirty-eight % (5/13) of services reported only a limited capacity to manage risks safely, citing factors such as a lack of staffing, long waiting lists, and staff stress (see Supplementary Table).

Fifty-four percent reported difficulties with service evaluation (e.g., insufficient staffing for data collection, analysis, and reporting of data/routine outcome measures). A summary of all survey questions and qualitative responses is available in the supplementary information.

#### **DISCUSSION**

To the best of our knowledge, this was the first large-scale survey of ACEDS demand, capacity, and provision in the UK since the Royal College of Psychiatry (CR170) report, 'Eating disorders in the UK: Service Distribution, Service Development, and Training,' published in 2012.<sup>10</sup>

Annual referral rates increased by 18.8 % between 2016/17 and 2019/2020, and the average referrals per million population in 2019/20 was 449 (range: 330–643). During the same period, the rate of accepted referrals fell from 94% to 84%, reflecting system stress and increasingly stringent referral acceptance criteria. In comparison, according to a 2008 survey of child and adult eating disorder services in the UK and Ireland, only 50% of services received more than 25 referrals per year. In parallel, inpatient admissions have also increased annually, indicating that the increased demand is not due to milder eating disorder cases.

In comparison with the 2015 NHSE staffing recommendations for CEDS-CYP services,<sup>5</sup> In 2019/20, ACEDS were only 15% funded and 14% staffed to meet the needs of annually referred patients. To achieve parity with CEDS-CYP (based on the CEDS-CYP workforce calculator and the PSSRU costs for health and social care in 2013-14), the estimated costs of an ACEDS with 449 referrals/million population/year should have been £7 million.

ACEDS, unsurprisingly, lacked the capacity to meet several NHSE commissioning standards, including the ability to provide timely evidence-based treatments, treat the entire spectrum of eating disorders (including BED, ARFID, and OSFED), manage transitions between services, and reach out to vulnerable, hard-to-reach populations. Liaison with primary care and acute medical services, as well as the ability to provide medical monitoring, also fell short of standards. The COVID-19 pandemic has further exacerbated the long waiting lists caused by the demand exceeding capacity.<sup>13</sup> <sup>14</sup>

Similar to the PACAC report in 2019,<sup>4</sup> the national picture in this survey reflects little progress since the death of Averil Hart in 2012<sup>3</sup> <sup>15</sup> and highlights the ongoing high risk in ACEDS, as well as the potential for additional avoidable deaths.

## **Demand: annual referral patterns**

The increase in annual referrals to ACEDS is comparable with the increase in eating disorder prevalence estimates reported in the 2019 Health Survey, and the hospital statistics.<sup>1 12</sup> It implies that only a small percentage of those who would benefit from treatment receive care. The geographical distribution of eating disorders differs according to factors such as the existence of higher education institutions and rural vs urban areas. The next adult psychiatry morbidity survey should contribute to a more accurate estimation of prevalence rates in the UK.

Even though both men and women could benefit from treatment, 92% of the referrals were female. This is consistent with earlier studies<sup>16</sup> and has further implications for improving access and funding for ACEDS.

The increasing demand for inpatient admissions<sup>11</sup> may indicate that ACEDS are unable to deliver timely evidence-based therapies to prevent patients from deteriorating severely. NHSE Digital<sup>12</sup> reported a fourfold rise in hospital admissions with primary or secondary eating disorder diagnoses between 2007/8 and 2020/21 (~70% are adults). In 2012, the Royal College of Psychiatrists suggested six inpatient beds per million population for the treatment of eating disorders.<sup>10</sup> In contrast, the Hope Provider Collaborative required an average of 12 inpatient beds per million population in 2018-19; after the pandemic, this number has climbed to 15.<sup>17</sup> These results strengthen the case for immediate investment in ACEDS to improve access to levels comparable to CED-CYP. This could help reverse the rising trend of hospitalizations.

It is important to note that only 3.7% of referrals were CAMHS transitions. This demonstrates the success of the investment in CED-CYP services: the majority of patients do not require further treatment for ACEDS after receiving timely evidence-based treatment. The small number of adolescents who transition to ACEDS usually have persistently low weight and significant levels of complexity and co-morbidity, necessitating intensive resources following transition.<sup>18</sup>

Approximately half of ACEDS referrals were between the ages of 18 and 25. This is consistent with recent research indicating that the median age of onset for eating disorders is 18 years old. There has been some minor investment in 18-25 programmes in recent years, particularly First Episode Rapid Early Intervention for Eating Disorders (FREED). Since the beginning of the pandemic, however, referrals to FREED services in England have increased by a factor of 1.4 (compared to a referral increase of 1.2 in CED-CYP services), with a relative increase in anorexia nervosa cases among these referrals. (Hyam et al., 2022, manuscript submitted) Given that more than half of ACEDS patients are older than 25 years old, it is evident that investments in FREED will not be sufficient to meet the needs of the patient population. In addition, FREED is not yet available outside of England and cannot be implemented on a large scale until substantial investments are made.

## Staffing levels on 31 March 2020

This survey confirmed geographical inequity of services with wide variations in staffing levels and roles. For example, the budgeted posts for consultant psychiatrists in ACEDS ranged from 0.3 to 2.2 FTE/million population, while those for psychologists/psychological therapists ranged from 1.4 to 7.1 FTE/million population. The budgeted FTE/million of the largest service (20.8) was double that of the least resourced ACEDS (10.3). The average caseload for psychiatrists was approximately 500/ year. This is incompatible with the safe management of physical and mental comorbidities, and results in poor staff recruitment and retention. Similarly, the CEDS-CYP workforce calculator suggested 36 FTE psychologists/therapists for 449 referrals annually, while ACEDS had an average of 3.5 psychologists/therapists in posts. With this level of staff, only a small fraction of patients can receive the NICE-recommended treatment. In addition, caseloads will increase dramatically once services accept the full spectrum of eating disorders, both in terms of diagnosis and severity.

The average total number of budgeted FTE posts in ACEDS was 14.6/million population. By comparison the CEDS-CYP workforce calculator recommended 96.5 FTE posts to meet the average demand of 449 referrals/million population. This means that, prior to the pandemic, ACEDS were only 15% funded and 14% staffed to meet demand. Such grossly inadequate resources endanger patient safety and may contribute to staff burnout across the UK. Furthermore, the situation has deteriorated since the pandemic.<sup>21</sup> Given that evidence-based treatment benefits two-thirds of patients,<sup>22</sup> investment into services would be cost effective, as it would help reduce the number of people developing a chronic condition.

## Capacity of ACEDS to meet the NHSE guidance for commissioners and providers

The aim of the NHSE commissioning guidance<sup>6</sup> was to provide guidance on the most effective models of service delivery to enhance access to treatment and support for adults with eating disorders. Due to the annual increase in referrals and inadequate staffing, most services were unable to adhere to all standards for good practice.

There was a waiting list for treatment for all except one service, and rationing strategies were implemented (e.g. BMI, severity, excluding some eating disorder diagnoses). This had an impact on patient safety throughout the care pathway. Long waiting lists for potentially lifethreatening eating disorders requiring hospital treatment, were reported, for example, by the HOPE Provider Collaborative. There were additional commissioning challenges for complex patients with co-morbidities (e.g., patients with personality disorders or autistic spectrum disorders), which have worsened since the pandemic. Excessive admission waiting times drive up the risks in ACEDS and are a contributing factor to an increasing number of emergency medical admissions prior to specialist eating disorder admissions. It is also likely that the ACEDS risk levels could contribute to recruitment and retention difficulties, which further exacerbate the situation.

Only 38% of services had the capacity to ensure seamless transition and treatment from day/inpatient units to the community. Research suggests that the risk of relapse is highest in the first 60-90 days after discharge from hospital, and intensive treatment is necessary to help the patient achieve the best outcome.<sup>23-27</sup> Without the ability to provide seamless transitions between inpatient and outpatient settings, more than 50% of patients relapse within a year of hospital discharge; this number could be reduced to 15% with integrated treatment, and the number of high-risk patients could be reduced over the medium term.<sup>24</sup>

Eating disorders are associated with high levels of co-morbidity and risk of mortality,<sup>28-30</sup> and the effective management of these requires sufficient highly-skilled staff. Sixty-two percent of services reported only a limited ability to modify treatment for patients with co-morbid conditions, such as autism spectrum disorders, substance abuse disorders, or personality disorders. Most teams lacked the necessary training to assist diabetic patients. This is a previously ignored patient population with a high risk of irreversible consequences and poor experience of services.<sup>31-34</sup>

Risk management had significant shortcomings. Only around 40% of services could provide complete medical monitoring and had good links with acute hospitals.

Responsibility for outreach, follow-up and engagement with patients who do not engage in treatment lies with the ACEDS<sup>6</sup> yet only 50% of services met the guideline. Unfortunately, as the severity of a patient's illness increases, the likelihood of seeking and accepting help decreases significantly, so the inability to provide assertive outreach further increases the risk of deterioration.

Students who leave home are an especially vulnerable group as poor transitions have a significant negative impact on their ability to achieve academic success or benefit from broader aspects of university life.<sup>6 22</sup>. NICE guidelines<sup>22</sup> recommend well-coordinated care for students who require help in different locations at different times of the year. Yet, only 38% of ACEDS were able to ensure seamless transitions between home and university services (including during holidays). Failure to provide safe transitions between services is associated with increased risk, poor care experiences, disengagement, poor treatment outcomes, and avoidable admissions.<sup>22 35 36</sup>

The co-production and co-delivery of ACEDS is essentiall<sup>37</sup>, yet co-production is often not costed or adequately remunerated for people with lived experience. In the future, this issue will need to be addressed and funded co-production has to be included in the staffing mix.

## **Strengths and limitations**

This paper addresses an important gap in the literature regarding the status of ACEDS in England and Scotland prior to the pandemic. The large dataset contained information for a population of 6-10 million people (17.2 % of the population of England and Scotland). We therefore consider the data to be representative of the majority of ACEDS in England and Scotland.

There are a number of limitations to this study. It will be interesting to learn how the results compare to service provision, demand, and capacity in Wales and Northern Ireland. Some services were unable to provide data on every aspect of the survey. Unlike CEDS-CYP, ACEDS are not required to record information about access and waiting times. Data on ethnicity and other protected characteristics, co-morbidities, and outcomes were unavailable for the majority of services. The pandemic not only impacted on data collection, but contributed to a worsening of the demand and capacity crisis highlighted by this survey.

#### Recommendations

Based on our findings the main recommendations are summarised in Text Box 1.

#### **Text box 1: Recommendations**

- The full implementation of the NHSE Commissioning guidelines,<sup>6</sup> the Welsh<sup>8</sup> and Scottish<sup>9</sup> reviews for adult eating disorder services, and achieving parity of access to timely evidence-based treatment across the age range all necessitate a cost estimate and targeted funding.
- As a result of an increase in the number and severity of eating disorder presentations related to the Covid-19 pandemic, emergency funding should be provided to meet the urgent needs of eating disorder patients and services.
- Access and waiting time for eating disorders should be monitored across the age range as part of a national audit of services.
- ACEDS should be co-designed, co-produced, and co-delivered in collaboration with adequately remunerated and diverse groups of patients and carers who have lived experience with a variety of eating disorders.
- The staff must be sufficiently trained to deliver high-quality ACEDS and modify therapies for co-morbid illnesses, such as autism spectrum disorders, substance misuse and personality disorders, and diabetes.
- Trainee placements should be established in all professional disciplines.
- Men and ethnic minorities with eating disorders, as well as other underserved populations, must be the focus of new funding for treatment developments.
- Transitions should be seamless for all patients across the care pathway to help patients achieve the best outcomes.
- Dedicated resources are required for ACEDS for research and audits to improve treatment and service development.

## **Conclusion and clinical implications**

Our survey shows that even before the pandemic ACEDS were severely underfunded and understaffed, leaving them unable to meet rising demand. This had major impact on their ability to provide timely evidence-based treatments and manage risks, and many of the NHSE Commissioning guidelines for ACEDS were not met. Considering that only 3.7% of patients are referred from CAMHS, investment in CEDS-CYP, while beneficial, cannot reverse the rising trend of patients over the age of 18. With the continued rise in eating disorders since the pandemic, ACEDS requires significant new funding to maintain its reputation for providing safe and effective NHS services to people of all ages without discrimination.

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