



# Eating Disorders Awareness Week 2022: Key Policy Asks

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Policies and research evidence cited in this briefing are accessible via hyperlinks. Quotes are included throughout from people with lived experience of eating disorders, professionals, organisations and others. All names attributed to quotes are pseudonyms.

# Summary of Key Policy Asks

This document outlines our key concerns and specific policy recommendations for the following priority areas:

## Medical training on eating disorders

**Eating disorders are appropriately taught and assessed at all UK medical schools and all junior doctors in the UK to gain clinical experience during foundation .**

Learning about eating disorders is generally overlooked in UK medical training, with severe consequences for the prognosis and safety of patients.

## Treatment for Adults

**Introduction of an ‘Access and Waiting Time Standard’ for adults with an eating disorder in England.**

An ambitious target, supported by sufficient funding, is required to enable progress towards an NHS where all adults with an eating disorder can quickly access evidence-based treatment.

## Treatment for Children and Young People

**Achievement of the ‘Access and Waiting Time Standard for Children and Young People with an Eating Disorder’ in every area of England.**

While good progress has been made overall, there is still a postcode lottery. Waiting times remain high, with a significant rise in referrals due to COVID-19, attributing to an even faster rise in the past two years.

## Research funding

**Increased funding for eating disorder research.**

Major advances are needed in our understanding of what causes eating disorders, how to prevent them developing and how best to treat them. Despite eating disorders having very high mortality rates, with anorexia having the highest mortality rate of any mental illness and 1 in 6 people with binge eating disorder trying to end their own life, eating disorders account for just 1% of the UK’s already severely limited mental health research funding.

# Introduction

## About Eating Disorders

Eating disorders are **serious mental illnesses**. Around 1.25 million in the UK have an eating disorder. Eating disorders affect people of any age, gender, ethnicity or background. They have major impacts on individuals, families, the NHS, social care and wider society.

Types of eating disorders include binge eating disorder, bulimia, anorexia, other specified feeding or eating disorder (OSFED) and avoidant/restrictive food intake disorder (ARFID). Eating disorders have **high mortality rates**, with anorexia having the highest mortality rate of any mental illness, and 1 in 6 people with binge eating disorder trying to end their life.

People with eating disorders typically develop severe physical health problems and overall quality of life has been estimated to be as low as in symptomatic coronary heart disease or severe depression. Without early intervention, many become unable to participate in education or employment.

However, **recovery is possible**. Access to the right treatment and support is life-changing, and early intervention provides the best chance for recovery. Delays prolong the suffering of the individual and those who care for them, as well as significantly increasing the costs to the NHS, as hospital admission becomes more likely. Despite this, those who are able to access treatment experience an average three-and-a-half-year gap between onset and start of treatment, due to delays in identification, referral, and waiting times.

Families and other carers can play an important role in recovery, yet they are often not empowered to provide this support.

## The difference you can make as an MP or Peer

In recent years the support of MPs and Peers has helped increase the political profile of eating disorders. This support has been crucial in unlocking much needed investment for NHS eating disorders services for children and young people in England and greater recognition of the need to improve medical training on eating disorders.

However, there is much more work to do before we have a health system and society that enables everyone affected by eating disorders to get the help they need.

**Tabling written or oral parliamentary questions and writing to Ministers are valuable actions that Members can take to support the cause. Members are also invited to join the All-Party Parliamentary Group on Eating Disorders.**

# Impact of COVID-19 on people affected by eating disorders

COVID-19 and the resulting necessary lockdown restrictions have had profound, negative impacts on people affected by eating disorders. The disruption caused to routines, living arrangements, opportunities for physical activity and access to treatment have made the pandemic especially challenging for people with eating disorders and those that support them.

In a Northumbria University survey of people with an eating disorder conducted in 2020 during the first lockdown, nine out of ten respondents said that their symptoms had got worse as a result of the pandemic, with 30% reporting that their symptoms had got much worse.

These findings are echoed in the increased scale of demand for Beat's support services. At its peak in March 2021, **Beat support services experienced a 300% rise in the number of people reaching out for help, in comparison to pre-pandemic levels, and in 2021 there were 1117 safeguarding concerns raised from calls to Beat's services.**

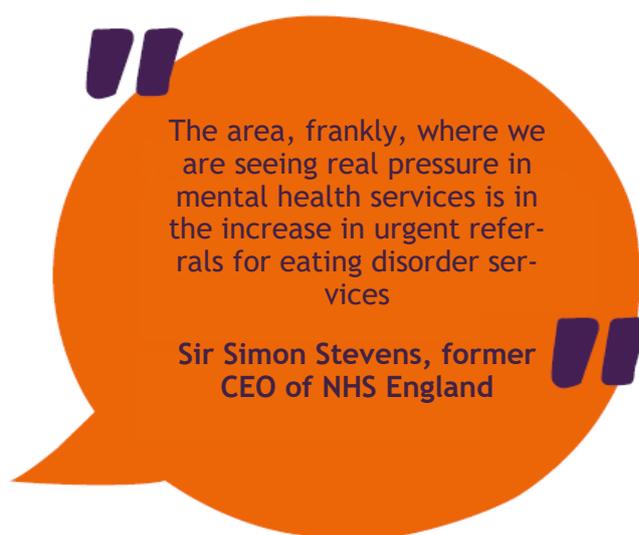
With a lack of data on adults with eating disorders in the UK it is difficult to understand the true scale of the impact from the pandemic, however recent data obtained from a Parliamentary Question shows that in England, referrals for both children and young people (CYP), and adults, have risen significantly from 2019/20 to 2020/21, increasing by 22% and 55% respectively.

A paper presented to the board of NHS England/Improvement in November 2021 heard the National Mental health Director reporting a "surge" in urgent eating disorder cases among CYP. Despite more children and young people starting treatment than ever before, waiting times have increased due to the scale of referrals, meaning that **the waiting time target has not been met.**

Clinicians across the country have also reported a significant increase in the proportion of people first presenting in a severely ill state. People with an eating disorder often suffer from low self-esteem. A study on the impact of COVID-19 on individuals with eating disorders reported a theme among participants of being reticent to seek help

during the pandemic, and cited a link to lack of self-worth. It is reasonable to suggest that this, combined with public messaging and regulations to stay at home, could have contributed to the presentation of sicker patients.

Echoing concerns for eating disorder services, (now Sir) Simon Stevens said in evidence given to a joint select committee inquiry on 26 January 2021:



As there is often a delay of years between developing an eating disorder and first seeking help, it is likely that the elevated demand for specialist treatment will persist.

**The Government and NHS England/Improvement must increase funding for eating disorder services from 2022/23–2024/25 in line with the current and projected rise in demand. And they must ensure that this funding reaches frontline services.**

# Eating Disorders Awareness Week 2022: Worth more than 2 hours

## Our key policy ask:

- Eating disorders are appropriately taught and assessed at all UK medical schools all junior doctors in the UK to gain clinical experience during foundation

Learning about eating disorders has been overlooked in UK medical training, with severe consequences for the prognosis and safety of patients.

This year the theme of Eating Disorders Awareness Week is medical training. Many of us rely on GPs to spot the early warning signs of an eating disorder, to intervene quickly and help us to recover.

However, on average, medical students receive less than two hours training on eating disorders in their training, with a fifth of medical schools offering no training whatsoever.

This lack of training has delayed access to treatment and led to misdiagnosis of eating disorders for years. The consequences for people living with these mental illnesses and their families can be devastating and sometimes deadly.

## This isn't good enough.

Our GPs want to provide the best quality care for people with eating disorders. But they need proper training to match the seriousness of these conditions.

This training exists. Beat has developed clear and comprehensive courses for medical students which some medical schools have started to teach.

## But 'some' is not enough.

We need all UK medical schools to include comprehensive training on eating disorders. So that people like Julia get early access to treatment.

**It's time for all UK medical schools to implement proper training on eating disorders. It's time to change lives.**

”

The doctor who finally referred me was someone who listened - not just to what I was saying but listened to all of me... He was very attentive to my body language and non-verbal cues as well as my words. The important thing is to really focus on what the person is telling you and what their mental state is.

Julia

”

I have encountered a number of problematic, stereotypical opinions of patients with eating disorders being spread through medical training  
(4th Year Medical student)

”

## Overlooked in medical training

Research published in 2018 found that:

- On average just **1.8 hours** is spent on teaching about eating disorders in UK medical schools.
- **One in five** medical schools do not provide any teaching.
- Assessment drives learning, yet 50% of medical schools **do not include a question about eating disorders** in their final exams.

Eating disorders are serious mental illnesses and it is crucial that all doctors understand eating disorders, know how to identify an eating disorder and know how to treat someone with an eating disorder.

In a Beat survey (2021) of 1,697 people who have experienced an eating disorder, many participants reported that when they first sought help from a GP they had a negative experience:

- **60% felt that their quality of care was poor**
- **58% of respondents felt that the first GP they sought help from did not understand eating disorders**
- **Only 42% felt that their GP emphasized the importance of getting help and treatment as soon as possible**

There are many fantastic GPs delivering excellent care to people with eating disorders. Unfortunately, we have heard many accounts of GPs failing to take people's disclosures seriously, where people with eating disorders have been told "*it's just a phase*", "*just eat a bit of toast*", "*you're a nice size so you don't have anything to worry about*" and even some cases where people have been encouraged to lose more weight in order for them to be taken seriously. These comments highlight the importance of training.

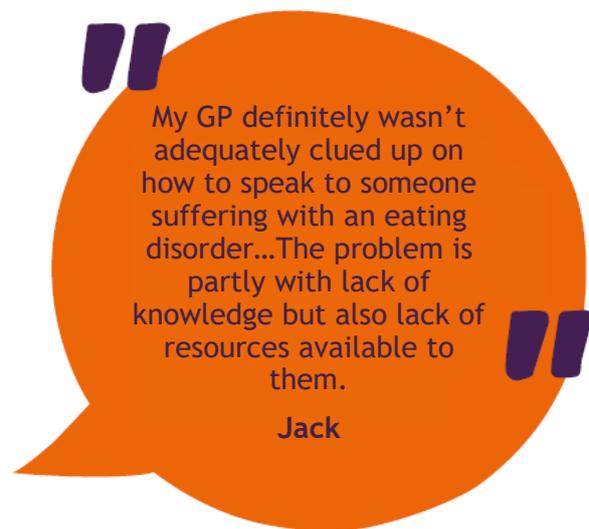
**Research suggests that most non-specialist doctors lack confidence in and knowledge of how to help patients with eating disorders, and that**

**this leads to delays in treatment and inappropriate management.**

### **'Ignoring the Alarms'**

The Parliamentary and Health Service Ombudsman's (PHSO) 2017 report found the tragic death of 19 year-old Averil Hart could have been avoided.

The report observed that low levels of knowledge among doctors and other medical professionals was among several failings that led to the deaths of Averil and two other people from eating disorders and recommended that the General Medical Council (GMC) conduct a review of the coverage of eating disorders in medical training.

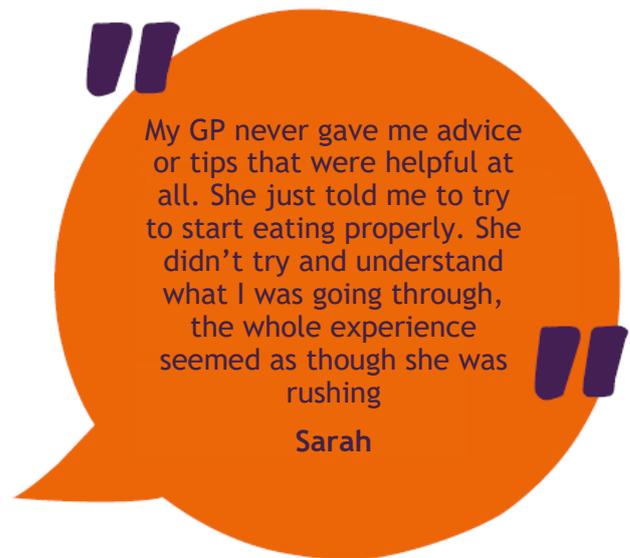


In 2019 the Parliamentary Administration and Constitutional Affairs Committee (PACAC) investigated the implementation of the PHSO's recommendations.

The investigation concluded that “two hours of training on such a complicated topic is insufficient” and recommended that the GMC use its influence to promote best practice, ensure that medical schools improve outcomes in relation to eating disorders and monitor medical schools’ progress.

PACAC also recognised the need for improvements in postgraduate training and called on the Academy of Medical Royal Colleges’ to continue its work in this area.

Health Education England has funded Beat in collaboration with the Faculty of Eating Disorders at the Royal College of Psychiatrists to develop training packages for medical schools and foundation programmes across the UK. The package is now freely available to all medical schools and foundation programmes in the UK.



As an MP or Peer we ask that you call on the Government to continue to hold the GMC and medical schools to account over their responsibility to ensure that trainee doctors leave medical school with basic levels of knowledge and skills in the identification, safe management and referral of patients with eating disorders.

# Treatment for adults

## Our key policy ask:

- Introduction of an 'Access and Waiting Time Standard' for adults with an eating disorder in England.

An ambitious target, supported by sufficient funding, is required to enable progress towards an NHS where all adults with an eating disorder can quickly access evidence-based treatment.

There are currently no waiting time targets in place for adults with an eating disorder in England.

A recent UK study suggests that in many cases eating disorder symptoms first develop in early adulthood. Additionally, many of those who access treatment from a children and young people's eating disorder service will need to continue their treatment into adulthood, or may require treatment in later life due to relapse.

## Service provision for adults in England

Adult eating disorder services in England are severely under-resourced, especially now that demand on these services has risen to even higher levels due to the COVID-19 pandemic.

They typically have either long waiting lists or referral criteria (or both), which means that many adults are unable to access the treatment they need until they have become even more seriously ill. This is despite evidence showing that the sooner a person with an eating disorder receives treatment, the better their chance of making a full and sustained recovery, and the lower the costs to the NHS.

By the time you've waited you just feel a bit abandoned and forgotten.

Claire

I really did think that the only way I would be seen is if I lost more weight.

Alice

Adults with eating disorders face a postcode lottery in trying to access specialist treatment.

In some areas, treatment is only granted to adults with anorexia based on whether their BMI is 'low enough'. Treatment for people with bulimia can be rationed by the frequency of bingeing and purging episodes. This contradicts guidance from the National Institute for Health and Care Excellence (NICE), which says that severity and risk can only be judged on the basis of a comprehensive clinical assessment. In many areas there is no treatment provided for people with binge eating disorder, despite its severity and relatively high prevalence.

Very little data is published on adult eating disorder services. A Beat Freedom of Information request submitted before the pandemic found:

- **Wide variation in the numbers of adults accessing specialist treatment.** The service with the biggest caseload treated 7 times more than the one with the smallest.
- **Only around a quarter of adult patients started treatment at a specialist service within four weeks.** On average patients waited nine weeks, although this varied widely, with an average waiting time at one service provider of five-and-a-half months.

- **Wide variation in staffing levels across the country.** After accounting for differences in the numbers of patients treated, the service with the most staff had 9 times more than the one with the least.
- **In 2020/21, 22% of adult eating disorder referrals in England were made to generic (non-specialist) mental health services.** This is concerning as these services often do not have the required capacity and expertise.

In 2017 the Parliamentary and Health Service Ombudsman (PHSO) published a damning report into the failings that led to the deaths of 19-year old Averil Hart from anorexia and two other adults with an eating disorder.

In its ‘Ignoring the alarms’ report the PHSO highlighted failures to coordinate care and the postcode lottery adults face when trying to access quality treatment. The Ombudsman explained that achieving parity in access and quality between adult eating disorder services and those for children and young people is needed to prevent further avoidable deaths.



## The need for greater urgency

In 2019 the Public Administration and Constitutional Affairs Committee (PACAC) conducted an inquiry to follow-up implementation of the recommendations made by the PHSO. It found that:

*“A number of steps have been set out in the evidence we have received but we do not think there is enough urgency. Such urgency must reflect*

*the fact that lives will continue to be lost under the status quo. There must accordingly be a clear picture of what actions will be delivered under each recommendation, what funding will be assigned to delivering those actions and by what timeframe those actions will be complete.”*

In March 2021 the Assistant Coroner for Cambridgeshire and Peterborough submitted a Prevention of Future Deaths report to the Department of Health and Social care and others following his inquests into the death of Averil Hart and four other (unnamed) women who had all died as a result of anorexia in the years following Averil’s death.

**The coroner found several common themes of concern, and reported that continued failure to adequately address the concerns raised by the PHSO and the subsequent PACAC inquiry “give rise to the risk of future deaths”.**

As part of the NHS Long Term Plan NHS England/Improvement has pledged to allocate additional investment to develop ‘new models of care for adults with severe mental illness’, (including adults with eating disorders) from 2021- 2024. As part of this work, from 2021/22 new early intervention services for young adults will be established in a further 18 areas of the country, building on a model developed in South London.

NHS England/Improvement has recently consulted on a proposed new ‘Access and Waiting Time Standard’ for adult community mental health services (which would include adult community eating disorder services). This new standard would ensure progress is made in ensuring parity in access and quality between adult and children and young people’s eating disorder services.

**As an MP or Peer we ask that you write to the Department of Health and Social Care calling for them to introduce an ambitious ‘Access and Waiting Time Standard’ for adults with an eating disorder.**

# Treatment for young people

## Our key policy ask:

- Achievement of the ‘Access and Waiting Time Standard for Children and Young People with an Eating Disorder’ in every area of England.

While good progress has been made, there is still a postcode lottery. The major rise in referrals due to COVID-19 has led to increased waiting times.

## The access and waiting time standard

The introduction in 2016 of the ‘[Access and Waiting Time Standard for Children and Young People with an Eating Disorder](#)’ set clear expectations around access to specialist eating disorder treatment for children and young people up to the age of 18.

**This standard says that 95% of children and young people should start NICE-approved eating disorder treatment within one week of referral in urgent cases, and within four weeks in all other cases.**

The Government and NHS England made extra funding available to support this. The [NHS Long Term Plan](#) confirmed that this standard would continue to be applied beyond 2021, supported by further additional funding.

## Good (but uneven) progress before the pandemic

In many areas significant improvements have been made in the care available for children and young people, however some areas have been left behind.

Before the pandemic around 4 in 5 cases started treatment within the waiting time targets. However, it is important to note that these [figures are national averages](#), and therefore do not illustrate variations both between and within regions.

NHS England’s [guidance to NHS commissioners and providers](#) stated that children and young people should be able to refer themselves for a specialist eating disorder assessment, to help speed up access to treatment.

In January 2020, [Beat found](#) that only a third of services were advertising self-referral as an option on their website.

## Waiting times are increasing

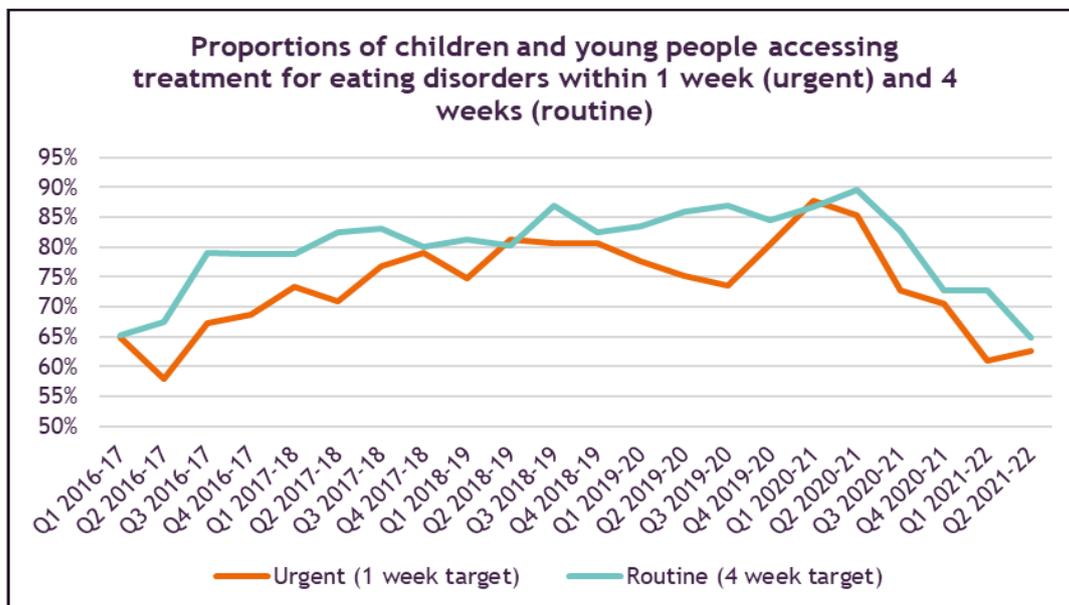
COVID-19 has led to an unprecedented increase in demand on eating disorder services for children and young people. These services received [55% more referrals in 2020/21 than in 2019/20](#). Clinicians have reported a [significant increase](#) in the proportion of young people first presenting in a severely ill state.

In response to a [survey conducted by NHS Providers \(May 2021\)](#), 85% of NHS Trust leaders said that they could not meet demand for children and young people’s eating disorder services. This was the highest result across all types of children and young people’s mental health services.

**Although far more young people are starting treatment now than before the pandemic, waiting times have increased (see chart overleaf).**

**[Between July and September 2021](#) only 63% of urgent cases started treatment within 1 week, and just 65% of all other cases started treatment within 4 weeks –well below the 95% standards.**

There continues to be wide variation between Integrated Care Systems (ICS) across England. From quarter 3 of 2020/21 (Oct–Dec 2020) to quarter 2 of 2021/22 (Jul–Sep 2021), performance against the waiting time targets ranged from 15-100% for urgent cases, and between 28-100% for all other routine cases.



## Funding not reaching frontline services

In 2019/20 NHS England/Improvement gave Clinical Commissioning Groups (CCGs) an extra £11m of funding for children and young people’s community eating disorder services (so increasing the total additional funding allocated for these services from £30m to £41m).

Analysis presented in the All-Party Parliamentary Group (APPG) on Eating Disorders’ ‘Short-Changed’ report showed that collectively CCGs spent just £1.1m more on these services in 2019/20 than they did in 2018/19. In other words, 90% of the new additional funding did not reach the services it was pledged to.

A fifth of CCGs actually spent less on these services in 2019/20 than in 2018/19. Spending per capita varied widely across the country in 2019/20. Whilst the median average spend was £4 per capita, spending ranged from nearly £13 per capita in one CCG, to 7 CCGs reporting a per capita spend of less than £2.

These findings were cited in a December 2021 report published by the Health and Social Care Committee.

In 2020/21 NHS England/Improvement allocated an extra £22m to Clinical Commissioning Groups (CCGs) for children and young people’s community eating disorder services, above the 2018/19 baseline.

According to data published by NHS England/Improvement in the NHS Mental Health Dashboard, collectively CCGs spent just £7m more on these services in 2020/21 than they did in 2018/19. The wide variation in spend per capita was repeated.

The access and waiting time standard for children and young people with an eating disorder has led to significant, albeit uneven improvements. But **increasing demand for underfunded services will mean many young people missing out on support when they need it most.**

As an MP or Peer we ask that you hold the Government and NHS leaders to account for full implementation of the ‘Access and Waiting Time Standard for Children and Young People with an Eating Disorder’, in every area of England.

# Research funding

## Our key policy ask:

- **Increased funding for eating disorder research**

Major advances are needed in our understanding of what causes eating disorders, how to prevent them developing and how best to treat them. Eating disorders account for just 1% of the UK's already severely limited mental health research funding.

## Why eating disorder research is so important

**Major advances are needed in our understanding of what causes eating disorders, how to prevent them developing and how best to treat them.**

Without this, eating disorders will continue to represent a significant public health issue, devastating millions of lives while leading to high costs to the NHS and the UK economy. The impacts of COVID-19 on demand for eating disorder services means that the need for advances in knowledge and innovation through research is more urgent than ever.

**Research into eating disorders should be seen as a prudent investment.** Often chances for early intervention are missed. Treatments are not always effective. As a result, many patients are admitted for expensive hospital treatment. Hospital admissions in England for people with eating disorders have risen significantly in recent years. In 2015 PwC estimated that eating disorders result in lost income to the UK economy of £6.8 - £8 billion per year.

## The APPG on Eating Disorders' inquiry

In 2020/21, the All-Party Parliamentary Group (APPG) on Eating Disorders conducted an inquiry into research funding. Its 'Breaking the Cycle' report sets out its findings and recommendations.

**The inquiry found that despite the prevalence and severity of eating disorders, they receive very little research funding.** Total UK investment (in terms of grant funding) amounted to just £1.13 per person affected per year between 2009 and 2019. From 2015-2019 just 1% of the UK's already severely limited mental health research funding went towards research on eating disorders. This is despite people with eating disorders accounting for around 9% of the total number of people with a

mental health condition in the UK.

A funding target for the UK eating disorder research field should as an absolute minimum be based on parity within mental health research. As explained in the report 'Breaking the Cycle', this would mean an increase of 9-13 times the current funding level in order to reach between £13m and £18m per year. However, to achieve the progress needed, the ambition should be much greater - at least £50m-£100m per year.

The inquiry found that **an historic lack of investment has led to a vicious cycle. As a result, there are few active researchers and research centres in the UK and therefore little research is published. This has helped stigmatising attitudes persist, which reinforce the small capacity of the field, and its lack of funding.**



Source: APPG on Eating Disorders (2021, p.15)

The inquiry also highlighted serious inequities within the eating disorder research field, with certain population/patient groups often overlooked.

The APPG's recommendations include:

- UK Research and Innovation (UKRI) to collaborate with a group of universities to establish an inter-disciplinary training programme for early-career researchers in eating disorders
- Establishment of a working group to develop and oversee implementation of a long-term UK eating disorder research strategy
- NHS England, NHS Scotland, NHS Wales and Health and Social Care Northern Ireland (HSCNI) to incorporate skills and capacity in audit and research into future workforce planning for eating disorder services and to ensure sufficient investment so that time for clinicians to lead or support research can be protected.

Implementation of the APPG's recommendations - by research funders (including Government departments/agencies), universities, the NHS and researchers - would enable us to break the cycle of underfunding in eating disorder research and achieve the much-needed advances in knowledge that research can deliver.

”

There is no doubt an urgent need to invest in building the capacity of the field, including work to nurture the next generation of research leaders.

”  
Wera Hobhouse MP,  
Chair of the APPG on  
Eating Disorders

”

At present, the field... is very much behind other specialties.

”  
Faculty of Eating  
Disorders at the  
Royal College of  
Psychiatrists

As an MP or Peer you can support our campaigning on this issue by asking questions in parliament to the Department of Health and Social Care and the Department for Business, Energy and Industrial Strategy about implementation of the recommendations made in the APPG's 'Breaking the Cycle' report.

## About Beat

Beat is the UK's eating disorder charity. We exist to end the pain and suffering of eating disorders, and we are here to help anyone affected by these serious mental illnesses.

We provide information and support through Helplines, which people can call, text or email. We also run online support groups and HelpFinder, an online directory of support services.

We provide expert training, resources and consultancy to health and social care professionals and schools, and support and encourage research into eating disorders.

## Beat's Helpline and other support services

Beat provides Helplines for people of all ages, offering support and information about eating disorders no matter where you are in your journey. These Helplines are free to call from all phones.

Individuals contacting our Helpline speak to trained advisors who are experienced in listening and talking to people affected by eating disorders. Anyone affected by an eating disorder can call, email or contact Beat's Helpline Advisors via one-to-one webchat.

England: 0808 801 0677  
[help@beateatingdisorders.org.uk](mailto:help@beateatingdisorders.org.uk)

Scotland: 0808 801 0432  
[Scotlandhelp@beateatingdisorders.org.uk](mailto:Scotlandhelp@beateatingdisorders.org.uk)

Wales: 0808 801 0433  
[Waleshelp@beateatingdisorders.org.uk](mailto:Waleshelp@beateatingdisorders.org.uk)

Northern Ireland: 0808 801 0434  
[NIhelp@beateatingdisorders.org.uk](mailto:NIhelp@beateatingdisorders.org.uk)

Our Helplines are open 365 days a year from 9am-midnight during the week, and 4pm-midnight on weekends and bank holidays.

## Annabel Smith

Policy and Public Affairs Officer

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