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All-Party Parliamentary Group
on Eating Disorders



BREAKING the CYCLE

An inquiry into eating disorder
research funding in the UK

September 2021

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Contents

Foreword

Executive summary

Introduction

Funding for UK eating disorder research from 2009-2019 and recent developments

Why there is so little funding for UK eating disorder research

Actions needed to secure greater funding for UK eating disorder research

Conclusions and recommendations

Appendices

Acknowledgements

About the All-Party Parliamentary Group (APPG) on Eating Disorders

Foreword

The All-Party Parliamentary Group (APPG) on Eating Disorders launched this inquiry in late 2020 in response to concern about the lack of investment in eating disorder research in the UK. This report highlights the stark fact that, despite their prevalence and severity, eating disorders receive far less research funding than almost all other mental health conditions, with mental health research as a whole severely underfunded.



Eating disorders are serious mental illnesses that affect people of all ages, genders and backgrounds. They result in high costs to the NHS and the UK economy. Despite some progress in recent years, there is much that we still do not know about how eating disorders develop and the best ways to provide treatment. Due to serious inequities within eating disorder research, there is a particular lack of evidence around the experiences of some groups of patients, including males, people with binge eating disorder and people from ethnic minority backgrounds, among others. The COVID-19 pandemic has had an alarming impact on many people with eating disorders and those that may have been at a higher risk of developing one, along with their families and other carers. Referrals to eating disorder services have risen significantly across the UK. This rise in demand means that the need for advances through research is more urgent than ever.

Our inquiry received evidence from research funders, academics, clinicians, professional bodies, charities and people with lived experience of eating disorders. The evidence we heard describes a vicious cycle, whereby despite strong interest in studying and researching eating disorders, lack of investment has limited recruitment and retention of researchers, in turn limiting the research being done. This has helped stigmatising attitudes persist. Taken together, all this makes the field ill-equipped to compete successfully for the major increase in funding that it needs.

I have been very concerned to learn that lack of training and career progression opportunities for early-career researchers is leading to the loss of many PhD graduates from the field. Especially worrying is that this failure of the system comes at a time when there are only a few senior researchers working in this area in the UK, many of whom are close to retirement. 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.

Our recommendations set out the actions that I believe can break the cycle of underfunding in UK eating disorder research. These include a series of targeted actions that can be taken in the short- and medium-term alongside a call to bring together funders, researchers and people with lived experience to develop a long-term UK eating disorder research strategy.

It has been a privilege to chair this important inquiry and I would like to offer my thanks to my fellow members of the APPG, Beat, and in particular all the experts who made written submissions and/or provided oral evidence and together have made this report possible. I look forward to working with you all to ensure that eating disorder research gets the investment it so urgently needs.

Wera Hobhouse

Wera Hobhouse MP, Chair of the All-Party Parliamentary Group on Eating Disorders

Executive summary

This report presents the findings of an inquiry into eating disorder research funding in the UK, conducted from December 2020 to Spring 2021 by the All-Party Parliamentary Group (APPG) on Eating Disorders. Major advances are needed in our understanding of what causes eating disorders, how best to treat them and how to prevent them from developing. Without this, eating disorders will continue to represent a significant public health issue with high costs to the National Health Service (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.

Data on research grants awarded from 2009-2019 in the UK shows that eating disorder research received very little funding during this time and that most grant funding was awarded to London-based (lead) institutions. Total UK funding amounted to just £1.13 per person affected per year. From 2015-2019, just 1% of UK mental health research funding - already severely limited as a whole - 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. This would mean an increase of 9-13 times the current funding level - 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 heard that an historic lack of funding for eating disorder research has led to a vicious cycle whereby there are few active researchers and research centres and therefore relatively little research published. This has helped stigmatising attitudes persist, including the perception of eating disorder research as a 'niche' and less important area of study. Eating disorders are often seen as rare and trivial or 'self-inflicted' conditions and as a result they are often left out of important datasets, overlooked by other closely related research fields such as obesity, and possibly side-lined by high-profile academic journals. All this conspires to mean that the eating disorder research field is ill-equipped to compete successfully for funding. There is also concern that lack of awareness and stigma may lead to unwarranted rejections by funders, but insufficient data was available to reach any conclusions on this matter.

Breaking the cycle of underfunding will require targeted actions and a coordinated, strategic approach towards building the capacity of the field. Such an approach should aim for a broader research agenda that is inclusive of historically under-served population/patient groups and based on co- production of both research priorities and the research itself. With this report the APPG on Eating Disorders makes a series of UK-wide recommendations. Some of these are addressed to the devolved Governments of Scotland, Wales, and Northern Ireland, or NHS leaders in each of the UK nations, due to the roles they can play in supporting research.

Recommendations

Encouraging grant applications

- ↳ National Institute for Health Research (NIHR), UK Research and Innovation (UKRI) and Wellcome Trust, either individually or jointly issue a ‘highlight notice’*, to encourage more proposals focused on eating disorder research, in particular studies based on:
 - ⇒ Early identification of those at greatest risk and the development of novel approaches to prevention and treatment
 - ⇒ Collaboration with other closely related fields such as obesity, diabetes or autism
 - ⇒ Understanding and addressing health inequalities in eating disorders and being inclusive of typically under-served population/patient groups (these groups include but are not limited to people with binge eating disorder, other specified feeding or eating disorder (OSFED), avoidant/restrictive food intake disorder (ARFID), males, people from ethnic minority backgrounds and older people)
 - ⇒ Meaningful and costed co-production/patient and public involvement.

Commissioning research

- ↳ NIHR and the devolved Governments/Government agencies of Scotland, Wales, and Northern Ireland to commission research to address key gaps in the evidence base that have been identified by NHS England, the National Institute for Health and Care Excellence (NICE), the Scottish Intercollegiate Guideline Network (SIGN), and the eating disorder service reviews that have been conducted in Scotland and Wales.

Building the capacity of clinical services to engage in research

- ↳ 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.
- ↳ NHS England, NHS Scotland, NHS Wales and Health and Social Care Northern Ireland (HSCNI) to support NHS Trusts/Health Boards/HSC Trusts to establish eating disorder research clinics or other innovations to build the capacity of eating disorder services to lead and support audit and research.

*‘Highlight notices’ are announcements published by research funders that are intended to encourage researchers to submit funding proposals under a specific topic or theme.

Investing in training to develop future research leaders

- ↳ UKRI to collaborate with a group of universities to establish an inter-disciplinary training programme for early-career researchers in eating disorders.

Improving data on grant applications and success rates

- ↳ NIHR, UKRI and Wellcome Trust to utilise new technologies to code rejected grant applications by condition and publish this data in the interest of transparency.

Collaboration to develop and implement a long-term UK eating disorder research strategy

- ↳ DHSC/NIHR to establish a working group to develop and oversee implementation of a long-term UK eating disorder research strategy.

Introduction

This report presents the findings and recommendations from an inquiry into eating disorder research funding conducted by the All-Party Parliamentary Group (APPG) on Eating Disorders from December 2020 to Spring 2021. The APPG on Eating Disorders is a cross-party group of MPs that works to improve policy and practice on eating disorders.

An analysis of investment in UK eating disorder research from 2009-2019 was conducted as part of the inquiry. Over a seven week period from 11 December 2020 the APPG called for written evidence from funders, researchers, professional bodies, charities and people with lived experience, and received 29 submissions. The APPG then held two oral evidence sessions (held online) in April 2021 (see Appendices 1 and 2).

Why eating disorder research is so important

Eating disorders are serious mental illnesses¹, affecting around 1.25 million people in the UK². They affect people of all ages, genders and backgrounds^{3;4;5;6;7}. Eating disorders have high mortality rates, with anorexia having the highest mortality rate of any mental illness^{8;9}. People with eating disorders often develop severe physical health problems. Quality of life has been estimated to be as low as in symptomatic coronary heart disease or severe depression¹⁰. Family and other carers typically experience high levels of psychological distress and financial costs¹¹.

Eating disorders typically begin between the ages of 15 and 25, threatening cognitive and social development¹². Despite the importance of early intervention there is an average delay of three and a half years between symptoms first developing, the condition being identified and the person or family/carer first seeking treatment (for those that are able to access it)¹³. Such delays prolong the suffering, seriously disrupt social life, education, and employment, and have significant impacts on families and other carers. Further research in this area would help ensure

¹ Schmidt, et. al. (2016) [Eating disorders: the big issue](#). *The Lancet Psychiatry*. Vol.3(4), p.313-315.

² Beat (2018) [How many people have an eating disorder in the UK?](#)

³ Sweeting, et. al. (2015) [Prevalence of eating disorders in males: a review of rates reported in academic research and UK mass media](#). *International Journal of Men's Health*. Vol.14(2)

⁴ Micali, et. al. (2017) [Lifetime and 12-month prevalence of eating disorders amongst women in midlife: a population-based study of diagnoses and risk factors](#). *BMC Medicine*. Vol.15(12)

⁵ Conceição, et. al. (2017) [Prevalence of eating disorders and picking/nibbling in elderly women](#). *International Journal of Eating Disorders*. Vol.50(7), p.793-800.

⁶ Waller, et. al. (2009) [Ethnic origins of patients attending specialist eating disorders services in a multiethnic urban catchment area in the United Kingdom](#). *International Journal of Eating Disorders*. Vol.42(5), p.459-463.

⁷ Huryk, Drury, and Loeb (2021) [Diseases of affluence? A systematic review of the literature on socioeconomic diversity in eating disorders](#). *Eat Behaviours*. Vol. 43(101548).

⁸ Arcelus, et. al. (2011) [Mortality rates in patients with anorexia nervosa and other eating disorders. A meta-analysis of 36 studies](#). *Archives of General Psychiatry*. Vol.68(7), p.724-31.

⁹ Chesney, Goodwin, and Fazel (2014) [Risks of all-cause and suicide mortality in mental disorders: a meta-review](#). *World Psychiatry*. Vol.13(2), p.153-60.

¹⁰ Schmidt, et. al. (2016) [Eating disorders: the big issue](#). *The Lancet Psychiatry*. Vol.3(4), p.313-315.

¹¹ Anastasiadou, et. al. (2014) [A Systematic review of family caregiving in eating disorders](#). *Eating Behaviours*. Vol.15(3), p.464-77

¹² Schmidt, et. al. (2016) [Eating disorders: the big issue](#). *The Lancet Psychiatry*. Vol.3(4), p.313-315.

¹³ Beat (2017) [Delaying for years, denied for months](#)

eating disorders can be identified early and that those affected are effectively encouraged to seek treatment quickly.

There is a pressing need for existing evidence-based therapies to be further developed along with innovative new treatments¹⁴.

Eating disorders are responsible for significant social and economic costs to the UK, largely through the disruption they cause to education and employment, with PwC having estimated in 2015 that they result in lost income to the UK economy of £6.8 billion - £8 billion per year¹⁵. The need for advances in our understanding has become even more urgent as referrals to eating disorder services have risen rapidly since the start of the COVID-19 pandemic^{16;17}, and hospital admissions have continued to rise¹⁸.

Properly addressing this major public health issue will only be possible if we fully understand what causes eating disorders, how best to treat them and how to prevent them from developing.

Research funding in the UK

In the UK there are three main funders of health research. These are:

- The Department of Health and Social Care, primarily through the National Institute of Health and Care Research (NIHR)
- UK Research and Innovation (UKRI)
- Wellcome Trust

Taken together these three funders awarded an estimated 73% of UK health research grant funding in 2018¹⁹.

As is the case globally, the majority of UK mental health research funding comes from either governments or public sector agencies. However, the contribution of philanthropy is significantly higher in the UK than in other countries, largely due to the presence of the Wellcome Trust. From 2015-2019 philanthropy contributed 22% of mental health research funding in the UK compared to a global average of 3%²⁰. Public donations constitute around just 4% of UK mental health research funding, which is very low compared to other research fields²¹. Public donations provide the majority of cancer research funding and a large proportion of funding for other research fields including cardiovascular disease and dementia²².

¹⁴ NICE (2017) [Eating Disorders: recognition and treatment Full guideline](#)

¹⁵ PwC (2015) [The costs of eating disorders Social, health and economic impacts](#)

¹⁶ Health and Social Care Select Committee (2021) [Oral evidence: Children and young people's mental health, HC 1194](#)

¹⁷ Royal College of Psychiatry (2021) [Hidden epidemic of eating disorders because of COVID-19, new research finds](#)

¹⁸ NHS Digital (2021) [Supplementary information requests](#)

¹⁹ UK Clinical Research Collaboration (2020) [UK Health Research Analysis 2018](#)

²⁰ IAMHRF (2020) [The Inequities of Mental Health Research Funding](#)

²¹ IAMHRF (2020) [The Inequities of Mental Health Research Funding](#)

²² MQ (2019) [UK Mental Health Research Funding 2014-2017](#)

Devolution

The devolved Governments of Scotland, Wales and Northern Ireland make contributions to the Department of Health and Social Care, which enable their researchers to apply to UK-wide NIHR funding programmes²³. Researchers in Scotland, Wales and Northern Ireland can also apply for UKRI funding. The devolved Governments' main direct contribution to health research is through investment in infrastructure. They award some grant funding for specific projects, although these budgets are relatively small, constituting a combined total of around 2% of total UK health research grant funding in 2018²⁴.

Strategies

In 2017 the Department of Health and Social Care published a UK 'Framework for mental health research' that made ten recommendations, including a greater focus on prevention and early intervention at all stages of life, improving patient and public involvement, strengthening the links between physical and mental health research, improving coordination and leadership, investing in data and technological infrastructure, more flexible approaches to funding, innovation in designing and testing interventions to help reach under-served populations, encouraging stronger engagement from industry, streamlining and improving the quality of regulation and governance, and building the overall capacity of the mental health research field²⁵.

In 2020, the Department of Health and Social Care published four 'Mental health research goals for 2020-2030'²⁶ to "*form an agenda for mental health research over the next decade*". These were developed from the UK 'Framework for mental health research' and discussion between funders, academics, clinicians and people with lived experience of mental health conditions. The goals are:

- Goal 1: Research to halve the number of children and young people experiencing persistent mental health problems.
- Goal 2: Research to improve understanding of the links between physical and mental health and eliminate the mortality gap.
- Goal 3: Research to develop new and improved treatments, interventions and support for mental health problems.
- Goal 4: Research to improve choice of, and access to, mental health care, treatment and support in hospital and community settings.

The UK Framework for mental health research and the mental health research goals for 2020-2030, along with the strategic priorities set by individual research funders and academic institutions, guide research funding decisions in the UK.

Although some valuable research can take place without formal grant funding, the impetus for this inquiry comes from a recognition that grant funding is key to the sustainability and development of capacity in the eating disorder research field.

²³ UK Clinical Research Collaboration (2020) [UK Health Research Analysis 2018](#)

²⁴ UK Clinical Research Collaboration (2020) [UK Health Research Analysis 2018](#)

²⁵ Department of Health (2017) [A Framework for mental health research](#)

²⁶ NIHR (2020) [Mental Health Research Goals 2020-2030](#)

Funding for UK eating disorder research from 2009-2019 and recent developments

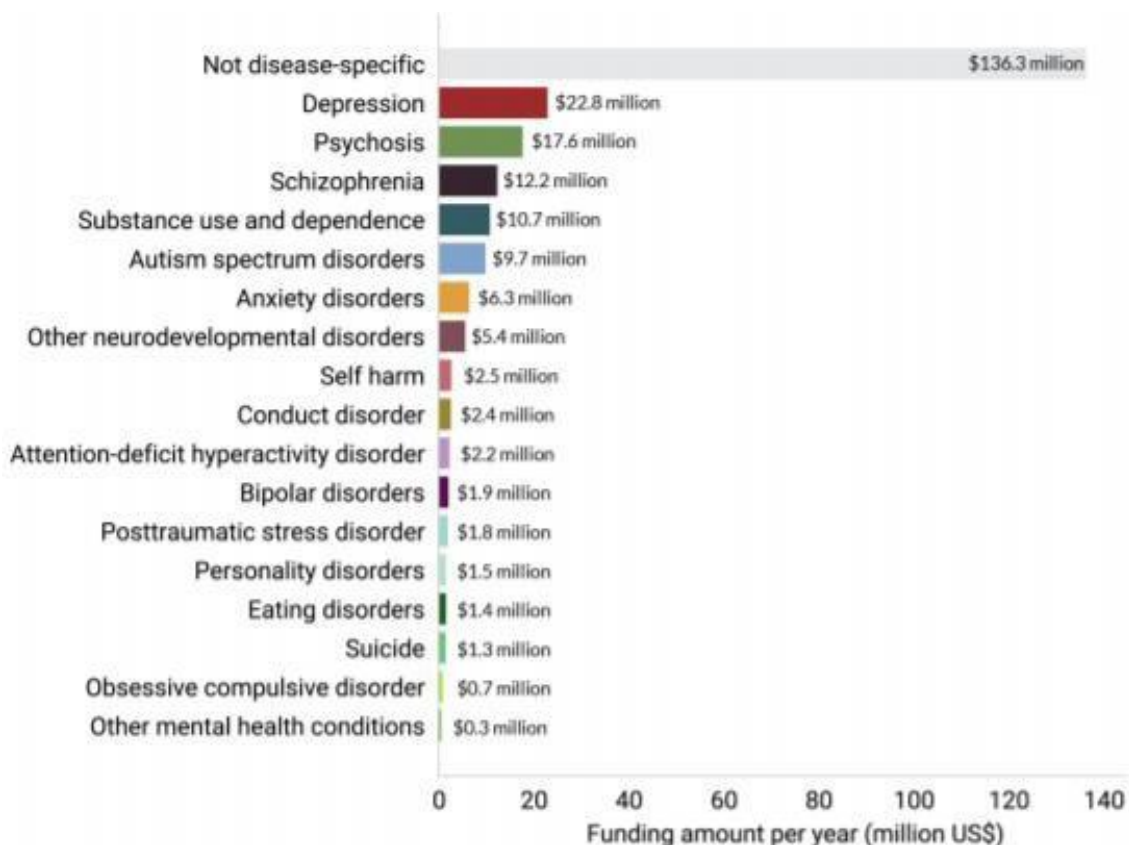
To inform the APPG’s inquiry, Beat investigated funding for UK eating disorder research from 2009-2019. This analysis was conducted to quantify investment over this period, compare investment by funder and to describe the geography of research institutions that were awarded funding.

Investment from UK funders

From 2009-2019 UK-based funders invested an estimated £15.6m (£16.4m in 2019 prices²⁷) in eating disorder research. This amounts to an annual average of £1.4m, or just **£1.13 per person** with an eating disorder per year²⁸. The average duration of these grants was three years.

A recent study by the International Alliance of Mental Health Research Funders (IAMHRF) used a methodology designed to enable comparison of investment in different research fields between 2015 and 2019²⁹. IAMHRF’s analysis showed that eating disorder research receives far less funding than research into almost all other mental health conditions (see figure 1).

Figure 1: Investment by UK research funders per year from 2015-2019 by specific mental health conditions (from IAMHRF, 2020, p.56)



²⁷ HM Treasury (2020) [GDP deflators at market prices, and money GDP March 2020 \(Budget\)](#)

²⁸ Beat (2018) [How many people have an eating disorder in the UK?](#)

²⁹ IAMHRF (2020) [The Inequities of Mental Health Research Funding](#)

Figure 1 illustrates that just 1% of UK mental health research funding went towards research on eating disorders per year between 2015 and 2019³⁰. This is despite people with eating disorders accounting for around 9% of the total number of people with a mental health condition in the UK³¹. Figure 1 also shows that psychosis received 13 times more research funding than eating disorders, despite estimates suggesting a lower prevalence³².

Therefore, just to achieve a form of parity with other mental health conditions, eating disorder research funding would need to increase by 9-13 times the current level, to reach £13m - £18m per year. However, the IAMHRF report and previous studies³³ have shown that mental health research as a whole is seriously underfunded.

Beyond mental health there are examples of conditions that affect fewer or similar numbers of people, that also have severe impacts on quality of life, yet attract funding on a completely different scale. For example, the UK Government has announced £50m worth of funding for research into long COVID³⁴. Although definitions of long COVID vary, estimates of the number of people in the UK who continue to experience symptoms of COVID-19 after at least 12 weeks currently range from around 700,000 to two million people, representing a similar prevalence to eating disorders^{35;36}. Around £115m per year is invested in vital dementia research in the UK³⁷. The prevalence of dementia is around two thirds that of eating disorders^{38;39}, and both have severe impacts on families and other carers, seriously reduce quality of life and have broadly comparable mortality rates⁴⁰.

Although comparison with other conditions cannot determine exactly how much funding eating disorder research will need, it seems reasonable to conclude that the goal for UK eating disorder research funding should be at least £50m and potentially closer to £100m per year.

³⁰ This calculation was based on dividing the funding that [IAMHRF estimated](#) had been invested in eating disorder research by UK funders during 2015-2019 (annual average of \$1.4m), by their combined disease-specific investment in mental health research (annual average of \$100.7m).

³¹ This calculation was based on data from [Beat \(2018\)](#) about the prevalence of eating disorders in the UK and an estimate from [MQ \(2019\)](#) of the number of people with a mental health condition in the UK.

³² Public Health England (2016) [Psychosis Data Report Describing variation in numbers of people with psychosis and their access to care in England](#)

³³ UK Clinical Research Collaboration (2020) [UK Health Research Analysis 2018](#); IAMHRF (2020) [The Inequities of Mental Health Research Funding](#); MQ (2019) [UK Mental Health Research Funding 2014-2017](#)

³⁴ Department of Health and Social Care (2021) [New research into treatment and diagnosis of long COVID](#)

³⁵ Office for National Statistics (2021) [Prevalence of ongoing symptoms following coronavirus \(COVID-19\) infection in the UK: 1 April 2021](#)

³⁶ Department of Health and Social Care (2021) [New research shows 2 million people may have had long COVID](#)

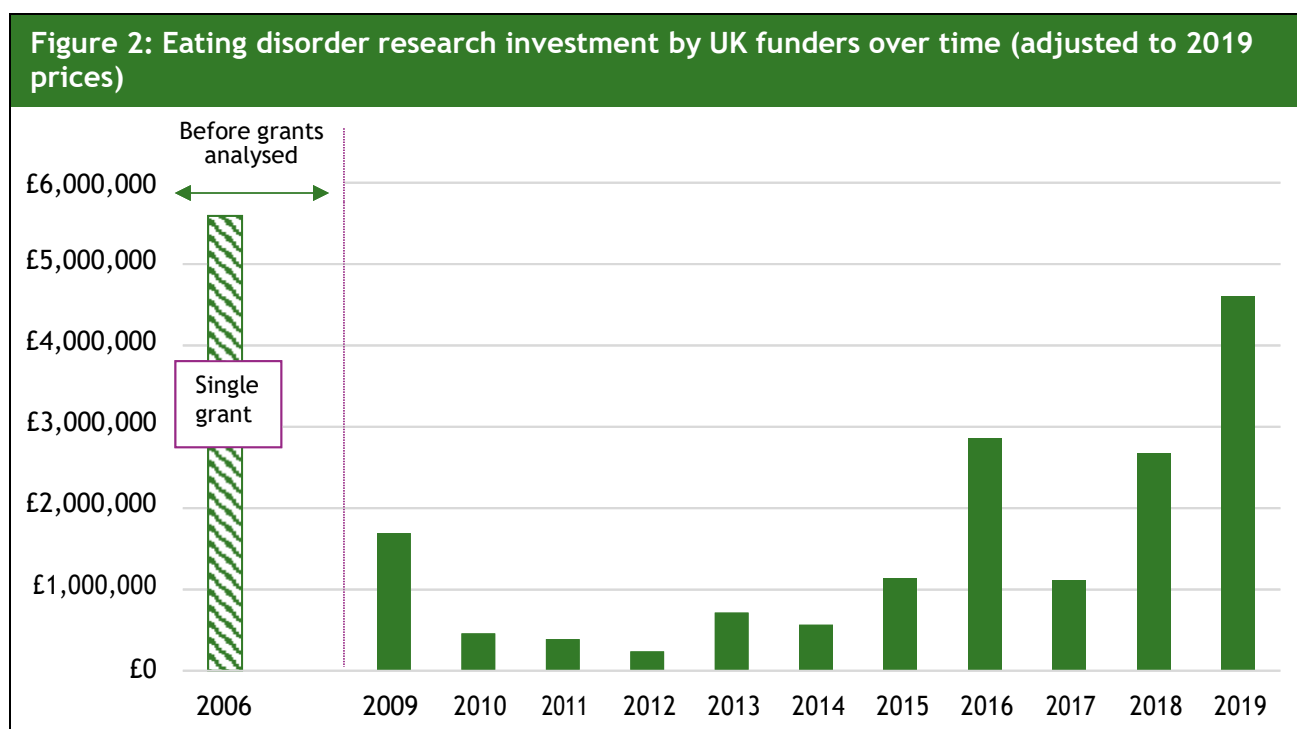
³⁷ MQ (2019) [UK Mental Health Research Funding 2014-2017](#)

³⁸ Beat (2018) [How many people have an eating disorder in the UK?](#)

³⁹ Alzheimer's Society (2021) [Alzheimer's Society's view on demography](#)

⁴⁰ Chesney, Goodwin, and Fazel (2014) [Risks of all-cause and suicide mortality in mental disorders: a meta-review](#). *World Psychiatry*. Vol.13(2), p.153-60.

Figure 2 shows that grant funding awarded for eating disorder research increased in recent years⁴¹. However, it has not come close to the level of funding required. Research fields with little capacity - such as eating disorders - are liable to experience peaks and troughs in investment over time. Figure 2 shows that a single grant⁴² was awarded in 2006 that on its own exceeded the total funding awarded to the whole field in 2019. This context highlights that the recent increase is not part of a long-term trend and suggests that without intervention the field may even experience another downturn in funding.



⁴¹ The data presented in figure 2 is based on allocating the full value of research grants to the start year of each grant, rather than distributing the funding evenly across the years of each grant. The average duration per grant was three years.

⁴² This grant was titled 'Transdiagnostic cognitive behaviour therapy for eating disorders: efficacy and mechanisms of action' and was provided by the Wellcome Trust.

How investment compares between UK funders

Table 1 shows investment in eating disorder research by UK funding organisations. It is important to note that this is based on data that does not include investment in research infrastructure as explained in the methodology (see Appendix 3). Table 1 shows that the National Institute for Health Research (NIHR) and a partnership between the Medical Research Foundation (MRF) and the Medical Research Council (MRC) accounted for two thirds of eating disorder research grant funding provided by UK funders from 2009-2019.

Between 2016 and 2019 the MRF in partnership with the MRC made two joint funding calls dedicated specifically to research into eating disorders and/or self-harm.

Table 1: Investment in eating disorder research by UK funding organisations (2009-2019)		
Funder	Funding amount (in 2019 prices)	Share
National Institute for Health Research (NIHR)	£8,544,424	52%
Medical Research Foundation (MRF)/Medical Research Council (MRC)	£2,328,948	14%
Wellcome Trust	£953,156	6%
Economic and Social Research Council (ESRC)	£914,574	6%
Health Foundation	£771,029	5%
Medical Research Council (MRC)	£726,139	4%
Big Lottery Fund	£544,097	3%
Research and Development Division (Welsh Government, Health & Social Services)	£294,535	2%
Psychiatry Research Trust	£292,938	2%
MQ: Transforming Mental Health	£229,195	1%
HSC Research and Development Division, Public Health Agency (Northern Ireland)	£133,530	1%
Innovate UK (IUK)	£130,793	1%
King's Health Partners	£99,036	1%
Biotechnology and Biological Sciences Research Council (BBSRC)	£98,695	1%
Others*	£382,616	2%

*Others' includes Chief Scientist Office (CSO) [Scotland], which awarded £21,146 (in 2019 prices).

UK research institutions awarded grants (as lead)

Analysis of the research institutions awarded grants (as lead institutions) shows that the majority of awards were made to King’s College London and/or South London and Maudsley NHS Foundation Trust (66%). The next highest recipient was University College London (14%).

Table 2. Research institutions awarded more than £100,000 in grants (as lead institution) by UK funders to conduct eating disorder research, sorted by share of total investment		
Research Institution	Location	Share
King’s College London and/or South London and Maudsley NHS Foundation Trust ⁴³	London	66%
University College London (UCL)	London	14%
Royal Holloway, University of London	Egham	3%
Beat ⁴⁴	Norwich	3%
University of Swansea	Swansea	2%
Barnet, Enfield and Haringey NHS Foundation Trust	London	2%
University of Bristol	Bristol	2%
Durham University	Durham	1%
Queen’s University Belfast	Belfast	1%
Cardiff University	Cardiff	1%
University of Leicester	Leicester	1%
		= 95% of grants

A total of 83% of eating disorder research funding invested by UK funders was awarded to London-based (lead) research institutions. No other single location accounted for more than 3% of the total share. This shows that UK eating disorder research funding is highly concentrated in London.

It is important to note that, due to limitations in the available data, this analysis covers only the *lead* research institutions to have received awards. The larger eating disorder research grants typically involve several research institutions, often distributed across the UK or even internationally and therefore in practice research funding is shared more equitably. However, it is important in its own right to consider the geographic distribution of lead research institutions given the influence this implies over the research agenda, and the potential for research activity to enrich clinical practice.

⁴³ This category combines all grants that were attributed to either or both of these two institutions.

⁴⁴ In 2009 Beat was awarded funding from the ‘Big Lottery Fund’ to coordinate a research project, in partnership with a senior academic and two NHS eating disorder services.

International funding into the UK

From 2009-2019 investment awarded to UK research institutions by international sources amounted to an estimated £1.1m (£1.2m in 2019 prices⁴⁵). From 2009-2019 total UK funding for eating disorder research combined with international funding received by UK institutions amounted to an estimated £16.7m (£17.6m in 2019 prices⁴⁶) with international funders accounting for 7% of the total.

Table 3 shows the amounts invested by international funders. The majority of this limited total was provided by the Swiss Anorexia Nervosa Foundation and the European Commission. It should be noted that the amount credited to the European Commission is an underestimate as it funded some eating disorder-focused research as a component of a multi-nation mental health study, but it was not possible to disaggregate the funding awarded⁴⁷. That study was the only eating disorder research to receive funding from HORIZON 2020 - the European Union's biggest ever research and innovation funding programme - with a total budget of around €77 billion over 2014-2020⁴⁸.

All international grants for which a funding amount was available were awarded to King's College London, as the lead (UK) institution.

Table 3. Investment in UK eating disorder research by international funders (2009-2019)	
International funder	Funding amount (in 2019 prices)
Swiss Anorexia Nervosa Foundation	£447,759
European Commission	£349,937
Dutch Research Council	£127,432
Brain and Behaviour Research Foundation	£104,190
National Institutes of Health (NIH)	£83,758
Swedish Research Council	£66,256
BIAL Foundation	£23,917
German Research Foundation	Amount not published
National Research Fund Luxembourg	Amount not published

Has this investment supported research with under-served groups and co-production of research?

It is evident from clinical guidance and the research literature that certain eating disorder experiences are often overlooked. This includes but is not limited to binge eating disorder, other specified feeding or eating disorder (OSFED), avoidant/restrictive food intake disorder (ARFID), comorbidities, and eating disorders in males, transgender people, people from ethnic minority

⁴⁵ HM Treasury (2020) [GDP deflators at market prices, and money GDP March 2020 \(Budget\)](#)

⁴⁶ HM Treasury (2020) [GDP deflators at market prices, and money GDP March 2020 \(Budget\)](#)

⁴⁷ European Commission (2020) [Integrating Technology into Mental Health Care Delivery in Europe](#)

⁴⁸ European Commission (2021) [What is HORIZON 2020?](#)

backgrounds, and older people⁴⁹. Consequently, there is a particular need for further research with these population/patient groups, to improve their access to and experiences of treatment and to ensure that new interventions can be effective for them. Unfortunately, it was not possible to consider this area of concern through analysis of data on research grants, as consistent information on whether a study would include or focus on the experiences of under-served groups was not available.

It was also impossible to analyse the extent to which the research that was funded was co-produced alongside people with lived experience, as information on this was not recorded in available grants data. Meaningful co-production is crucial to ensuring that research meets the needs of people with eating disorders and those that support them⁵⁰.

Recent developments

In 2020 and 2021, there have been some positive developments for UK eating disorder research.

- The Eating Disorders Genetics Initiative (EDGI) has begun investigating the genetic and environmental risk factors for the development of eating disorders⁵¹. The UK branch of this international study is funded by NIHR and led by researchers at King's College London. Beat is supporting this study by assisting with participant recruitment.
- In June 2021 UKRI announced that it would be awarding King's College London and the University of Edinburgh a £3.8m grant⁵² to improve understanding of how eating disorders develop and how best to tailor treatment to individual young people's needs.
- In 2021 the Medical Research Foundation built on previous ring-fenced investment in eating disorders and self-harm in young people by awarding a further £1.1m to four new projects⁵³.

Although these developments are very welcome, a step-change in research funding is required in order to achieve significant advances in our understanding of what causes eating disorders, how best to treat them and how to prevent them from developing. A funding target for the UK eating disorder research field should as an absolute minimum be based on parity within mental health research. This would mean an increase of 9-13 times the current funding level, 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.

⁴⁹ NICE (2017) [Eating Disorders: recognition and treatment Full guideline](#); Murray et. al. (2017) [The enigma of male eating disorders: A critical review and synthesis](#). *Clinical Psychology Review*. Vol.57 (Nov), p.1-11; Malina (2021) [Unique Causes and Manifestations of Eating Disorders Within Transgender Populations](#). *Columbia Social Work Review*, Vol. 19(1), p.138-157; Rodgers, Berry, and Franko (2018) [Eating Disorders in Ethnic Minorities: an Update](#). *Current Psychiatry Reports*. Vol.20 (90); Mangweth-Matzek and Hoek (2017) [Epidemiology and treatment of eating disorders in men and women of middle and older age](#). *Current Opinion in Psychiatry*. Vol.30(6), p.446-451.

⁵⁰ Department of Health (2017) [A Framework for mental health research](#)

⁵¹ EDGI (2021) [Take Part in the Eating Disorders Genetics initiative \(EDGI\)](#)

⁵² UK Research and Innovation (2021) [£24 million investment into adolescent mental health](#)

⁵³ Medical Research Foundation (2021) [New projects to tackle eating disorders and self-harm](#)

Why there is so little funding for UK eating disorder research

The cycle that maintains low research funding

Witnesses described progress in understanding of eating disorders being held back by a vicious cycle (see figure 3), where a chronic lack of research funding leads to a field with few researchers and research centres that only has the capacity to publish a small amount of research. This helps maintain stigmatising attitudes towards eating disorders, including the perception of the field as ‘niche’ and a less important area of study. Taken together, all this leaves the field ill-equipped to compete successfully for funding.

Figure 3: The cycle that maintains low funding for eating disorder research



Few researchers and research centres

Many academics⁵⁴ told us that there are only a small number of researchers and research centres in the UK that conduct eating disorder research.

Professor Schmidt told us⁵⁵ that:

“It is of note how few research groups in the UK conduct eating disorder research. For example, I can easily think of around 12 eating disorder research groups in Germany that have international renown, yet in the UK we are limited to a handful of research groups in this area.”

⁵⁴ Written evidence: Faculty of Eating Disorders at the Royal College of Psychiatrists; McMahon; Nicholls; Schmidt; Solmi *et. al.*; Westwater (see Appendix 2)

⁵⁵ Written evidence: Schmidt (see Appendix 2)

Professor Schmidt also informed us that since they started working in the UK, several eating disorder research centres have closed⁵⁶.

The Faculty of Eating Disorders at the Royal College of Psychiatrists said⁵⁷:

“At present, the field of eating disorders is very much behind other specialties: only a handful of university departments have eating disorder research programmes, and there are very few clinical academics, which is in stark contrast with physical illnesses, such as diabetes, or even in [other] psychiatric research fields, such as psychosis or depression.”

Having few researchers and research centres that focus on eating disorders will mean proportionally fewer research grant applications being submitted to funders⁵⁸. It will also mean fewer senior academics able to provide training and supervision to PhD students, early and mid-career researchers⁵⁹ and also potentially less representation and understanding of eating disorders on journal editorial boards and the funding boards/panels that review grant applications⁶⁰.

We were pleased to hear that there is strong interest from young people in studying eating disorders, including at PhD level⁶¹.

“So usually we have no difficulties finding PhD students to do PhDs in eating disorders...we get inundated with requests for PhD students and we have excellent PhD students. We get really, really bright, young people.” (Prof. Schmidt)

“We’ve got more PhD students requesting than we’ve got capacity to supervise. So there’s a huge interest in terms of doing research on eating disorders.” (Dr Duffy).

However, we were very concerned to learn that due to very limited opportunities being available to early- and mid-career researchers many of those who complete a PhD in eating disorders do not continue their studies beyond this point⁶².

“The real difficulty [is] arising at the next step when people go to post-doc[toral level]. That’s a real bottleneck and we lose a lot of people at that stage...” (Prof. Schmidt)

“...it’s the next step of actually being able to retain really good researchers within the field of eating disorders. We’re losing people as a result of the lack of streamlined funding.” (Dr Duffy)

“...as someone who’s in this transition period I can confirm that there are very few opportunities for postdoctoral research in this area.” (Dr Westwater)

“...we need to really boost early career researchers. We often find that any research that is funded is often targeting those with a proven track record.” (Becca Randell).

The British Association of Behavioural and Cognitive Psychotherapies (BABCP), Dr Duffy and Dr McMahon⁶³ told us that there are many clinicians working in eating disorder services across the UK that have strong interest and skills in research but that do not receive formal grant funding.

⁵⁶ Written evidence: Schmidt (see Appendix 2)

⁵⁷ Written evidence: Faculty of Eating Disorders at the Royal College of Psychiatrists (see Appendix 2)

⁵⁸ Written evidence: Solmi *et. al.* (see Appendix 2)

⁵⁹ Written evidence: Nicholls; Solmi *et. al.* (see Appendix 2)

⁶⁰ Written evidence: Nicholls (see Appendix 2)

⁶¹ Written evidence: Nicholls. Oral evidence: Duffy; Schmidt (see Appendix 2)

⁶² Oral evidence: Duffy; Randell; Schmidt; Westwater (see Appendix 2)

⁶³ Written evidence: BABCP; McMahon. Oral evidence: Duffy (see Appendix 2)

Although some have still been able to conduct important research⁶⁴ this situation means that the UK is failing to capitalise on their expertise to lead or support larger and more complex studies⁶⁵.

Dr Karen McMahon told us ⁶⁶ that greater collaboration between academia and clinicians would encourage more research focused on the priorities of patients and their families or other carers:

“Working across both academia and clinical practice positions professionals to take forward the issues that matter most to those with lived experience and their families. Currently this is an opportunity open to very few nurses in Scotland.”

We were told that typically clinicians have either little or no time protected for research in their contracts and that they often come under pressure to sacrifice any time that has in theory been protected⁶⁷. Eating disorder services were facing severe pressures before COVID-19, which has led to a sharp rise in demand for treatment^{68;69}. Although this makes the case for further research even more urgent, it risks further restricting the capacity of clinical staff to support research or to explore opportunities for grant funding and submit the often lengthy applications required⁷⁰.

Given the small scale of the field, eating disorder research could also be vulnerable to universities making strategic decisions to focus investment on other areas of mental health research in which they have a stronger track record of attracting funding⁷¹. Most of the field’s senior researchers are close to or beyond a typical retirement age, while there are few early and mid-career researchers coming through to take their places and train and supervise future generations⁷². This indicates that the eating disorder research field is at a dangerous point. Although small at present it appears that there are serious risks that its capacity could reduce even further in future years unless action is taken.

Little research

The limited investment and capacity of the field (in terms of the number of researchers and research centres) is reflected in relatively low research output. From 2005-2015 only 15,615 articles were published worldwide on eating disorders, compared with around 200,000 papers on depression⁷³. Dr Nicholls reported that from a quick search of clinical trials databases they found just 190 studies of eating disorders (72 of which were for anorexia nervosa) recruiting or not yet recruiting. This compared with 5,905 for psychosis (500 of which were for schizophrenia). Dr Nicholls added that there has been only one large scale drug trial in adults with anorexia nervosa,

⁶⁴ Written evidence: Lacey/Schoen Clinic (see Appendix 2)

⁶⁵ Written evidence: BABCP (see Appendix 2)

⁶⁶ Written evidence: McMahon (see Appendix 2)

⁶⁷ Dr Erica Cini - (Personal communication, 2021)

⁶⁸ Health and Social Care Select Committee (2021) [Oral evidence: Children and young people’s mental health, HC 1194](#); Public Administration and Constitutional Affairs Committee (2019) [Ignoring the Alarms follow-up: Too many avoidable deaths from eating disorders](#); Royal College of Psychiatry (2021) [Hidden epidemic of eating disorders because of COVID-19, new research finds](#)

⁶⁹ Written evidence: Nicholls; Nowell. Oral evidence: Duffy; Randell; Schmidt (see Appendix 2)

⁷⁰ Written evidence: Kent, Surrey and Sussex AHSN and NIHR Kent, Surrey and Sussex ARC. Oral evidence: Duffy; Randell; Schmidt (see Appendix 2)

⁷¹ Written evidence: HCRW (see Appendix 2)

⁷² Written evidence: Solmi *et. al.* Oral evidence: Ayton (see Appendix 2)

⁷³ Schmidt, *et. al.* (2016) [Eating disorders: the big issue](#). *The Lancet Psychiatry*. Vol.3(4), p.313-315.

and few studies to test whether previous findings around the effectiveness of psychological interventions can be replicated⁷⁴.

This translates into several fundamental gaps in the evidence base for early identification, effective treatment and prevention. The National Institute for Health and Care Excellence (NICE) found only a relatively small number of studies that could be used to inform the development of its latest clinical guidance and assessed much of the available evidence as being of low quality⁷⁵. In 2021 this finding was echoed by the Scottish Intercollegiate Guideline Network (SIGN) in its draft clinical guidance for the treatment of eating disorders in Scotland⁷⁶. The BABCP said⁷⁷ that it was concerned that “*without further research, clinicians may be at risk of treating the evidence base as too limited to be relevant to their work*”.

The protracted lack of research funding also means that, despite some progress in recent years, eating disorder research lags behind that of other fields in understanding the biological mechanisms that underly the development and maintenance of eating disorders - the kind of research that is typically more costly^{78;79}. This puts the field at a further disadvantage when competing for funding, including from the pharmaceutical industry, which is a major source of funding for several physical health conditions^{80;81}.

As well as noting the limited amount of research conducted in eating disorders it is important to recognise that there are particular inequities within the field. Clinical guidance and the research literature demonstrate that certain population/patient groups have been historically underserved by eating disorder research. These groups include but are not limited to people with binge eating disorder, other specified feeding or eating disorder (OSFED) or avoidant/restrictive food intake disorder (ARFID), people with certain comorbid conditions including Autism, males, transgender people, people from ethnic minority backgrounds, and older people⁸².

⁷⁴ Written evidence: Nicholls (see Appendix 2)

⁷⁵ NICE (2017) [Eating Disorders: recognition and treatment Full guideline](#)

⁷⁶ This draft guidance was temporarily available on the [SIGN website](#) during the public consultation phase.

⁷⁷ Written evidence: BABCP (see Appendix 2)

⁷⁸ Murray, et. al. (2017) [When illness severity and research dollars do not align: are we overlooking eating disorders?](#) *World Psychiatry*, Vol.16(3), p.321

⁷⁹ Written evidence: Faculty of Eating Disorders at the Royal College of Psychiatrists; First Steps ED; Solmi et. al.; Westwater (see Appendix 2)

⁸⁰ Written evidence: Faculty of Eating Disorders at the Royal College of Psychiatrists; First Steps ED; Solmi et. al.; Westwater (see Appendix 2)

⁸¹ Cressey (2011) [Psychopharmacology in crisis](#). *Nature*.

⁸² NICE (2017) [Eating Disorders: recognition and treatment Full guideline](#); Murray et. al. (2017) [The enigma of male eating disorders: A critical review and synthesis](#). *Clinical Psychology Review*. Vol.57 (Nov), p.1-11; Malina (2021) [Unique Causes and Manifestations of Eating Disorders Within Transgender Populations](#). *Columbia Social Work Review*, Vol. 19(1), p.138-157; Rodgers, Berry, and Franko (2018) [Eating Disorders in Ethnic Minorities: an Update](#). *Current Psychiatry Reports*. Vol.20 (90); Mangweth-Matzek and Hoek (2017) [Epidemiology and treatment of eating disorders in men and women of middle and older age](#). *Current Opinion in Psychiatry*. Vol.30(6), p.446-451.

Stigma

The relatively small amount of research focused on eating disorders limits efforts to improve awareness and challenge stigma. First Steps ED told us⁸³:

“The more one can understand the mechanisms underlying the behaviours demonstrated by the sufferer, the less the stigma and shame the sufferer will... endure.”

Eating disorders are often perceived as rare and only affecting a limited demographic⁸⁴. Dr Solmi and colleagues told us⁸⁵ that:

“Several studies, including our own research, have shown that compared to other mental illnesses, eating disorders are more commonly viewed as less severe, self-inflicted, and under an individual’s control, both by health professionals and the general population.”

Zoe John, a Beat Ambassador told us⁸⁶:

“The language expressed in my experiences with medical professionals echoes in other [Beat] Ambassadors and their own experiences, which primarily blames those suffering.”

The limited (or in some cases non-existent) coverage of eating disorders within the training of doctors and other health professionals in the UK has no doubt contributed to such attitudes⁸⁷.

Academics, professional bodies, and people with lived experience argued⁸⁸ that lack of awareness and stigmatising attitudes about eating disorders were responsible for creating and now helping to maintain the cycle of underfunding. Dr Solmi and colleagues told us⁸⁹ that:

“Stigma towards eating disorders is at the root of the current underfunding of eating disorder research.”

Overlooked by top psychiatry and psychology journals

Dr Nicholls told us that the eating disorder field has developed its own speciality journals, partly in response to difficulties experienced in getting papers accepted by general psychiatry and psychology journals⁹⁰. Strand and Bulik (2018) found that the proportion of eating disorder research papers being published in eating disorder-specific journals increased from 81% during 1997-2001, to 89% during 2012-2016⁹¹.

Dr Solmi and colleagues⁹² found that in 2018 the top five psychiatry journals (according to impact factor) published 443 new articles, of which only 3 (0.7%) featured research focused on eating

⁸³ Written evidence: First Steps ED (see appendix 2)

⁸⁴ Written evidence: BABCP; Kent, Surrey and Sussex AHSN and NIHR Kent, Surrey and Sussex ARC; Nicholls; Solmi *et. al.*; Westwater (see Appendix 2)

⁸⁵ Written evidence: Solmi *et. al.* (see Appendix 2)

⁸⁶ Written evidence: John (see Appendix 2)

⁸⁷ Ayton and Ibrahim (2017) [Does UK medical education provide doctors with sufficient skills and knowledge to manage patients with eating disorders safely?](#) *Postgraduate Medical Journal*. Vol.94(1113), p.374-380.

⁸⁸ Written evidence: AH; BABCP; Hughes; Davies; Faculty of Eating Disorders at the Royal College of Psychiatrists; First Steps ED; Kent, Surrey and Sussex AHSN and NIHR Kent, Surrey and Sussex ARC; Mary P; McMahon; Nicholls; Schmidt; Solmi *et. al.*; The University of Edinburgh Eating Disorders and Behaviours Research Group; Westwater. Oral evidence: Ayton; Duffy (see Appendix 2)

⁸⁹ Written evidence: Solmi *et. al.* (see Appendix 2)

⁹⁰ Written evidence: Nicholls (see Appendix 2)

⁹¹ Strand and Bulik (2018) [Trends in female authorship in research papers on eating disorders: 20-year bibliometric study](#). *BJPsych Open*, Vol.4(2), p.39-46.

⁹² Solmi (2021) [The shrouded visibility of eating disorders research](#). *Lancet Psychiatry*, Vol.8(2), p.91-92.

disorders, in contrast to 89 (20%) on schizophrenia and 79 (18%) on depression. They found that of all academic papers published on eating disorders in 2018, only 0.2% were published in the top five psychiatry journals, in contrast to 1.6% of those on bipolar disorder, 1.5% on schizophrenia, 0.9% of those on depression and 0.8% on neurodevelopmental disorders. This may at least in part be a consequence of the chronic under-investment in eating disorder research, however we heard concerns from some academics that stigma contributes to these deficits⁹³. Professor Schmidt told us⁹⁴ that “*some top journals may be biased against eating disorders.*”

The difficulties the field has experienced in achieving publication in the leading mainstream mental health journals reduces the status of eating disorders as a field of study, reinforcing the field’s limited grant funding⁹⁵.

Data

Eating disorders has generally been excluded from important datasets, including general population surveys and longitudinal cohort studies⁹⁶. This limits evidence of the true prevalence and severity of eating disorders, and the potential to develop greater understanding of key risk factors⁹⁷. Being able to utilise these valuable datasets can help researchers to develop compelling funding proposals⁹⁸.

We heard about three key examples of this:

- Eating disorders and problem gambling were the only conditions excluded from the most recent Adult Psychiatric Morbidity Survey (conducted in 2014)⁹⁹. This survey is the main means of estimating the prevalence of mental health conditions among adults in England.
- The most recent edition of the influential Global Burden of Diseases, injuries and risk factors (GBD) study - conducted in 2019 - seriously underestimated the true burden of eating disorders by only including anorexia and bulimia¹⁰⁰. A recent study estimated that including binge eating disorder and other specified feeding or eating disorder (OSFED) would increase the total prevalence by 42 million and more than double the total Disability Adjusted Life Years (DALYs) attributed to eating disorders¹⁰¹
- In England GP practices administer a ‘SMI (severe mental illness) register’. The definition of SMI applied in this case excludes eating disorders¹⁰². This is out of step with the approach

⁹³ Written evidence: Nicholls; Schmidt; Solmi *et. al.* (see Appendix 2)

⁹⁴ Written evidence: Schmidt (see Appendix 2)

⁹⁵ Written evidence: Nicholls; Solmi *et. al.*; The University of Edinburgh Eating Disorders and Behaviours Research Group; Westwater (see Appendix 2)

⁹⁶ Written evidence: First Steps ED; Kent, Surrey and Sussex AHSN and NIHR Kent, Surrey and Sussex ARC; Schmidt; Solmi *et. al.*; The University of Edinburgh Eating Disorders and Behaviours Research Group. Oral evidence: Westwater (see Appendix 2)

⁹⁷ Written evidence: Solmi *et. al.* Oral evidence: Duffy; Westwater (see Appendix 2)

⁹⁸ Written evidence: Solmi *et. al.* (see Appendix 2)

⁹⁹ NHS Digital (2016) [Adult Psychiatric Morbidity Survey: Survey of Mental Health and Wellbeing, England, 2014](#)

¹⁰⁰ Lancet (2019) [Global Burden of Disease](#)

¹⁰¹ Santomauro (2021) [The hidden burden of eating disorders: an extension of estimates from the Global Burden of Disease Study 2019](#). *The lancet Psychiatry*, Vol.8(4), p.320-328.

¹⁰² NHS England (2018) [Improving physical healthcare for people living with severe mental illness \(SMI\) in primary care Supporting Annexes to guidance for CCGs](#)

taken in the NHS Long Term Plan¹⁰³, which recognises eating disorders as severe mental illnesses. This limits our understanding of the number of people who have been diagnosed with an eating disorder, their experiences of care, and the total number of deaths. Dr Kumar cited¹⁰⁴ some US data as evidence that the number of people who have died as a result of an eating disorder in the UK may have been seriously underestimated.

Failure to recognise extent of comorbidity

Witnesses told us that there is little awareness of the extent of comorbidity in eating disorders, resulting in eating disorder research often being unable to benefit from collaboration with other closely related - and often much better funded - research fields including obesity, diabetes, autism, substance misuse and others¹⁰⁵. As a result, there are notable gaps in the evidence base around the treatment of those with an eating disorder and certain comorbid conditions and - although this is not a justification - this may explain why these patients often face particular difficulties in accessing treatment from eating disorder services¹⁰⁶.

Possible decision biases in funding decisions

We heard concerns from some experts¹⁰⁷ that stigmatising attitudes towards eating disorders and the perception of the research field as 'niche' or less important may lead to strong funding applications being unfairly rejected.

We were informed by funders that generally they award their grant funding through open competition and that while on some occasions funding may be ringfenced for broad areas it is rare that this approach is taken for particular conditions or groups of conditions. NIHR said¹⁰⁸:

"It is not usual practice for the NIHR to ringfence funding for particular topics or conditions. The NIHR welcomes funding applications for research into any aspect of human health, including eating disorders."

The MRC said¹⁰⁹:

"...our current ringfence is neuroscience and mental health... as a rule, we would tend not to commission calls specifically focused on a clinical diagnosis. We would commission calls, but they would be of broader benefit and more focused on enhancing capability across the field."

In an email Wellcome Trust said: "...proposals are ultimately in competition across the whole of biomedical science...". However, in 2019 it announced¹¹⁰ a five-year £200m commitment to investing in research on anxiety and depression in young people.

¹⁰³ NHS (2019) [NHS Long Term Plan](#)

¹⁰⁴ Oral evidence: Kumar (see Appendix 2)

¹⁰⁵ Written evidence: Alcohol Change UK; End the Eating Disorder Crisis Now; Faculty of Eating Disorders at the Royal College of Psychiatrists; Kent, Surrey and Sussex AHSN and NIHR Kent, Surrey and Sussex ARC; Nowell; Schmidt; The University of Edinburgh Eating Disorders and Behaviours Research Group; Westwater (see Appendix 2)

¹⁰⁶ Written evidence: End the Eating Disorder Crisis Now; Faculty of Eating Disorders at the Royal College of Psychiatrists (see Appendix 2)

¹⁰⁷ Written evidence: Davies; Nicholls; Schmidt; Solmi *et. al.* Oral evidence: Duffy (see Appendix 2)

¹⁰⁸ Written evidence: NIHR (see Appendix 2)

¹⁰⁹ Oral evidence: MRC (see Appendix 2)

¹¹⁰ Wellcome Trust (2021) [Mental health programme strategy](#)

The Head of Programmes for Health and Care Research Wales (HCRW)¹¹¹ said that HCRW does not ringfence funding for specific topics.

Professor Schmidt told us¹¹² that:

“We know from the literature that all eating disorders are highly stigmatised and are seen as self-inflicted. Those with anorexia nervosa predominantly are often characterised as ‘vain, self-obsessed or narcissistic’. I have heard several senior academics from other mental health fields describing people with eating disorders in these terms. ... Bulimic-type eating disorders are often perceived as related to gluttony, personal weakness and as a moral failing. Men hold more stigmatising views about eating disorders than women. Thus, it is likely that those views are also being held by a proportion of policymakers, funders and perhaps also by senior academics on funding panels... who may therefore see eating disorders as less worthy of funding than other mental health disorders, such as depression or psychosis.”

Professor Schmidt also told us¹¹³ that:

“...sometimes when we’ve had... a couple of applications from eating disorders to the same kind of funding mechanisms you’d think nobody would bat an eyelid if there were two or three from schizophrenia or two or three from depression, but if there were two from eating disorders you would only ever fund one because it is still seen as a little bit niche, a little bit on the margins...”

Dr Nicholls told us¹¹⁴ that:

“I have made or been involved in five applications in the past three years to undertake research in the area of obesity and eating disorders prevention in collaboration with leading academics in the prevention field. None have been successful; in some cases the application was not even prioritised for review. Despite being one of only a handful of academic child psychiatrists specialising in eating disorders, I have chosen not to focus on eating disorders for recent grant submissions, in order to increase the chances of funding success.”

We asked NIHR and the MRC about the criteria they use when awarding funding. NIHR told us¹¹⁵ that:

“Applications are subject to peer review and judged in open competition, with awards being made on the basis of the importance of the topic to patients and health and care services, value for money and scientific quality.”

The criteria that NIHR asks its advisory committees to use states that proposals will be assessed on (among other criteria):

“...the importance or burden of the health or care problem to those who would use the evidence generated by the proposed study”

“The proposed costs to health and care services in supporting the research are reasonable in relation to the likely benefits of the research to decision-makers, patients and the public.”¹¹⁶

¹¹¹ Written evidence: HCRW (see Appendix 2)

¹¹² Written evidence: Schmidt (see Appendix 2)

¹¹³ Oral evidence: Schmidt (see Appendix 2)

¹¹⁴ Written evidence: Nicholls (see Appendix 2)

¹¹⁵ Written evidence: NIHR (see Appendix 2)

¹¹⁶ NIHR (2019) [General criteria used by advisory committees when assessing applications](#)

The MRC told us¹¹⁷ that when assessing applications, they define ‘importance’ in terms of the proposal’s ability to address a knowledge gap or substantially advance a field, as well as the importance of a clinical problem. After peer reviews have been conducted it is the relevant funding board within the MRC that assesses whether the proposed study is likely to answer the question that the researchers have identified and the importance of that question. The MRC told us that applicants’ chances of success would be enhanced by demonstrating how their work could also benefit other fields and aligning with relevant strategies including the mental health research goals.

The Head of Programmes at Health and Care Research Wales (HCRW) told us¹¹⁸ that:

“Our schemes are researcher-led but include assessment processes that assess application first on the basis of ‘need’, and on ‘scientific quality’ thereafter (a ‘needs-led, science added’ approach.) Only applications deemed by our All Wales Prioritisation Panel to be of clear public, practice or policy relevance proceed to the scientific peer review and Funding Board stages of the assessment process.”

The MRC told us¹¹⁹ that in the last five years, its Neuroscience and Mental Health funding board¹²⁰ has only received in the region of 10 grant applications that were focused on eating disorders. They told us that this board typically has three ‘funding rounds’ per year and would expect to receive in the region of 70 applications per ‘board round’. It should be noted that grant applications to conduct eating disorder research may have been made to other MRC boards including its Population and Systems Medicine board¹²¹ that covers obesity and unhealthy eating behaviours, and applications may have been made to conduct fellowships focused on eating disorder research¹²².

We found insufficient evidence to conclude whether eating disorder-focused grant applications are being unfairly rejected in open/competitive funding calls, or whether the lack of funding predominately flows from a lack of applications, or applications not meeting quality criteria. This is an area of concern that warrants further investigation.

¹¹⁷ Oral evidence: MRC (see Appendix 2)

¹¹⁸ Written evidence: HCRW (see Appendix 2)

¹¹⁹ Oral evidence: MRC (see Appendix 2)

¹²⁰ Medical Research Council (2021) [Neurosciences & Mental Health Board](#)

¹²¹ Medical Research Council (2021) [Population & Systems Medicine Board](#)

¹²² Medical Research Council (2021) [Fellowships](#)

Actions needed to secure greater funding for UK eating disorder research

Encouraging grant applications

Targeted actions are needed in order to break the cycle of underfunding¹²³. Evidence we have received suggests a need to encourage more grant applications. Some researchers - including those with a background in other research fields - may not consider applying for grant funding to conduct research on eating disorders due to scepticism around whether such research would be of interest to funders.

“I know quite a few colleagues and doctors and nurses who wanted to do research but because of very limited chances of them succeeding to get the funds they were dissuaded.” (Dr Ashish Kumar)¹²⁴

In recent years some ringfenced funding for research into eating disorders and self-harm has been provided through a partnership between the MRF and the MRC. The MRC described the aim of this funding as being: *“...to support researchers, to generate data, to generate new ideas, to put them in a more competitive position to come through our standard board processes”¹²⁵*. This indicates a recognition of the need for targeted action to enable the field to compete successfully within standard funding calls. Although the MRF/MRC investment is very welcome, as reflected in the written evidence received from the MRF¹²⁶, these awards alone will not be enough to sufficiently build the capacity of the field to the point where it can achieve the major advances needed.

Although we believe that ringfenced funding for eating disorder research would send the strongest signal to the research community (and wider society), evidence provided by the major funders suggests that they are currently unwilling to take such a step¹²⁷. We would prefer them to reconsider this position but, if that proves fruitless, we would encourage them to publish a ‘Highlight notice’ focused on eating disorders. Highlight notices are announcements published by research funders that are intended to encourage researchers to submit funding proposals under a specific topic or theme.

We recommend that the National Institute for Health Research (NIHR), UK Research and Innovation (UKRI) and Wellcome Trust, either individually or jointly issue a ‘highlight notice’, to encourage more proposals focused on eating disorder research, in particular studies based on:

- **Early identification of those at greatest risk and the development of novel approaches to prevention and treatment**
- **Collaboration with other closely related fields such as obesity, diabetes or autism**

¹²³ Written evidence: Nicholls; Schmidt; Solmi *et. al.* (see Appendix 2)

¹²⁴ Oral evidence: Kumar (see Appendix 2)

¹²⁵ Oral evidence: MRC (see Appendix 2)

¹²⁶ Written evidence: MRF (see Appendix 2)

¹²⁷ Written evidence: NIHR; Oral evidence: MRC (see Appendix 2)

- Understanding and addressing health inequalities in eating disorders and being inclusive of typically under-served population/patient groups (these groups include but are not limited to people with binge eating disorder, other specified feeding or eating disorder (OSFED), avoidant/restrictive food intake disorder (ARFID), males, people from ethnic minority backgrounds and older people)
- Meaningful and costed co-production/patient and public involvement.

Commissioning research

Another important area in which action should be taken is through the commissioning of research to address specific evidence-gaps for the treatment of eating disorders. These evidence gaps present a significant challenge to governments and the NHS across the UK in their efforts to improve care for people with eating disorders, often as part of national mental health strategies.

We recommend that NIHR and the devolved Governments/Government agencies of Scotland, Wales, and Northern Ireland commission research to address key gaps in the evidence base that have been identified by NHS England, the National Institute for Health and Care Excellence (NICE)¹²⁸, the Scottish Intercollegiate Guideline Network (SIGN)¹²⁹, and the eating disorder service reviews that have been conducted in Scotland and Wales¹³⁰.

Building the capacity of clinical services to engage in research

Action is needed to build the capacity of eating disorder services across the UK to lead and support research, particularly in light of the pressure these services are experiencing, with rising demand for treatment and workforce shortages^{131;132}. When eating disorder services have the capacity and culture necessary to effectively lead and support audit and research this can bring important benefits for patient care and staff recruitment and retention^{133;134}.

Professor Schmidt told us¹³⁵ that:

“I think it’s very rewarding for patients and for clinicians to be part of these big endeavours. We’ve seen it with various projects that it contributes to clinician morale. It contributes to clinician training. Everyone takes more pride, even more pride and passion in their work.”

¹²⁸ NICE (2017) [Eating Disorders: recognition and treatment Full guideline](#)

¹²⁹ The draft clinical guidance was temporarily available on the [SIGN website](#) during the public consultation phase.

¹³⁰ Tan, et. al. (2018) [Welsh Government Eating Disorder Service Review 2018](#); Oakley, Tan, Anderson, et. al. (2021) [Scottish Eating Disorder Services Review: Summary Recommendations](#)

¹³¹ Health and Social Care Select Committee (2021) [Oral evidence: Children and young people’s mental health, HC 1194](#); Royal College of Psychiatry (2021) [Hidden epidemic of eating disorders because of COVID-19, new research finds](#); NHS Digital (2021) [Supplementary information requests](#)

¹³² Written evidence: HIN; Faculty of Eating Disorders at the Royal College of Psychiatrists; Kent, Surrey and Sussex AHSN and NIHR Kent, Surrey and Sussex ARC. Oral evidence: Duffy; Randell; Schmidt (see Appendix 2)

¹³³ Academy of Medical Sciences (2020) [Transforming health through innovation: Integrating the NHS and academia](#)

¹³⁴ Written evidence: Lacey/Schoen Clinic. Oral evidence: Kumar; Schmidt (see Appendix 2)

¹³⁵ Oral evidence: Schmidt (see Appendix 2)

The importance of research activity does not appear to be reflected within key quality standards used to assess and accredit eating disorder services in the UK¹³⁶. In England, guidance for commissioners and providers of NHS eating disorder services does not emphasise the importance of a strong research culture or recommend that workforce planning considers skills and capacity to support audit and research^{137;138}. We heard that clinical academics often lose the limited time that is supposed to be protected for research to clinical demands¹³⁹.

We recommend that NHS England, NHS Scotland, NHS Wales and Health and Social Care Northern Ireland (HSCNI) incorporate skills and capacity in audit and research into future workforce planning for eating disorder services and ensure sufficient investment so that time for clinicians to lead or support research can be protected.

In England the NHS Long Term Plan asserts that “*Performance on...research in mental health services will become part of core NHS performance metrics and assessment systems, as well as benchmarking data...*” (p.77)¹⁴⁰ and pledges to invest in spreading innovation between organisations. We hope that this will help focus attention from NHS leaders and mental health trusts in England on building the research capacity of eating disorder services.

Research clinics based within or across groups of NHS Trusts/Health Boards/HSC Trusts could provide a valuable research infrastructure based on collaboration between clinical services and academic institutions along with policy makers and people with lived experience.

Becca Randell from Kent, Surrey and Sussex Academic Health Science Network (AHSN) told us¹⁴¹ that Sussex Partnership NHS Foundation Trust has established an eating disorder research clinic working across Sussex (see Appendix 4). Becca Randell described the clinic as a hub that brings together enthusiastic and skilled people and builds “*passion, skills and confidence*”, with experience to date showing how a relatively small investment can make a big impact in building local research capacity and supporting the application of research findings into clinical practice.

Such clinics would also be well placed to:

- Work with local public health teams to integrate eating disorders into other datasets supporting a population-health approach to commissioning/service planning and research
- Assist with the evaluation of initiatives to embed whole-school/college/university approaches to mental health
- Support greater use of outcome measures
- Assist with audit and redesign of services
- Share learning around improving staff recruitment and retention.

¹³⁶ Oral evidence: Duffy; Schmidt (see Appendix 2)

¹³⁷ NHS England (2015) [Access and Waiting Time Standard for Children and Young People with an Eating Disorder Commissioning Guide](#)

¹³⁸ NHS England (2019) [Adult Eating Disorders: Community, Inpatient and Intensive Day Patient Care - Guidance for commissioners and providers](#)

¹³⁹ Dr Erica Cini - (Personal communication, 2021)

¹⁴⁰ NHS (2019) [NHS Long Term Plan](#)

¹⁴¹ Written evidence: Kent, Surrey and Sussex AHSN and NIHR Kent, Surrey and Sussex ARC (see Appendix 2)

We recommend that NHS England, NHS Scotland, NHS Wales and Health and Social Care Northern Ireland (HSCNI) support NHS Trusts/Health Boards/HSC Trusts to establish eating disorder research clinics or other innovations to build the capacity of eating disorder services to lead and support audit and research.

Investing in training to develop future research leaders

We are particularly concerned about the combination of early-career researchers being lost from the field due to what Professor Schmidt described as a “*bottleneck*”¹⁴² and the limited opportunities for mid-career researchers, while the very small number of senior researchers approach retirement¹⁴³.

“Significant further advances in the eating disorders field will only arise if there is a critical mass of early career researchers (ECRs) who are trained in a range of state-of-the art and emerging methodologies/technologies that can address new questions in the field.” (Prof. Schmidt)¹⁴⁴

We note that building capacity is a key priority within the MRC’s mental health strategy and that having recognised the need to support transitions and career development in the addictions field it now funds the MRC Addiction Research Clinical (MARC) training programme, bringing together three universities to develop future leaders in that field¹⁴⁵.

A training programme for early-career researchers in eating disorders could equip them with the inter-disciplinary skills and experience needed to significantly advance the field¹⁴⁶. Such a programme should be established across a group of institutions with different strengths, including staff from different professional backgrounds¹⁴⁷.

We recommend that UKRI collaborates with a group of universities to establish an inter-disciplinary training programme for early-career researchers in eating disorders.

Collecting and publishing data on grant applications and success rates

Research funders should collect and publish data that provides more transparency around their decision making and success rates for grant applications¹⁴⁸. The MRC told us that it does not routinely code rejected grant applications in terms of whether or not they are focused on specific mental health conditions. As far as we are aware this is also the case for the other major UK health research funders.

Such data could provide important evidence around the number of grant applications being submitted that focus on or include eating disorders (or any other conditions) and possible decision

¹⁴² Oral evidence: Schmidt (see Appendix 2)

¹⁴³ Oral evidence: Ayton (see Appendix 2)

¹⁴⁴ Written evidence: Schmidt (see Appendix 2)

¹⁴⁵ Medical Research Council (2017) [Strategy for Lifelong Mental Health Research](#)

¹⁴⁶ Written evidence: Faculty of Eating Disorders at the Royal College of Psychiatrists; Schmidt; The University of Edinburgh Eating Disorders and Behaviours Research Group; Westwater (see Appendix 2)

¹⁴⁷ Written evidence: Faculty of Eating Disorders at the Royal College of Psychiatrists; Schmidt (see Appendix 2)

¹⁴⁸ Written evidence: Davies; Faculty of Eating Disorders at the Royal College of Psychiatrists; Schmidt; Westwater (see Appendix 2)

biases, although caution would be needed in interpreting and comparing success rates, particularly if the numbers of applications were very low. As first highlighted by Eva Woelbert and colleagues in their *Lancet Psychiatry* paper¹⁴⁹, natural language processing (such as that used by the Dimensions.ai platform¹⁵⁰) could be used by funders to automate the coding of their rejected as well as accepted grant applications.

If eating disorders was shown to be subject to low success rates, then these decisions could be reviewed and validated for possible decision biases. If any common weaknesses were uncovered this could provide important feedback for the research field. This could also help funders understand whether they have received disproportionately few applications to conduct eating disorder research (including in comparison to peers), which may be of use in informing their marketing.

We recommend that NIHR, UKRI and Wellcome Trust utilise new technologies to code rejected grant applications by condition and publish this data in the interest of transparency.

Collaboration to develop and implement a long-term UK eating disorder research strategy

The UK Framework for mental health research¹⁵¹ highlighted the importance of collaboration between researchers, funders (including governments), the voluntary sector and people with lived experience in building research capacity. Health and Care Research Wales told us¹⁵² that:

“Capacity building often requires concerted and co-ordinated effort across research funders”.

Many of those that submitted evidence to this inquiry called for a UK eating disorder research strategy, arguing that a coordinated and strategic approach will be essential to leveraging increased investment and ensuring this leads to sustainable capacity building, while addressing the most important gaps and inequities in the evidence base¹⁵³.

A broader research agenda that is inclusive of all those affected by eating disorders will be crucial to improving access to and experiences of treatment and to ensuring that new interventions are effective¹⁵⁴. There is an important responsibility upon funders and academics to ensure that studies take an active approach to involving people from under-served groups, including through partnership with community groups and charities and promoting and conducting research in alternative settings^{155;156}. In some cases, studies whose focus is the needs of specific

¹⁴⁹ Woelbert, *et. al.* (2019) [How much is spent on mental health research: developing a system for categorising grant funding in the UK](#). *Lancet Psychiatry*. Vol. 6(5), p.445-452.

¹⁵⁰ Digital Science (2021) [Dimensions](#)

¹⁵¹ Department of Health (2017) [A Framework for mental health research](#)

¹⁵² Written evidence: HCRW (see Appendix 2)

¹⁵³ Written evidence: Mary P; McMahon; Nicholls; Schmidt; The University of Edinburgh Eating Disorders and Behaviours Research Group. Oral evidence: Randell (see Appendix 2)

¹⁵⁴ NIHR (2020) [Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project](#)

¹⁵⁵ Department of Health (2017) [A Framework for mental health research](#); NIHR (2020) [Improving inclusion of under-served groups in clinical research: Guidance from INCLUDE project](#)

¹⁵⁶ Written evidence: RCOT; The McPin Foundation; Westwater (see Appendix 2)

demographics and diagnoses will be essential to help redress the current inequalities in research activity¹⁵⁷.

This UK eating disorder research strategy should support both research priorities and research projects being co-produced with people with lived experience (including parents/other carers and clinicians)¹⁵⁸.

Several experts¹⁵⁹ called for a James Lind Alliance Priority Setting Partnership¹⁶⁰ exercise to be commissioned to determine the top 10 research questions from the perspectives of people who have or have had eating disorders, families/carers and clinicians. The McPin Foundation has used this approach for children and young people's mental health and told us that this has led to research being commissioned by NIHR¹⁶¹.

NIHR told us¹⁶² that it “regularly brings together key stakeholders and funders to improve research in under-researched areas” and cited the example of a roundtable that the Department of Health and Social Care (DHSC)/NIHR had hosted for research on hearing loss and tinnitus, which has led to the establishment of a working group dedicated to building the capacity of that field¹⁶³.

We recommend that the DHSC/NIHR establish a working group to develop and oversee implementation of a long-term UK eating disorder research strategy.

¹⁵⁷ Written evidence: BABCP; RCOT; The McPin Foundation (see Appendix 2)

¹⁵⁸ Written evidence: F.E.A.S.T; First Steps ED; McMahon. Oral evidence: Duffy; Randell (see Appendix 2)

¹⁵⁹ Written evidence: Faculty of Eating Disorders at the Royal College of Psychiatrists; HCRW; Lewis and Foye; Nicholls; RCOT; Schmidt; The McPin Foundation (see Appendix 2)

¹⁶⁰ James Lind Alliance (2021) [About Priority Setting Partnerships](#). The James Lind Alliance states that: “Priority Setting Partnerships (PSPs) enable clinicians, patients and carers to work together to identify and prioritise evidence uncertainties in particular areas of health and care that could be answered by research. While the James Lind Alliance (JLA) facilitates these partnerships, the funding and organising is done by the PSP itself.”

¹⁶¹ Written evidence: The McPin Foundation (see Appendix 2)

¹⁶² Written evidence: NIHR (see Appendix 2)

¹⁶³ NIHR University College London Hospitals Biomedical Research Centre (2021) [New working group for Research on Hearing Loss and Tinnitus](#)

Conclusions and recommendations

Major advances are needed in our understanding of what causes eating disorders, how best to treat them and how to prevent them from developing. Without this, eating disorders will continue to represent a significant public health issue, with rising costs to the NHS and the UK economy.

Despite the prevalence and severity of eating disorders, research into these conditions receives very little funding. From 2009-2019 UK funders invested just £1.13 per person affected per year in eating disorder research. Most eating disorder research grant funding was awarded to London-based (lead) research institutions. From 2015-2019 just 1% of UK mental health research funding - already severely limited as a whole - went towards research on eating disorders¹⁶⁴. This is despite people with eating disorders accounting for around 9% of the total number of people with a mental health condition in the UK¹⁶⁵. A funding target for the UK eating disorder research field should as an absolute minimum be based on parity within mental health research. This would mean an increase of 9-13 times the current funding level - 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 chronic lack of investment in UK eating disorder research has led to a vicious cycle, whereby the field has only been able to recruit and retain a small number of researchers and research centres, leading to a limited amount of research output. This helps maintain stigmatising attitudes towards eating disorders, including the perception of the field as 'niche' and a less important area of study. Taken together, all this leaves the field ill-equipped to compete successfully for funding.

With few active researchers and research centres there is insufficient capacity to train and support the development of the next generation of research leaders, at a time when many of the UK's senior eating disorder researchers are nearing retirement. The limited number of academics is also likely to translate into less representation within academic journal editorial boards and research funding boards.

We were pleased to hear that there is strong interest in studying eating disorders at PhD level but concerned to hear that there is a "bottleneck" after this stage due to a failure to provide sufficient training and support for early-career researchers. We also heard that there are limited opportunities for mid-career eating disorder researchers to progress.

We are concerned that the UK is failing to capitalise on the expertise of clinicians working in eating disorder services to drive innovation through research. Without sufficient investment the rapid rise in demand on eating disorder services due to COVID-19¹⁶⁶ risks this being further compromised even though this rise in demand means that the need for research advances is more urgent than ever.

¹⁶⁴ This calculation was based on dividing the funding that [IAMHRF estimated](#) had been invested in eating disorder research by UK funders during 2015-2019 (annual average of \$1.4m), by their combined disease-specific investment in mental health research (annual average of \$100.7m).

¹⁶⁵ This calculation was based on data from [Beat \(2018\)](#) about the prevalence of eating disorders in the UK and an estimate from [MQ \(2019\)](#) of the number of people with a mental health condition in the UK.

¹⁶⁶ Royal College of Psychiatry (2021) [Hidden epidemic of eating disorders because of COVID-19, new research finds](#)

The limited research output has led to serious gaps in the evidence base to guide clinicians¹⁶⁷. There is a need for a broader research agenda that is inclusive of and serves those groups that have to date often been overlooked by eating disorder research, including but not limited to males, people from ethnic minority groups and older people. Research priorities and research projects must be co-produced with people affected by eating disorders to ensure that research is beneficial to people with eating disorders, those that support them and clinicians.

We believe that lack of awareness and stigma has created, and now helps maintain, the cycle of underfunding in eating disorder research. This has led to the perception of eating disorders as being a 'niche' and less important area of study. Eating disorders has been omitted from important datasets, meaning that the full prevalence and impact of eating disorders remains underestimated and denying the research field valuable resources to support competitive grant funding applications.

There is often little appreciation of the extent of comorbidity with eating disorders from other closely related and often much better funded fields including obesity. Eating disorder papers are often overlooked by the highest profile psychiatry and psychology journals, so further limiting the visibility and status the field has within academia.

Considering the persistence of stigmatising attitudes towards eating disorders in society and even among health professionals, we heard reasonable concerns that eating disorder grant applications may be unfairly rejected when in competition against studies from other fields. However, there was not sufficient evidence to determine whether this has been the case.

Breaking the cycle of underfunding will require targeted actions and a coordinated, strategic approach toward building the capacity of the field. With this report the APPG on Eating Disorders makes a series of UK-wide recommendations. Some of these are addressed to the devolved Governments of Scotland, Wales, and Northern Ireland, or NHS leaders in each of the UK nations, due to the roles they can play in supporting research.

Recommendations

Encouraging grant applications

- National Institute for Health Research (NIHR), UK Research and Innovation (UKRI) and Wellcome Trust, either individually or jointly issue a 'highlight notice'¹⁶⁸, to encourage more proposals focused on eating disorder research, in particular studies based on:
 - ⇒ Early identification of those at greatest risk and the development of novel approaches to prevention and treatment
 - ⇒ Collaboration with other closely related fields such as obesity, diabetes or autism
 - ⇒ Understanding and addressing health inequalities in eating disorders and being inclusive of typically under-served population/patient groups (these groups include

¹⁶⁷ NICE (2017) [Eating Disorders: recognition and treatment Full guideline](#)

¹⁶⁸ 'Highlight notices' are announcements published by research funders that are intended to encourage researchers to submit funding proposals under a specific topic or theme. For example: <https://www.nihr.ac.uk/documents/nihr-highlight-notice-dementia/27316>.

but are not limited to people with binge eating disorder, other specified feeding or eating disorder (OSFED), avoidant/restrictive food intake disorder (ARFID), males, people from ethnic minority backgrounds and older people)

⇒ Meaningful and costed co-production/patient and public involvement.

Commissioning research

- ↪ NIHR and the devolved Governments/Government agencies of Scotland, Wales, and Northern Ireland to commission research to address key gaps in the evidence base that have been identified by NHS England, the National Institute for Health and Care Excellence (NICE)¹⁶⁹, the Scottish Intercollegiate Guideline Network (SIGN)¹⁷⁰, and the eating disorder service reviews that have been conducted in Scotland and Wales¹⁷¹.

Building the capacity of clinical services to engage in research

- ↪ 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.
- ↪ NHS England, NHS Scotland, NHS Wales and Health and Social Care Northern Ireland (HSCNI) to support NHS Trusts/Health Boards/HSC Trusts to establish eating disorder research clinics or other innovations to build the capacity of eating disorder services to lead and support audit and research.

Investing in training to develop future research leaders

- ↪ UKRI to collaborate with a group of universities to establish an inter-disciplinary training programme for early-career researchers in eating disorders.

Improving data on grant applications and success rates

- ↪ NIHR, UKRI and Wellcome Trust to utilise new technologies to code rejected grant applications by condition and publish this data in the interest of transparency.

Collaboration to develop and implement a long-term UK eating disorder research strategy

- ↪ DHSC/NIHR to establish a working group to develop and oversee implementation of a long-term UK eating disorder research strategy.

¹⁶⁹ NICE (2017) [Eating Disorders: recognition and treatment Full guideline](#)

¹⁷⁰ The draft clinical guidance was temporarily available on the [SIGN website](#) during the public consultation phase.

¹⁷¹ Tan, et. al. (2018) [Welsh Government Eating Disorder Service Review 2018](#); Oakley, Tan, Anderson, et. al. (2021) [Scottish Eating Disorder Services Review: Summary Recommendations](#)

Appendix 1: The inquiry questions

Call for written evidence

The call for written evidence asked for submissions responding to a set of nine questions based on the priorities identified by the UK Framework for mental health research¹⁷²:

- What are the main factors that currently limit funding for eating disorders research in the UK, and internationally?
- What steps should be taken to increase the number of researchers and institutions across the UK that pursue funding for eating disorders research?
- How can UK eating disorders research be funded in ways that would encourage collaboration between different academic disciplines and promote greater involvement from industry (including the pharmaceutical and digital sectors) and the voluntary sector?
- How can the eating disorders research community identify the gaps in knowledge that matter most to people with lived experience and clinicians in the UK?
- How can UK eating disorders research be funded in ways that support meaningful coproduction/patient and public involvement (PPI)?
- How can research funding programmes encourage an emphasis on prevention and early intervention at all stages of life in eating disorders research?
- How can research funding programmes promote a broader research agenda, so that more eating disorders research investigates the experiences of people from under-represented groups? These groups would include (but would not be limited to) people with experiences of eating disorders other than Anorexia Nervosa, people with certain concurrent health conditions, males, people from Black, Asian and minority ethnic communities and older people.
- How can data collection and reporting by research funders and others improve our understanding of investment in eating disorders research and funding decisions?
- Would you like to make any further comments or recommendations on eating disorders research funding in the UK, and internationally?

¹⁷² Department of Health (2017) [A Framework for mental health research](#)

Oral evidence sessions

The following questions/topics were prepared as suggestions for the APPG to use in the oral evidence sessions.

Session 1 - For research funders

Ringfencing and commissioning research

We understand that most Medical Research Council (MRC) funding is awarded through competitive/open funding calls...

- Would the MRC consider making dedicated funding calls for specific mental health conditions?
- How does the MRC decide what (if any) research topics/questions/conditions it is going to commission research on? Is this influenced by Government and/or NHS policy agendas?

Governance of competitive/open funding calls

Research has shown that misunderstanding and stigmatising attitudes towards eating disorders are common amongst medical professionals and wider society. With this in mind...

- How are peer reviewers selected?
- We understand that applications are judged on the importance of the topic to patients and health services, as well as scientific quality. How are decisions made about the former?
- Are rejected applications counted and analysed as well as those awarded funding, in order to help understand gaps and possible decision biases?
- When judging the scientific quality of a proposal focused on a particular condition or group of conditions, is there an expectation that this will have considered common co-morbidities (for example an expectation that a study into obesity prevention or management of diabetes will include assessment of eating disorders/disordered eating symptoms)?
- How can research funding programmes promote a broader research agenda, encouraging more (eating disorders) research into experiences of people from under-represented groups?

Collaboration between funders

We were pleased to learn about the dedicated funding calls for eating disorders and self-harm that have been made by the Medical Research Foundation, through collaboration with the MRC...

- How did this come about? What role has the MRC played in this collaboration?
- In what other ways might collaboration between funders enable greater investment?

Capacity-building

- What are the best ways to increase the capacity of small research fields (such as eating disorders), in terms of the number and geographic spread of researchers/centres and the quality of applications submitted?

A research strategy for eating disorders

- Several submissions called for a UK research strategy for eating disorders, based on a co-production exercise to agree the top research priorities for the field. What are your views on this suggestion? What should such a strategy include?

Closing

- Are there any other comments or recommendations you would like to make on this subject?

Session 2 - For researchers/clinicians/professional bodies

Experiences of applying for funding

- What are your experiences of applying for funding to conduct eating disorders research? *This could cover both project-specific grants and studentship/fellowship applications.*
- When you have been unsuccessful, what kind of feedback has typically been provided about the grounds for rejection?

Capacity-building

- What recommendations would you advise us to make on developing the capacity of the eating disorders research field, across the UK?
Prompts: What needs to be done to:
 - *Attract interest from researchers that have not previously studied eating disorders;*
 - *Support development of early-career and mid-career researchers and new centres;*
 - *Increase awareness of funding opportunities and how to develop strong applications;*
 - *Support more eating disorder services to conduct and facilitate research, including through collaboration with universities*
- Some written evidence submissions called for a ‘formal training structure/programmes’ for early-career eating disorders researchers in the UK. How might this be achieved? Are there examples from other fields to draw on? Would it require ringfenced investment from major funders, significant philanthropy or charitable giving?
- Do current means of quality assuring eating disorder services in the UK assess and acknowledge the value of contributions to research?
- Is more dialogue needed between eating disorders researchers and those from other closely related areas of mental health and medical research (i.e., obesity, diabetes, autism, psychosis, addictions and others)? If so, how should this be facilitated?

A research strategy for eating disorders

- Several submissions called for a UK research strategy for eating disorders, based on a co-production exercise to agree the top research priorities for the field. What are your views on this suggestion? What should such a strategy include?

Closing

- Are there any other comments or recommendations you would like to make on this subject?

Appendix 2: Individuals and organisations that submitted evidence

Written submissions

Research funders

- Head of Programmes, Health and Care Research Wales (HCRW)/Research and Development Division, Welsh Government
- Medical Research Foundation (MRF)
- National Institute for Health Research (NIHR)

Academics and/or clinicians

- Dr Helena Davies (King's College London)
- Kent, Surrey and Sussex Academic Health Science Network (KSS AHSN) and NIHR Kent, Surrey and Sussex Applied Research Collaboration
- Professor Hubert Lacey/Schoen Clinic UK
- Hannah Lewis (Queen Mary, University of London) and Dr Una Foye (King's College London)
- Health Innovation Network (HIN) [the Academic Health Science Network for South London]
- Hereford and Worcestershire Health and Care NHS Trust
- Dr Karen McMahon (University of the West of Scotland)
- Dr Dasha Nicholls (Imperial College London and Central and North West London NHS Foundation Trust)
- Professor Ulrike Schmidt (King's College London and South London and Maudsley NHS Foundation Trust)
- Dr Francesca Solmi (University College London), Dr Helen Bould (University of Bristol and Gloucestershire Health and Care NHS Foundation Trust), Dr E. Caitlin Lloyd (Columbia University) and Professor Glyn Lewis (University College London)
- The University of Edinburgh Eating Disorders and Behaviours Research Group
- Dr Margaret Westwater (University of Cambridge)

Professional bodies

- British Association of Behavioural and Cognitive Psychotherapies (BABCP)
- Faculty of Eating Disorders (FED) at the Royal College of Psychiatrists
- Royal College of Occupational Therapists (RCOT)

Third sector

- Alcohol Change UK
- F.E.A.S.T. (Families Empowered and Supporting Treatment of Eating Disorders)
- First Steps ED
- The McPin Foundation

Private sector

- Tunstall Healthcare (UK) Ltd.

Lived experience

- AH
- Ceri Hughes
- End the Eating Disorder Crisis Now campaign
- Zoe John
- Mary P.
- Sara Nowell

Oral evidence session (conducted online)

Session 1 [3-3.45pm, 22 April 2021]

Karen Brakspear, Head of Programme for Mental Health at the Medical Research Council (which is part of UKRI).

Session 2 [3-4.30pm, 29 April 2021]

This session was split into two sections of approximately 45 minutes each.

Section 1: Dr Fiona Duffy (University of Edinburgh, and NHS Lothian); Professor Ulrike Schmidt (King's College London, and South London and Maudsley NHS Foundation Trust); Dr Margaret Westwater (University of Cambridge).

Section 2: Dr Agnes Ayton (Faculty of Eating Disorders at the Royal College of Psychiatrists, and Oxford Health NHS Foundation Trust); Dr Ashish Kumar (Faculty of Eating Disorders at the Royal College of Psychiatrists, and North West Boroughs Healthcare NHS Foundation Trust); Becca Randell (Kent, Surrey and Sussex Academic Health Science Network and NIHR Kent, Surrey and Sussex Applied Research Collaboration).

Appendix 3: Methodology for research funding landscape analysis

In 2020 and early 2021 Beat conducted an analysis to quantify and describe investment in UK eating disorder research from 2009-2019.

Data sources

The primary source of data was the Dimensions platform (provided by Digital Science)¹⁷³. This contains searchable grants details (title, abstract, researchers, lead research institution and funding amount) from over 200 major funders. This was supplemented through requests sent to the relevant agencies of the devolved Governments, all members of the Association of Medical Research Charities (AMRC) that fund mental health research, all members of the UK Alliance of Mental Health Research Funders (AMHRF), the Academy of Medical Sciences, the British Academy and a wide range of other individual funders, and by searching the European Commissions' CORDIS repository¹⁷⁴ and King's College London's 'Research portal' website¹⁷⁵. This set of grants was also cross-checked against the data published by the UK Clinical Research Collaboration on research grants that were active in 2018¹⁷⁶.

Determining relevant grants

The searches and requests were made for research grants with start dates between 1 January 2009 and 31 December 2019, and where grant titles or abstracts contained any of the following keywords:

“Anorexia” OR “bulimia” OR “binge eating” OR “eating disorder” OR “emotional eater” OR “emotional eating” OR “eating pathology” OR “pathological eating” OR “body dissatisfaction” OR “avoidant-restrictive food intake disorder” OR “ARFID”, “OSFED” OR “EDNOS” OR “Night eating syndrome” OR “Purging disorder” OR “Orthorexia” OR “disordered eating”.

The key data fields available through Dimensions¹⁷⁷ and requested from funders were:

- Grant Title
- Abstract
- Total funding in GBP
- Start date (or just year if specific date not available)
- End date (or just year if specific date not available)
- Name of researchers
- Research Institutions that received the award
- City and country of research institution/s
- Name of any collaborating funders (and their country location)
- HRCS Research Activity Codes attributed to the grant (if available)

¹⁷³ Digital Science (2021) [Dimensions](#)

¹⁷⁴ European Commission (2021) [CORDIS](#)

¹⁷⁵ King's College London (2021) [\[Research Portal\] Research Funding - Grants](#)

¹⁷⁶ UK Clinical Research Collaboration (2020) [UK Health Research Analysis 2018](#)

¹⁷⁷ Digital Science (2021) [Dimensions](#)

A broad set of keywords were used to minimise the risk of missing relevant grants that had short abstracts or spelling errors. A total sample of 184 grants were retrieved that contained at least one of the search terms above in either their title or abstract. One hundred and thirty three (72%) of these were sourced from the Dimensions platform¹⁷⁸. The resulting grant titles and abstracts were then manually reviewed. Beat adopted the definition of ‘research’ used by the NHS Health Research Authority and the four UK Health Departments: “*The attempt to derive generalisable or transferable new knowledge*” (p.27)¹⁷⁹. The definition of eating disorders was based on the major diagnostic systems (DSM-5 and ICD-11)^{180;181}. Grants to study obesity in the absence of an eating disorder were not included.

Only grants deemed to have been focused on eating disorders were included in the data analysis. In line with the approach taken by Woelbert et al (2019)¹⁸², this involved considering for each grant whether eating disorders was:

“...the actual focus of the research, rather than just being mentioned as an example to illustrate potential downstream impact or mentioned as one outcome or independent variable among many.” (p.2)¹⁸³.

And any grants that focused on eating disorders, along with more than four other conditions were classified as ‘transdiagnostic’ (in line with the UK Health Research Classification System), and so considered out of the scope of this analysis¹⁸⁴.

Given the complexity of eating disorders and mental health in general it can be difficult to determine which studies should be classified as being focused on eating disorders or not¹⁸⁵. The grant abstracts were also manually reviewed by two volunteers with lived experience of an eating disorder (see Acknowledgements). After discussion, the group reached agreement on the inclusion/exclusion of 97% of the grants (179 out of 184). The final set of grants included in the analysis was determined by Beat’s Policy Advisor, however this was influenced by the judgements of the volunteers and the high level of agreement shown by this exercise provides some validation for the manual coding of abstracts undertaken in this analysis.

¹⁷⁸ Digital Science (2021) [Dimensions](#)

¹⁷⁹ NHS Health Research Authority, Department of Health and Social Care (England), the Department of Health (Northern Ireland), the Scottish Government Health and Social Care Directorates and the Department for Health and Social Services (Wales) (2017) [UK policy framework for health and social care research](#)

¹⁸⁰ American Psychiatric Association (2013) [Diagnostic and Statistical Manual of Mental Disorders \(DSM-5\)](#)

¹⁸¹ World Health Organisation (2019) [International Classification of Diseases 11th Revision](#)

¹⁸² Woelbert, et. al. (2019) [How much is spent on mental health research: developing a system for categorising grant funding in the UK](#). *Lancet Psychiatry*, Vol.6(5), p.445-452.

¹⁸³ Woelbert et al (2019) [Online Appendix to ‘How much is spent on mental health research: developing a system for categorising grant funding in the UK’](#). *Lancet Psychiatry*. Vol. 6(5), p.445-452.

¹⁸⁴ Woelbert et al (2019) [Online Appendix to ‘How much is spent on mental health research: developing a system for categorising grant funding in the UK’](#). *Lancet Psychiatry*. Vol. 6(5), p.445-452.

¹⁸⁵ Woelbert, et. al. (2019) [How much is spent on mental health research: developing a system for categorising grant funding in the UK](#). *Lancet Psychiatry*, Vol.6(5), p.445-452.

Approach toward counting funding for studies that included co-morbidities

There were some important differences between the methodology used for this analysis and that used by MQ¹⁸⁶ and the International Alliance of Mental Health Research Funders (IAMHRF)¹⁸⁷, meaning that the resulting estimates are not directly comparable. The main difference concerns the approach to attributing funding for studies that investigated co-morbid conditions. As MQ and IAMHRF were intending to compare investment in mental health research and physical health research and to compare mental health funding per condition, when a mental health condition was studied in the context of another physical or neurological disorder, or when a study focused on more than one mental health condition, the funds were split evenly between the relevant categories. The purpose of Beat's analysis was to quantify investment over this period, compare investment by funder and describe the geography of lead research institutions awarded funding. Therefore, splitting funding for eating disorder-focused studies that incorporated the study of co-morbid conditions - given the importance of such research - was not considered suitable for this analysis.

Including UK research council-funded PhD studentships

In this analysis the value of UK research council-funded PhD studentships were estimated based on UKRI's minimum stipend (including London weighting where applicable), tuition fees and research training support grants, along with information on additional expenses for travel, fieldwork and conference attendance¹⁸⁸. This is likely to mean that the full value of some of these grants has been slightly underestimated.

Data analysis

Eating disorder research funding in the UK from 2009-2019 was analysed in the following ways:

- Investment from UK funders
- How investment compares between UK funders
- UK research institutions awarded grants (as lead)
- International funding into the UK
- Has this investment supported research with under-served groups and co-production of research?

To show the trend in funding over time all grants were attributed to the starting year in full. Funding for grants that started before 2019 were adjusted upwards to 2019 prices, using HM Treasury Gross Domestic Product (GDP) deflators to account for changes to the value of goods and services across the economy over time¹⁸⁹.

¹⁸⁶ MQ (2019) [UK Mental Health Research Funding 2014-2017](#)

¹⁸⁷ IAMHRF (2020) [The Inequities of Mental Health Research Funding](#)

¹⁸⁸ ESRC (2021) [What is an ESRC studentship worth?](#); ESRC (2021) [ESRC Postgraduate funding guide](#); BBSRC (2021) [BBSRC PhD Funding](#); MRC (2021) [Minimum stipend and allowances](#)

¹⁸⁹ HM Treasury (2020) [GDP deflators at market prices, and money GDP March 2020 \(Budget\)](#)

Limitations

Research centres and other infrastructure

Awards for research centres and other important forms of research infrastructure could not be included within the scope of this analysis, because the abstracts tend not to provide information on the internal distribution of the funding¹⁹⁰, meaning that it is not possible to estimate the proportion invested in supporting eating disorder-focused research.

Industry funding

Some industry funding may have been missed from the analysis, as in some cases this information is not published as grants, however investment from the pharmaceutical industry in eating disorder research (and mental health research overall) is known to be very low¹⁹¹. RAND Europe estimated that globally from 2009-2014 industry funding accounted for only 4% of funding acknowledgements in academic eating disorder papers¹⁹². According to King's College London's Research portal website, less than 5% of research grants awarded to its Institute of Psychiatry, Psychology and Neuroscience (IoPPN) have come from industry¹⁹³.

¹⁹⁰ Woelbert, *et. al.* (2019) [How much is spent on mental health research: developing a system for categorising grant funding in the UK](#). *Lancet Psychiatry*, Vol.6(5), p.445-452.

¹⁹¹ Cressey (2011) [Psychopharmacology in crisis](#). *Nature*; Woelbert, *et. al.* (2019) [How much is spent on mental health research: developing a system for categorising grant funding in the UK](#). *Lancet Psychiatry*, Vol.6(5), p.445-452.

¹⁹² RAND Europe (2016) [Project Ecosystem Mapping the global mental health research funding system](#)

¹⁹³ King's College London (2021) [\[Research Portal\] Institute of Psychiatry, Psychology and Neuroscience](#)

Appendix 4: Case study - Sussex Eating Disorder Research Clinic

This overview was supplied by Becca Randell of Kent, Surrey and Sussex Academic Health Science Network (AHSN) and NIHR Kent, Surrey and Sussex Applied Research Collaboration

The ‘Sussex Partnership Innovation and Research in Eating Disorders (SPIRED) clinic’ is an innovative, co-produced eating disorder research clinic, with close ties to the Sussex Eating Disorder Service (SEDS) as well as the University of Sussex. SPIRED was launched in Autumn 2020 and is directed by two consultant clinical psychologist-researchers, a research assistant, an assistant psychologist, an undergraduate intern as well as undergraduate and postgraduate students. It is committed to conducting research that improves the treatment and support available to people with eating disorders.

Guiding principles

Through a series of co-production events between the Lived Experience Panel and other members of the SPIRED clinic, six core principles to guide the clinic’s research have been developed:

1. **Real-World.** Research should make an immediate, practical impact on the lives of people with eating disorders.
2. **Tailored.** Existing evidence-based treatments should be adapted to ensure they work effectively for marginalised groups.
3. **Hopeful.** More research is needed that focuses on improving people’s sense of hope in their recovery from eating disorders.
4. **Experiential.** Research should find ways of conveying the voices and experiences of people with eating disorders, and not solely rely on quantitative outcomes.
5. **Broad.** More evaluation of innovative and creative approaches to eating disorder treatment is needed, considering the therapeutic impact of artistic, occupational and other creative activities as well as the role of peers and family members.
6. **Democratic.** All eating disorder research should be co-produced with people who have lived experience of eating disorders.

Engaging people with lived experience in a research clinic

All research conducted by the clinic is guided by a Lived Experience Panel - 20 individuals with lived experience of eating disorders that have been recruited to ensure representation from groups typically marginalised in eating disorder research; in particular men, LGBT people and people who are neuro-diverse. It sets the agenda for the clinic’s research priorities, develops research projects and funding proposals and is involved in carrying out research.

Examples of some of the core projects being delivered through the research clinic include:

- ***Increasing Hope and Connection for People with Eating Disorders.*** This is a service-user led study that aims to develop and evaluate an intervention to increase hope and a sense of connectedness during the pandemic. The intervention harnesses the importance of peer-support in recovery, and consists of recovery-focused post-card writing, a lived-experience podcast, and a weekly facilitated 'chat'.
- ***SPEAKS.*** SPEAKS is an NIHR funded, mixed-methods feasibility study (across Kent and Sussex) evaluating a psychotherapeutic intervention targeting difficulties in emotional experience and regulation for adults with anorexia nervosa.
- ***Feasibility and Acceptability of Group-based MANTRA treatment for Anorexia.*** This qualitative study explores patient and therapist perspectives of a novel adaptation of a NICE recommended treatment for anorexia in a group setting. Qualitative analysis for this project is conducted by members of the Lived Experience Group, alongside other SPIRED researchers.
- ***Meta-Analysis of Studies Evaluating Eating Disorder Therapies for Patients with Personality Disorder.*** This review examines the effectiveness of existing therapies for a neglected group; patients with eating disorders alongside diagnoses of personality disorder. Extraction frameworks for this meta-analysis were decided in collaboration with the Lived Experience Panel for the SPIRED clinic, as well as a lived experience panel specific to personality disorders.
- ***Systematic Review of Group-Based Treatments for Anorexia Nervosa.*** This review looks at barriers to and facilitators of group-based treatments for anorexia. The importance of peers in recovery for anorexia is well established in the literature, however clinicians are unwilling to develop group-based treatments due to their anxieties around peer-support for service users with anorexia.
- ***Service Evaluation of an Inpatient Transitions Pathway.*** A novel pathway has been developed in collaboration with the Sussex Eating Disorders Service for people leaving inpatient care, including an adapted WRAP plan developed with service users. This is being evaluated in collaboration with the University of Sussex.
- ***Other Service Evaluations.*** SPIRED is also evaluating the following projects as part of routine clinical delivery: 1) The translation of CBT-T to being delivered in a virtual format 2) The delivery of integrated individual and group treatment for bulimia nervosa and binge eating disorder and 3) health inequalities and eating disorders.

Acknowledgements

The APPG would like to recognise the crucial contributions made to this inquiry by all those that provided written submissions and those who participated in an oral evidence session (see Appendices 1 and 2).

While the analysis of research grants data presented in this report was conducted by Beat, the APPG greatly appreciates the advice provided on a pro-bono basis by Eva Woelbert and Terry Bucknell, and staff from several research funders around obtaining, analysing and interpreting such data.

Data was sourced from Dimensions, an inter-linked research information system provided by Digital Science (www.dimensions.ai). Grants data was also provided directly by several research funders.

The APPG would also like to acknowledge the valuable contributions made to the analysis of grants data presented in this report by two volunteers with personal experience of an eating disorder - Dr Joanna Blackburn and Kathryn King. They each independently reviewed and coded research grant abstracts to help determine which should be classified as focused on eating disorders, and therefore included in the analysis.

About the All-Party Parliamentary Group (APPG) on Eating Disorders

The All-Party Parliamentary Group on Eating Disorders (APPG) was formed in 2019 and since then it has been bringing together MPs from across Parliament to improve policy, in particular improving access to evidence-based treatment for people affected by eating disorders and measures that support prevention and early intervention. Beat has provided the Secretariat to the APPG since its formation.

In December 2020, the APPG launched this inquiry into funding for UK eating disorder research which ran to Spring 2021. The inquiry included a call for written evidence and two subsequent oral evidence sessions (held online).

This report was compiled by Beat. Please contact Jonathan Kelly (Beat's Policy Advisor) with any queries: j.kelly@beateatingdisorders.org.uk.