

House of Commons

Public Administration and Constitutional Affairs Committee

Ignoring the Alarms follow-up: Too many avoidable deaths from eating disorders

Seventeenth Report of Session 2017–19

Report, together with formal minutes relating to the report

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Public Administration and Constitutional Affairs Committee

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Summary

In December 2017, the Parliamentary and Health Service Ombudsman (PHSO) presented to Parliament a report entitled Ignoring the Alarms: How NHS eating disorder services are failing patients, which was published following the PHSO's investigations into the case of the death of Averil Hart (aged 19) and two others (Miss B and Miss E).

The report made five wider recommendations relating to: the training of doctors and other medical professionals; the quality and availability of adult services, and the transition from child to adult services; improving coordination when more than one service is involved; using training to address gaps in provision of eating disorder specialists; and improving investigation and learning, in particular from serious incident investigations.

The purpose of our inquiry was to examine what progress had been made on each of the PHSO's recommendations. While we welcome the steps a number of organisations have taken in response to the PHSO's report, we have concluded that further action needs to be taken under each of the report's recommendations.

We found there is a serious lack of training for doctors about eating disorders and recommend that the General Medical Council use its influence to ensure medical schools improve outcomes in relation to eating disorders.

We also find the lack of precise information about the prevalence of eating disorders to be shocking, given claims up to 1.25 million may have eating disorders. As a matter of urgency NHS England should commission a national population-based study to properly assess how many people have an eating disorder.

We believe the Minister and the Department for Health and Social Care can play a leadership role in ensuring progress against the PHSO's recommendations. We have therefore asked the Government, in its response to our report, to produce a timeline against each of the PHSO's recommendations; what steps have been taken, what further steps will be taken under each recommendation and what funding will be allocated for those actions, with deadlines and responsible owners listed.

Due to the ongoing inquest into Averil Hart's death we have confined our inquiry to the wider recommendations, out of observance of the House's *sub judice* rule. Once proceedings relating to that have finished, we will consider the PHSO's investigation in greater detail. As part of that work, we will return to examine progress against the five wider recommendations.

1 Introduction: The PHSO report and our inquiry

Ignoring the Alarms

- 1. One estimate of the numbers of people with eating disorders in the UK is between 600,000 and 725,000.¹ An alternative estimate suggests the figure is 1.25 million.² Regardless of precise figures, it has been suggested that eating disorders may be one of the most common mental health problems.³ Accordingly the provision of effective treatment and services for people who have an eating disorder is a serious matter for society.
- 2. In December 2017, the Parliamentary and Health Service Ombudsman presented to Parliament a report entitled *Ignoring the Alarms: How NHS eating disorder services are failing patients* ("the report").⁴ The report was published following the PHSO's investigations into the case of the death of Averil Hart (aged 19) and two others (Miss B and Miss E). The report's conclusions were as serious as the title suggested. The investigation into Averil's death found that:
 - several NHS organisations missed opportunities to prevent Averil's deterioration which led to her hospital admission;
 - there was inadequate coordination planning of Averil's care;
 - there were failures in two acute trusts when she was seriously ill; and
 - there were failures in the handling of the family's complaints about the circumstances of her death.
- 3. The report found that these failures were not unique to Averil's case and concluded that "there were serious issues that required national attention."⁵
- 4. The PHSO's report listed five wider recommendations which broadly highlighted five key areas for improvement:
 - training of doctors and other medical professionals;
 - the quality and availability of adult services, and the transition from child to adult services;
 - improving coordination when more than one service is involved;
 - using training to address gaps in provision of eating disorder specialists; and
 - improving investigation and learning, in particular from serious incident investigations.

¹ Department of Health and Social Care, Health Education England and the National Institute for Care Excellence,

² https://www.beateatingdisorders.org.uk/how-many-people-eating-disorder-uk

Q95

⁴ Ignoring the Alarms: How NHS eating disorder service are failing patients, Parliamentary and Health Service Ombudsman, December 2017, HC 634. The report was presented to Parliament pursuant to Section 14(4) of the Health Service Commissioners Act 1993.

⁵ Ignoring the Alarms: How NHS eating disorder service are failing patients, Parliamentary and Health Service Ombudsman, December 2017, HC634, p 2

The Ombudsman and our inquiry

- 5. The Parliamentary and Health Service Ombudsman (PHSO, or 'the Ombudsman') is independent of the Government, the NHS and Parliament. It reports to Parliament and is accountable to the Public Administration and Constitutional Affairs Committee (PACAC), which scrutinises its reports, and the overall performance of the PHSO and for its use of resources. PACAC usually holds an annual evidence session based on the PHSO annual report and accounts. The Ombudsman can lay reports before Parliament, often to highlight cases that he feels raise issues of wider concern. *Ignoring the Alarms* was one such report.
- 6. We launched this inquiry to highlight the report's findings and investigate what progress had been made in implementing the PHSO's recommendations. To respect the House's *sub-judice* resolution, we have only considered the report's wider recommendations, as the inquest in the case of Averil Hart has not yet been concluded.
- 7. For this inquiry we received 17 pieces of written evidence. Due to the sensitivities involved and with the agreement of the witness, we have not published one of the submissions we received. We also held an evidence session, hearing from:
 - The charity, Beat Eating Disorders ("Beat"), and the Faculty of Eating Disorders of the Royal College of Psychiatrists;
 - Health Education England and the General Medical Council; and
 - NHS Improvement and NHS England, and The Minister for Mental Health, Jackie Doyle-Price MP.
- 8. We also held an informal seminar on 6 June with people who had lived experience of having, or being carers for people who have, a variety of eating disorders to better understand their experiences. We are grateful to everyone who supported our inquiry.
- 9. If you are affected by any of the issues raised in this report or are looking for support with an eating disorder, one provider of such support is Beat: https://www.beateatingdisorders.org.uk/support-services.

2 Training of doctors and other medical professionals

Box 1: PHSO Recommendation One

The General Medical Council (GMC) should conduct a review of training for all junior doctors on eating disorders.

Source: Ignoring the Alarms: How NHS eating disorder service are failing patients, Parliamentary and Health Service Ombudsman, December 2017, p 15

Background to the recommendation

- 10. The PHSO's report described how training for doctors on the serious and complex subject of eating disorders is limited "to just a few hours". GPs are often the first port of call for people with eating disorders seeking help and therefore "should be equipped with enough knowledge of the illness to know what steps to take next, including when and where to refer a patient to another service." The report continued that medical professionals in acute settings needed to understand both "the nature of anorexia nervosa and the behaviours that sufferers may display."
- 11. In written evidence to this inquiry the PHSO said that the amount of training received by most doctors was "not enough" and repeated the point about GP training in particular:

GPs, often the first port of call for people with eating disorders who seek help, should be equipped with enough knowledge of the illness to know what steps to take next, including when and where to refer a patient to another service.⁹

The lack of training that doctors receive in medical schools about eating disorders was a consistent theme in the evidence to this inquiry. A study published in 2018 found that less than two hours is spent on eating disorder teaching in medical schools and that "Postgraduate training adds little more, with the exception of child and adolescent psychiatry" and concluded "given the risk of mortality and multimorbidity associated with these disorders this needs to be urgently reviewed to improve patient safety." ¹⁰

12. Beat carried out surveys in 2017 and 2018 of medical schools and junior doctors. Their written evidence reported some stark comments from respondents:

Extremely limited education on ED [eating disorders] during medical school. No training whatsoever as a junior doctor (Junior Doctor: Foundation Year 2, 2017).

- 7 Ibid
- 8 Ibid

⁶ Ignoring the Alarms: How NHS eating disorder service are failing patients, Parliamentary and Health Service Ombudsman, December 2017, p 15

⁹ Parliamentary and Health Service Ombudsman, IDF0010

Does UK medical education provide doctors with sufficient skills and knowledge to manage patients with eating disorders safely?, Ayton A, Ibrahim A, Postgraduate Medical Journal 2018;94:374–380

We have been told about eating disorders briefly in one lecture I believe, along with other disorders like body dysmorphic disorder. We weren't told who to refer these patients on to. (Year 5 student, 2017).

I have encountered a number of problematic, stereotypical opinions of patients with eating disorders being spread through medical training and have not felt comfortable countering these. Additionally I have found myself having to educate my fellow students about different aspects of eating disorders because of a lack of education from our tutors, which I feel is inappropriate. (Year 4 student, 2018).

The theory is adequately covered but [we] don't get any clinical skills experience so that would be useful (Year 4 student, 2018).

Source: Beat IDF0012

- 13. Miss Hope Virgo, the leader of the #DumpTheScales campaign, told us that many clinicians were still using BMI to determine whether people could access treatment and support. This is contrary to NICE guidelines that recommend not using single measures such as "BMI or duration of illness to determine whether to offer treatment for an eating disorder. The Eating Disorders Health Integration Team in Bristol echoed this, telling us that in relation to young people with eating disorders, GPs were overly reliant on low BMI as an indicator of an eating disorder. This point of over reliance on BMI was further raised in the discussions we had in our informal seminar, attendees likened gating treatment for eating disorders behind BMI as akin to suggesting a cancer patient should not receive treatment until the cancer had spread throughout their body.
- 14. In the report, the PHSO stated "The failure of staff in both Averil's and Miss E's case to recognise the nature of their illness and seek appropriate advice about treatment could have been easily remedied with some additional training and awareness of the relevant guidance." Rethink Mental Illness argued there should be greater training for all junior doctors on eating disorders and Family Mental Wealth suggested that adequate learning about eating disorders should be made a mandatory part of medical education within medical schools and subsequent continuing professional development. In the informal seminar we heard the stark example of a GP who was concerned that a person with an eating disorder may die but believed they "could not section them because they were not suffering from a mental illness". This example demonstrates that some GPs do not appreciate that an eating disorder is a mental illness.
- 15. Attendees to our informal seminar also told us about how, in their experience, some GPs had used triggering language when discussing their condition with them, such as suggesting another patient was more deserving of treatment because they were thinner. This suggests GPs need more training not just on recognising eating disorders but also in how they communicate with people who have eating disorders.

¹¹ Miss Hope Virgo, IDF0005

¹² Eating disorders: recognition and treatment, para 1.2.8, NICE guideline [NG69]

¹³ Eating Disorders Health Integration Team, IDF0008

¹⁴ Ignoring the Alarms: How NHS eating disorder service are failing patients, Parliamentary and Health Service Ombudsman, December 2017, p 15

¹⁵ Rethink Mental Illness, IDF0003

¹⁶ Family Mental Wealth, IDF0004

16. We conclude that there is a serious lack of training for doctors about eating disorders and the treatment of eating disorder patients, as evidenced, for example, by GPs relying on BMI as a sole indicator of whether people can access treatment for eating disorders, contrary to published guidance. This is particularly important because preventing patients from receiving treatment for eating disorders by reference to single measures such as BMI prevents the access to early treatment which can help prevent a patient from becoming seriously ill. While the number of hours spent in training does not on its own determine the competence of clinicians, two hours of training on such a complicated topic is insufficient.

Progress made on the recommendation

The General Medical Council's review

- 17. The General Medical Council (GMC) said in their evidence that it was unable to undertake the review envisaged by the PHSO because it is limited by the scope of its powers afforded by the Medical Act 1983. Its role is purely one of oversight and it does not write curricula.¹⁷ It could not, for example, prescribe the number of hours of teaching on a subject or the precise nature of that teaching. Instead its powers are limited to quality assuring the medical schools against broader educational skills, knowledge and outcomes they expect undergraduate medical students to achieve.¹⁸
- 18. Individual medical schools and other training establishments set their own curriculum. For undergraduate education, the GMC set the outcomes which UK graduates must meet for entry to the medical register, and this includes several specified practical procedures. The GMC said:

The outcomes that we set are, by definition, broad in nature. We do not believe it would be practical for us to include all possible presentations or conditions that a newly qualified doctor could expect to encounter.¹⁹

- 19. The GMC approves curricula for the Foundation Programme, a two-year programme all graduate doctors are required to undertake to achieve full GMC registration. The curriculum for the Foundation programme is set by the Academy of Medical Royal Colleges (AoMRC) and the GMC's regulatory role is to approve that curriculum. This approval is not subject to the inclusion of specific content but rather the GMC sets "out a process that the AoMRC should follow to ensure that appropriate consultation is undertaken and appropriate medical expertise is brought to bear in its development."²⁰
- 20. Following completion of the foundation programme, a doctor may elect to pursue a specialist field. The GMC explained that there are 65 recognised medical specialities in the UK, each of which has a specific curriculum. These curricula are formulated by 25 medical royal colleges and faculties.²¹ Under Sections 34H–34M of the Medical Act 1983, the GMC has powers to approve these curricula as well as the assessment systems attached

¹⁷ General Medical Council, IDF0015

¹⁸ Ibio

¹⁹ Ibio

²⁰ General Medical Council, IDF0015

²¹ Ibic

to them. The GMC does not base this approval on the inclusion of specific treatments or the diagnosis of individual conditions. Rather, the organisations must show how they have determined the content of their curricula.²²

- 21. Despite this, the GMC suggested it had done everything it could to progress the recommendation, including writing to every medical school in the UK seeking information on:
 - how eating disorders are currently taught and covered in curricula;
 - the relationship between teaching on eating disorders and teaching in mental health, nutrition and physical health; and
 - the exposure medical students get to eating disorders as part of their clinical attachments.

The GMC has also asked royal colleges and faculties to identify where there are overlaps between specialities and where curricula content could be shared. The Academy of Medical Royal Colleges is coordinating a discussion between relevant specialities and colleges on sharing resources and best practice.²³

22. Beat expressed frustration at the lack of progress made under this recommendation:

The General Medical Council (GMC) has not, to the best of our knowledge, agreed to conduct the review recommended by the PHSO.²⁴

23. The CEO of Beat, Mr Radford elaborated further on this point in oral evidence:

We are unhappy with the progress made by the General Medical Council. It seems to have taken it a long time to get going and I have not heard any public statement that it is going to take the action the PHSO recommends it takes. There seems to be a certain amount of deflecting of responsibility going on there and I hope that you will scrutinise that point later. Clearly its mandate has its limits but I feel, when we look at some of the other things the GMC has done in the past, it is pulling back on this issue and it could push harder and take more responsibility.²⁵

24. Professor Colin Melville, Director of Education and Standards in the General Medical Council, told us that he absolutely accepted the "need for change" and explained in more detail the steps GMC had taken with medical schools:

We have written to medical schools. We can now go back to them, once we have heard from them all, and talk about where we think some of those changes are. We can work in partnership with the Royal College of Psychiatrists and its eating disorders faculty. We have indicated that

²² Ibid

²³ Ibid

²⁴ Beat, IDF0012

²⁵ Q10

²⁶ Q50

we would be keen to help it support the development of curricula content across all the colleges. Ultimately, we need the colleges to accept that they are willing to allow that.²⁷

- 25. Dr Melville also explained to us that the prevalence of eating disorders was now higher than schizophrenia and that the balance of teaching should reflect that change.²⁸ Dr Meville offered to provide to us a summary of the GMC's findings once it had received all the responses from the medical schools.²⁹
- 26. In relation to postgraduate training, Dr Nicholls, the Chair of the Faculty of Eating Disorders in the Royal College of Psychiatrists, told us about the difficulty of getting a question on eating disorders into the psychiatry curriculum:

Within psychiatry, there is currently a curriculum review happening, but there are, as ever, a thousand competing demands on that curriculum and in fact the size of the curriculum is being reduced rather than increased. As somebody from the GMC said earlier, nobody ever wants to take a question out of a curriculum, they only ever want to add another one in. We are struggling to get another one in at the moment because we are a minority voice in that dialogue. We are repeatedly making recommendations about what the need is and what the problem is, referring to the recommendations and so on, but I cannot yet say to you that this has resulted in concrete changes to the curriculum.³⁰

27. She also highlighted the need for the inclusion of eating disorders in the curricula of other speciality areas and expressed frustration at the lack of mechanisms for cross-college working:

I would very much like to know what the mechanisms are for effective cross-college working. That is what I am currently struggling with. I have only a few months left in my role as chair but it has been one of the things I have been trying to find my way through for the last year. The approach we have taken from the faculty is to write a position paper based on the recommendations of the PHSO report. That needs to be endorsed internally by the college first and that is pretty much done and dusted, but then I am assuming that the best mechanism is for the Academy of Medical Royal Colleges to take that for cross-college dialogue and engagement around the recommendations. If there are other effective mechanisms that people are aware of, we would be very open to that dialogue.³¹

28. The steps taken by the General Medical Council (GMC) in support of the PHSO's recommendation are welcome. While we acknowledge the limits of the GMC's powers, the GMC has a strong influencing role to play, which would recognise the urgency of taking this work forward. We look forward to receiving a summary from the General Medical Council of the responses they have received from medical schools about the way eating disorders are taught. We recommend the GMC acts on this information and

²⁷ Q54

²⁸ Q53

²⁹ Q61

³⁰ Q42

³¹ Q38

uses the responses received from medical schools to identify examples where education has not been effective, to share best practice where it is identified and overall use its influence to ensure that medical schools improve outcomes in relation to eating disorders. We recommend that the GMC undertakes to write again to medical schools after one year to find out what changes to medical student training have been implemented.

29. We recognise that for eating disorder training to improve postgraduate training is also critical. We agree with witnesses who identified the need for greater cross-college working to ensure eating disorders are included in relevant curricula and support the Academy of Medical Royal Colleges' work in coordinating a discussion between relevant specialties and colleges on sharing resources. We note that participants in the informal seminar highlighted the importance of training for General Practitioners in this context. We recommend that the Academy should also coordinate the necessary actions arising from this work and report on how the learning from these discussions are implemented.

The MARSIPAN guidelines

30. The Royal College of Psychiatrists drew our attention to the Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN) guidelines, which were developed by the Royal College of Psychiatrists with the hope of reducing the number of avoidable deaths of patients with severe anorexia nervosa. The guidance "particularly prescribes active communication and consultation between Psychiatric services, including eating disorder and liaison psychiatry, and medical services" and includes for quick reference an all-age checklist for use by clinicians.³² The Royal College of Psychiatrists argued that if the guidelines had been followed then Averil's death and the deaths of Miss B and Miss E would have been avoided.³³ While medical professionals have begun to take on the guidance, the Royal College of Psychiatrists suggested there was a need to monitor and accelerate uptake and suggested one way to improve such uptake would be to include it in undergraduate medical curricula.³⁴ Dr Nicholls explained in oral evidence that the uptake of MARSIPAN guidance, in particular, needed to be improved in relation to non-specialists:

Eating disorder services are all using the MARSIPAN guidance. Where I think it is less clear is whether emergency medicine, acute trusts and primary care are also following that MARSIPAN guidance. It is embedded in all the best practice guidelines. Its reach, penetration and impact outside the speciality is the issue.³⁵

31. Dr Nicholls' point about the lack of knowledge of the MARSIPAN guidelines among non-specialists was furthered in our roundtable discussions with people with lived experience of eating disorders. Although the guidelines were described as "lifesaving" by participants, they told us that most doctors did not have any awareness of the guidelines.

³² Royal College of Psychiatrists, IDF0011

³³ Ibio

³⁴ Ibid

³⁵ Q35

32. There must be wider take up of the Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN) guidelines. They are a vital tool to promote active communication and consultation between psychiatric services, including eating disorder and liaison psychiatry, and medical services and includes for quick reference an all-age checklist for use by clinicians. These guidelines are lifesaving for people who have anorexia nervosa. We recommend that Health Education England should work with NHS England to improve uptake of the MARSIPAN guidance by practitioners, particularly practitioners who are not specialists in eating disorders, and the Care Quality Commission should ensure that the MARSIPAN guidelines are being adopted at all levels in NHS England.

3 The quality and availability of adult services, and the transition from child to adult services

Box 2: PHSO Recommendation Two

The Department of Health and NHS England should review the existing quality and availability of adult eating disorder services to achieve parity with child and adolescent services.

Source: Ignoring the Alarms: How NHS eating disorder service are failing patients, Parliamentary and Health Service Ombudsman, December 2017, p 16

Background to the recommendation

- 33. The PHSO's report indicated that "moving between services is a particularly challenging time for people with eating disorders" and that, "there also needs to be greater availability of good quality adult eating disorder services, which are currently subject to significant geographical variation meaning access to specialist support can be hugely divergent." It notes that child and adolescent services have "received specific focus in recent years" in terms of funding and development of guidance to improve services and establish and maintain community eating disorder services. The report suggested that the Department of Health should consider developing benchmarking guidance for adult eating disorder services and appropriate measures for monitoring the success of such guidance.³⁶
- 34. Evidence to this inquiry was consistent; it described adults' access to eating disorder services as geographically variable. Beat, Miss Hope Virgo and participants in our informal seminar described such access as a "postcode lottery". The Beat further stated that waiting times for adult community services varied but were "long in many areas". The Royal College of Psychiatrists echoed this, saying that "the experience of Miss E, in the PHSO report, with no apparent access to specialist services, is not unusual" but suggested that "solving this problem is not simply a matter of money. There is a shortage of specialist staff and many Trusts find it difficult to fill vacancies across the professions. The people we spoke to with lived experience confirmed that they had experienced very long waiting times and, in some cases, complete lack of access to specialist treatment. Nic Hart, Averil Hart's father, highlighted in a written submission a number of vacancies currently in the Norwich Clinical Commissioning Group, which helps demonstrate the staff shortages currently affecting services. The services are described adults and participants in our informal participants are described by the services are specialist treatment. The people we spoke to with lived experience confirmed that they had experienced very long waiting times and, in some cases, complete lack of access to specialist treatment. Nic Hart, Averil Hart's father, highlighted in a written submission a number of vacancies currently in the Norwich Clinical Commissioning Group, which helps demonstrate the staff shortages currently affecting services.

³⁶ Ignoring the Alarms: How NHS eating disorder service are failing patients, Parliamentary and Health Service Ombudsman, December 2017, p 15

³⁷ Beat, IDF0012; Miss Hope Virgo, IDF0005

³⁸ Beat, IDF0012

³⁹ Royal College of Psychiatrists, IDF0011

⁴⁰ Nic Hart, IDF0007

35. Dr Nicholls told us in oral evidence that the pressure on adult mental health services was "probably about six times that on child and adolescent services" and that:

The reasons for investing in child and adolescent eating disorders were very clear at the time. We were spending a huge amount of money on inpatient treatment for adolescents at a time when we could and should have been intervening in a home environment with families. The evidence for that was very clear. The evidence in adults was less clear and, therefore, I think there was a strong rationale for investing in child and adolescent services at the time. However, what that has now created is a cliff edge at the age of 18 for people who are trying to access services.⁴¹

- 36. In our round table discussions, we heard from people with lived experience about a stark difference in the level of care when they or those they cared for moved from child and adolescent to adult services. The cut off at 18 years old was particularly difficult as this often coincided with a move to university, as was the case for Averil Hart. They, therefore, advocated extending child and adolescent services to ensure a smoother transition. A number of participants also noted the difference in the approach of medical professionals to parental involvement which was sometimes no longer welcomed.
- 37. Specific concern was raised in written evidence to us about the availability of services for people who have autism. Autistica explained that one in five women with anorexia in eating disorder services are autistic and they "face worse outcomes than their non-autistic peers, with reduced levels of recovery and more persistent difficulties with their wider mental health, social skills and employment." An anonymous contributor to our inquiry, A1, explained that in their family's experience "eating disorder services are not equipped to deal with autistic people who develop eating disorders and NHS staff are unwilling to have their expertise challenged."

Progress made on the recommendation

- 38. When asked about progress against this recommendation, NHS England described a number of steps they have taken:
 - In 2017, NHS England commissioned NHS Benchmarking to collect data on the levels of provision across community and inpatient services for adults with an eating disorder in 2016/17. The outputs on provision, investment and workforce were reported to NHS England in March and June 2018. The outputs of this data collection informed a modelling exercise to establish the baseline, understand the geographical variation, and the cost and workforce required to achieve parity with children and young people's eating disorder services.
 - In 2018, NHS England established an Adult Eating Disorder Expert Reference Group, chaired by Professor Tim Kendall and Jess Griffiths, an expert by experience, to help review the data and modelling for the NHS Long Term Plan.

¹¹ Q2

⁴² Autistica, IDF0001

⁴³ A1, IDF0013

- NHS England commissioned the National Collaborating Centre for Mental Health at the Royal College of Psychiatrists to work with the Adult Eating Disorder Expert Reference Group to:
 - develop guidance and helpful resources on effective models and costs of delivery;
 - establish the staffing skill-mix required; and
 - define quality measures and data metrics to demonstrate outcomes and test potential waiting time standards that will address inequity and create parity with children and young people eating disorder services.⁴⁴

There is also a commitment in the NHS long term plan to trial four-week waiting times for adult and older adult community mental health teams, 45 although we note this is not specific to eating disorders.

- 39. One of the primary responses to the PHSO's report was the setting up of a working group, the PHSO Delivery Group. The Group was established by NHS England and chaired Professor Tim Kendall, the NHS England and NHS Improvement National Clinical Director for Mental Health. The Group's objectives were to:
 - support and inform the delivery and implementation of each recommendation;
 - help coordinate and support stakeholders' work streams to deliver the recommendations and implementation plans;
 - provide timely and relevant data and reporting products to inform the PHSO and stakeholder programme boards on progress;
 - ensure alignment between this programme of work and other relevant work programmes across the stakeholder organisations; and
 - receive the operational elements of developed programme proposals for discussion and approval prior to sign off by Mental Health and Parity of Esteem Programme Board.⁴⁶

The Group is comprised of representatives of the following organisations:

Table 1: The PHSO Delivery Group

| Organisation | Job title |
|--|--|
| Department of Health and Social Care | Programme Lead: Mental Health Delivery |
| National Institute of Clinical Excellence (NICE) | Implementation Manager–System Support for Implementation |
| Health Education England | Programme Manager |

Department of Health and Social Care, Health Education England and the National Institute for Care Excellence, IDF0017

The NHS Long Term Plan, January 2019, p 69

Department of Health and Social Care, Health Education England and the National Institute for Care Excellence, IDF0017

| Organisation | Job title |
|--|--|
| NHS England–Mental Health Policy | National Clinical Director for Mental Health; Programme Manager; Business support officer |
| NHS Improvement | Deputy Director of Patient Safety (Policy and Strategy) |
| General Medical Council (GMC) | Head of Policy (Education) |
| Implementation partners | |
| Care Quality Commission | Head of Mental Health Policy |
| Royal College of Psychiatrists | Chair of the Eating Disorder Faculty |
| NHS England-Primary Care | Director of Primary Care Commissioning |
| NHS England–Diabetes | National Clinical Director for Diabetes and Obesity at NHS E and Strategic Clinical Network Lead |
| NHS England–Specialised Commissioning (inpatient care) | Mental Health Programme of Care Senior Manager |
| Expert by Experience | Student and co-chair of clinical network for eating disorders in East of England. |

Source: Department of Health and Social Care, Health Education England and the National Institute for Care Excellence, IDF0017

- 40. The Government's written evidence described this recommendation as having been "implemented".⁴⁷ No other witnesses to our inquiry suggested this was the case.⁴⁸
- 41. Professor Tim Kendall accepted that there is a 'postcode lottery' in terms of access to specialist services.⁴⁹ When we asked what was being done to remedy this, he pointed to two "major pieces of work":
 - Repatriating the investment in eating disorder in-patient beds and asking localities to reinvest that money into community eating disorders services; and
 - Refining the long-term plan to develop community-based services "covering all the main serious mental illnesses", which included eating disorders. ⁵⁰
- 42. Repatriating investment from inpatient care to community services has the potential to deliver value for money. Mr Radford argued that community services are as effective as inpatient care and much cheaper to provide. Beat's research has suggested that providing treatment to people as soon as possible can provide benefit to patients and families as well as delivering "significant cost savings" for the NHS. Specifically the research suggested a relatively short inpatient stay can cost over £40,000 more than intensive community-based treatment. The report concluded:

⁴⁷ Department of Health and Social Care, Health Education England and the National Institute for Care Excellence, IDF0017

⁴⁸ See for example: Parliamentary and Health Service Ombudsman, IDF0010; Royal College of Psychiatrists, IDF0011

⁴⁹ Q133

⁵⁰ Q134

⁵¹ Q23

Delaying for years, denied for months: The health, emotional and financial impact on sufferers, families and the NHS of delaying treatment for eating disorders in England, Beat, November 2017

While outcomes cannot be guaranteed, early intervention will always have a better chance of achieving a positive outcome than delayed intervention, and always at lower cost to the NHS.⁵³

- 43. As part of the NHS Long Term Plan, mental health will receive a growing share of the NHS budget "worth in real terms at least a further £2.3 billion a year by 2023/24." Professor Kendall explained that a "sizeable" part of this will be devoted to community mental health and would include eating disorders, although the exact figures had not yet been decided. 55
- 44. People with lived experience of eating disorders described a "cliff edge" in relation to the transition from inpatient care to community care. One attendee to our informal seminar said there was an "almost farcical" difference in the provision between inpatient care and community care. Another agreed there was a "massive problem" with community services their level of provision varied greatly between areas. It was stressed to us that it was vital that there were proper "step down" services to support a person's transition from inpatient to community care to help patients from relapsing. We were further told that many people are discharged from inpatient care based on their weight and that a person's physical recovery did not guarantee that they had also mentally recovered.
- 45. We welcome the increased funding for mental health within the NHS long term plan but we recommend that NHS England set out how much of this funding will be specifically allocated to adult eating disorder services.
- 46. We support NHS England's plans to transfer investment from inpatient services to community care which has the potential to deliver greater value for money. Better community service provision is essential not only to help prevent people from becoming so ill that they need hospitalisation but also to support people who are discharged from hospital, to avoid relapsing and therefore requiring further hospitalisation. Although we accordingly welcome greater funding for community services, NHS England must also ensure that there is adequate inpatient capacity.
- 47. In our informal seminar with people who had lived experience of eating disorders, we were told there was potential for more involvement of family or carer support in adult eating disorder services. Though we recognise this is a complicated matter, such support can be extremely important for people with eating disorders.
- 48. The PHSO in its written evidence welcomed "the leadership" NHS England had shown in response to the report and expressed that "this will set the groundwork for achieving tangible improvements in the quality and availability of adult eating disorder services." ⁵⁶
- 49. We welcome the steps that have already been taken and that the NHS is piloting the introduction of a four-week waiting time target for adult and older adult community mental health teams, which has the potential to improve the provision of services for patients. We hope this will be transformed from a pilot to an appropriately funded business as usual target.

⁵³ Ibid, p 21

⁵⁴ NHS Long Term Plan, NHS, January 2019, p 68

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⁵⁶ Parliamentary and Health Service Ombudsman, IDF0010

- 50. Although there are a number of welcome ambitions to improve quality and availability of adult eating disorder services, it is clear that there has not yet been delivery of substantive improvements in that provision. Accordingly we find it disturbing that the Government claims that the PHSO's recommendation on achieving parity of adult eating disorder services with child and adolescent services has been implemented, when this it is clear that this is not the case. This work must be done and this should be championed by the PHSO Delivery Group. As part of its work under this PHSO recommendation, we recommend the NHS have particular regard to ensuring the needs of autistic patients are met.
- 51. We asked Dr Kendall in oral evidence about when the work of the Expert Reference Group would be published, in his answer he gave further details on the work that Group had done:

I am not 100% sure when it will be published, but I am pretty sure we will be publishing it over the next few months. The work we have done is basically to get a group of experts of different kinds—research, practice, experts by experience—to take the NICE guidelines, the NICE quality standards, which a number of us were involved in producing, and look at how we can get this into practice at the same time as finding out what the gap was between where we are and where we need to be. That has meant doing quite a lot of work around workforce: what sort of workforce are we going to need and how will we get that workforce in the face of the difficulties that Sir Bernard has already referred to? It is quite a complex piece of work, and we do want to get it right. I anticipate that over the coming months we will publish something from that work that will be helpful to the system. That is the key thing, that it will be helpful to the system, rather like a recipe would be helpful to a cook.57

- 52. Dr Nicholls in oral evidence told us that the expert reference group's work to develop commissioning guidance for adult eating disorder services was completed and the report was currently with NHS England awaiting release.58
- 53. NHS England established an Adult Eating Disorder Expert Reference Group, chaired by Professor Tim Kendall and Jess Griffiths, an expert by experience, to help review the data and modelling for the NHS Long Term Plan. We Commend NHS England for establishing the Adult Eating Disorder Expert Reference Group to help review data and modelling for the NHS Long Term Plan but the Government must publish the Expert Reference Group's report as soon as possible. If the Group's report has not been published by the time the Government publishes its response to our report, the Government should provide a timeline for the publication of the Expert Reference's Group's report in that response.

Prevalence of eating disorders

54. The appropriate level of provision of eating disorder services is further complicated by the fact that information on the prevalence of eating disorders is imprecise. In its evidence to us, the Government cited a 2015 report commissioned by Beat, suggesting the

Q7

number of patients with eating disorders is between 600,000 and 725,000.⁵⁹ Beat has more recently estimated the figure to be 1.25 million.⁶⁰ The Government's written evidence noted that SCOFF, the eating disorder screening tool, will be added to the 2019 Health Survey England, to improve information about the prevalence of eating disorders.⁶¹

- 55. In oral evidence, Dr Nicholls told us that the "prevalence data are not as good as we would like"⁶² and that a national clinical audit would be needed to fully understand the picture.⁶³ Andrew Radford, suggested that even the 1.25 million figure was "almost certainly" an underestimate, which in turn causes under-resourcing.⁶⁴ Professor Kendall explained there was contradictory information but the best estimate, in view of the Expert Reference Group, was that "over a lifetime 6% of people will develop an eating disorder."⁶⁵
- 56. The lack of information about the prevalence of eating disorders is made even more serious by the fact that we were told, in our roundtable discussions, that eating disorders have the highest mortality rate of mental illnesses. We were also told by attendees that eating disorders "thrive in secrecy" and therefore go undiagnosed which further makes it difficult to measure their prevalence and that estimates of the number of people with eating disorders were very likely to be underestimates.
- 57. A lack of precise information on the prevalence of eating disorders is shocking, given the claims that up to 1.25m people are suffering from eating disorders and the fact that eating disorders have the highest mortality rate of mental illnesses. This vagueness limits the ability of NHS commissioners to gauge what services need to be provided and encourages them to devote resources to better recorded diseases and conditions. We welcome the inclusion of SCOFF (the eating disorder screening tool) in the 2019 Health Survey England to improve this information about the prevalence of eating disorders but recommend as a matter for urgent action that NHS England commissions a national population-based study to accurately assess the number of people who have eating disorders. It is essential such research does not simply look at the numbers of people who have been diagnosed with eating disorders, the evidence we have heard suggests that eating disorders are under-reported and are inherently secretive conditions.

⁵⁹ Department of Health and Social Care, Health Education England and the National Institute for Care Excellence, IDF0017

⁶⁰ https://www.beateatingdisorders.org.uk/how-many-people-eating-disorder-uk

⁶¹ Department of Health and Social Care, Health Education England and the National Institute for Care Excellence, IDF0017

⁶² Q2

⁶³ Q3

⁶⁴ Q2

⁶⁵ Q100

4 Coordination of services

Box 3: PHSO Recommendation Three

The National Institute for Health and Care Excellence (NICE) should consider including coordination as an element of their new Quality Standard for Eating Disorders.

Source: Ignoring the Alarms: How NHS eating disorder services are failing patients, Parliamentary and Health Service Ombudsman, December 2017, p 16

Background to the recommendation

58. The PHSO's report notes that NICE guidance on eating disorders "identifies that particular care should be taken to ensure services are well coordinated when more than one service is involved" but found that there were wide variations in how eating disorder care was coordinated and that poor coordination of services was a "starkly common issue". 66 In written evidence to us the PHSO further explained:

A detailed care plan that all providers involved in a patient's care pathway understand, and that comprehensively assesses an individual's needs and considers risks is an essential part of ensuring care is properly managed. Without this, and in the absence of frequent and clear communication between providers and the engagement of appropriate multidisciplinary expertise, there can be tragic consequences.⁶⁷

Progress on the recommendation

59. NICE has included coordination of services in its quality standard on eating disorders⁶⁸ and we welcome the timely implementation of this recommendation; however, it is important to ensure that organisations embed such standards. Dr Nicholls said in oral evidence:

What I am not clear about is what the impetus or leverage is to enforce those quality standards and what expectation there is for services to adhere to those quality standards. It is the standard but as to whether there has been an audit against that standard as yet, I have not seen any evidence of that.⁶⁹

- 60. Rethink Mental Illness, while welcoming the NICE quality standard, argued that transitions must not only improve between NHS services but also between NHS services and educational institutions, noting that students' transitions from home to university pose issues for many students.⁷⁰
- 61. To help support the implementation of the quality standard, the Government's evidence described work NICE is undertaking with national partners

⁶⁶ Ignoring the Alarms: How NHS eating disorder service are failing patients, Parliamentary and Health Service Ombudsman, December 2017, p 16

⁶⁷ Parliamentary and Health Service Ombudsman, IDF0010

⁶⁸ Eating disorders quality standard [QS175], NICE, September 2018

⁵⁹ Q7

⁷⁰ Rethink Mental Illness, IDF0003

Care Quality Commission: NICE has developed a checklist in line with the quality standard, for inspectors to use when assessing services for people with an eating disorder;

Beat (the eating disorders charity), Royal College of General Practitioners, and Royal College of Paediatrics and Child Health have agreed to be supporting organisations for the quality standard and to promote the standard within their networks.⁷¹

62. We welcome the inclusion of coordination in the new NICE quality standard on eating disorders but further work is necessary to embed those standards. We recommend that the PHSO Delivery Group, as part of its work, commission an audit of the extent of implementation of the NICE guidelines. This could be completed over the next few months (before we report again on this topic - see paragraph 84 below).

5 Using training to address gaps in provision of eating disorder specialists

Box 4: PHSO Recommendation Four

Health Education England should review how its current education and training can address the gaps in provision of eating disorder specialists we have identified. If necessary it should consider how the existing workforce can be further trained and used more innovatively to improve capacity. Health Education England should also look at how future workforce planning might support the increased provision of specialists in this field.

Source: Ignoring the Alarms: How NHS eating disorder services are failing patients, Parliamentary and Health Service Ombudsman, December 2017, \overline{p} 16

Background to the recommendation

63. The PHSO identified a further barrier to good quality care transitions as being a scarcity of specialists who can provide the type of care required"⁷² saying there are often only "one or two professionals have responsibility for patients with eating disorders across a large geographical area, or that people are unable to access support where they live."⁷³

Progress on the recommendation

- 64. The Government's evidence pointed to a number of steps being taken by Health Education England (HEE), including:
 - Working with the General Medical Council and other partners, such as the Academy of Medical Royal Colleges and Universities across the UK to review specialty training to ensure that:
 - Medical training and curricula meet the standards set by the GMC aligned to the General Professional Capabilities Framework;
 - training is structured and designed to best meet the health care needs of the population now and in the future-e.g. a greater focus on generalism, flexibility and the interface between Primary and Secondary Care.
 - Working with the Royal College of Psychiatrists and other workforce stakeholders, exploring innovative training models to address any gaps in eating disorder education and training for Psychiatrists. For example, offering credentialing opportunities in eating disorders as an add-on to specialty training and as a post training opportunity.⁷⁴

⁷² Ignoring the Alarms: How NHS eating disorder service are failing patients, Parliamentary and Health Service Ombudsman, December 2017, p 16

⁷³ Ibio

⁷⁴ Department of Health and Social Care, Health Education England and the National Institute for Care Excellence, IDF0017

- 65. In recognition of the fact that people with eating disorders can present in a variety of settings, not just in mental health services, HEE has broadened its education and training scoping exercise to include the learning needs of the wider workforce, this project is scheduled to report in June 2019.⁷⁵ Beat has welcomed the steps taken by HEE, describing them as being in line with the PHSO's recommendation.⁷⁶
- 66. Beat recommended that Health Education England should work with NHS England and others "to ensure that all junior doctors complete a four month psychiatry placement, and that these include clinical experience in eating disorders." In oral evidence the Minister signalled her support for a four month psychiatry placement. 78 Professor Bayliss-Pratt, Chief Nurse for Heath Education England, was somewhat more cautious, saying:

It is important that we have a flexible, responsive training circuit for junior doctors so that they can be in a variety of settings, get exposure to these issues and be trained and supported appropriately. The fear is that if we just put everybody into a four-month training pathway would we achieve what we really want to with this agenda? Again, we need to work with our partners to really test that a lot more to see if that is the optimum way forward.⁷⁹

But also explained that her mind was "open to it". 80 Professor Bayliss-Pratt made clear that work was being undertaken not just in relation to doctors, but also the wider workforce:

The other important thing to recognise is that it is not just about the medical profession, it is about the wider workforce. For example, we are just piloting an education mental health practitioner role that works between mental health services, primary care services and schools, because we think it is really important to get to children and young people and to spot people who are identifying these problems early. It is about that wider workforce at the moment and we are currently exploring how we create a more professional competency framework to ensure we get this education and training into everybody who comes into contact with people who require health and care services, including school nurses, health visitors and the whole public health agenda too.⁸¹

67. People with lived experience strongly supported the need for teachers and university staff to be included in training. They explained that people with eating disorders can present in a variety of circumstances therefore providing effective training to a wide range of professionals would aid the early detection and provision of support for people with eating disorders. We also had our attention drawn specifically to the need to provide training to nurses. We were told that many people with eating disorders see nurses more often than GPs or specialists, so providing training to nurses and nurse practitioners could potentially improve the early detection of eating disorders. It was suggested to us that training delivered by people who have lived experience can be particularly effective.

⁷⁵ Ibid

⁷⁶ Beat, IDF0012

⁷⁷ Ibid

⁷⁸ Q109

⁷⁹ Q78

⁸⁰ Q79

⁸¹ Q57

- 68. All junior doctors should complete a four-month psychiatry placement and we welcome the Minister's support for this proposal. Such placements should include exposure to eating disorders. We recommend Health Education England take this recommendation forward and assess whether it is possible to ensure each such placement includes exposure to patients with eating disorders.
- 69. We welcome the efforts of Health Education England to develop competency within the wider workforce in relation to eating disorders. People with eating disorders can present in a variety of circumstances and through a number of different pathways, therefore improving the wider workforce's knowledge of eating disorders can significantly improve the early detection and provision of support for people with eating disorders. This work should specifically consider the provision of training to nurses and nurse practitioners. Health Education England should take steps to facilitate the delivery of such training by people who have lived experience of eating disorders. In circumstances where that is not viable, solutions such as online training should be pursued.

6 Improving investigation and learning, in particular from serious incident investigations

Box 5: PHSO Recommendation Five

Both NHS Improvement and NHS England have a leadership role to play in supporting local NHS providers and CCGs to conduct and learn from serious incident investigations, including those that are complex and cross organisational boundaries. NHSE and NHSI should use the forthcoming Serious Incident Framework review to clarify their respective oversight roles in relation to serious incident investigations. They should also set out what their role would be in circumstances like the Harts, where local bodies are failing to work together to establish what has happened and why, so that lessons can be learnt.

Source: <u>How NHS eating disorder service are failing patients</u>, Parliamentary and Health Service Ombudsman, December 2017, p 17

Background to the recommendation

70. The Ombudsman's report details how Nic Hart had been in correspondence with six organisations over a year and a half yet none of them worked towards a coordinated investigation of Averil Hart's death, which is something the PHSO has encountered "time and time again". The Patient Experience Library, in written evidence, stated this issue is systemic across the NHS and "a common factor throughout is a failure to hear from patients and bereaved relatives, and to understand the patient experience." The issue of NHS learning from investigations is something that we, and our predecessor committees, have taken an active interest in. 4

Progress on the recommendation

- 71. The Government described work under this recommendation as being "underway" and the following steps have been taken:
 - NHS Improvement's work with regional teams across NHS Improvement and NHS England to design a new system for oversight and support for incident management, including incidents that may require cross system investigation.
 - In December 2018, NHS Improvement reported that they had conducted an engagement exercise to inform a review of the Serious Incident Framework for the NHS between April and July 2018.

⁸² Ignoring the Alarms: How NHS eating disorder service are failing patients, Parliamentary and Health Service Ombudsman, December 2017, p 17

⁸³ Patient Experience Library, IDF0006

Public Administration and Constitutional Affairs Committee, Seventh Report of Session 2016–17, Will the
NHS never learn? Follow-up to PHSO report 'Learning from Mistakes' on the NHS in England, HC 743; Public
Administration and Constitutional Affairs Committee, First Report of Session 2016–17, PHSO review: Quality of
NHS complaints investigations, HC 94

- Work has been undertaken to develop new regional functions which support the
 overarching patient safety strategy,⁸⁵ the public consultation on which closed on
 15 February 2019.
- Finally, a new Serious Incident Framework is to be published in the Spring of 2019.⁸⁶
- 72. The PHSO, in written evidence, told us that the feedback NHS Improvement had received, as part of its engagement on revising the Serious Incident Framework, demonstrated the need for a "fundamentally different approach to the management of serious incidents." This was likely to "support the development of broader systems, processes, skills and behaviours that enable an appropriate response to patient safety incidents." While awaiting the publication of the revised framework, the PHSO welcomed NHS Improvement's direction of travel but noted the need for clear funding and timescales for implementation. 89
- 73. The Care Quality Commission told us that they had found evidence that some trusts had "established more robust practices to review, investigate and share learning from deaths" but progress was variable between trusts. ⁹⁰ The Commission continued that for further progress to be made:

the culture of many organisations needs to improve and there is a need for further specialist training, engagement with bereaved families, and guidance and support from trusts and other bodies is required to encourage more openness and learning across the NHS.⁹¹

74. In oral evidence Dr Kendall told us about the need to encourage senior doctors to talk about their mistakes:

One of the things that the previous Secretary of State did, I thought very well—I used to go around with him to visit mental health trusts and it was all about patient safety and mental health—was he began a whole programme of patient safety in mental health. One of the things that he did was that he got us senior doctors, including from the Royal College of Physicians and others, to stand up and talk about their experiences of making a mess of things. We have to create a culture in which we are all a lot more honest and that does include senior doctors at the top being honest about where we have made mistakes.⁹²

75. As part of our roundtable discussions with people who had lived experience of eating disorders, it was made clear that there was a need for the NHS to move from prioritising short-term reputation management to focusing on facilitating learning and longer-term improvements.

⁸⁵ Developing a patient safety strategy for the NHS: Proposals for consultation, NHS Improvement, December 2018

⁸⁶ Department of Health and Social Care, Health Education England and the National Institute for Care Excellence, IDF0017

⁸⁷ Parliamentary and Health Service Ombudsman, IDF0010

⁸⁸ Ibid

⁸⁹ Ibio

⁹⁰ Care Quality Commission, IDF0009

⁹¹ Ibid

⁹² Q162

Health Service Safety Investigations

76. Following work by our predecessor Committee,⁹³ the creation of the Healthcare Safety Investigation Branch (HSIB) which became operational on 1st April 2017, was a welcome development in the area of healthcare investigations. The purpose of the organisation, which is funded by the Department for Health and Social Care but operates independently from it and NHS Improvement, is to improve safety through effective and independent investigations that don't apportion blame or liability.⁹⁴ In written evidence to this inquiry, HSIB informed the Committee that, alongside investigations, it has spent the first two years "developing and refining our methodology" for conducting investigations through developing a seven-point "framework for professionalising safety investigations in the NHS."

77. The work of the Joint Committee on the Draft Health Service Safety Investigations Bill was concluded in August 2018 with the publication of its report. He Bill would establish the full statutory independence of HSIB and would allow it to conduct national investigations under protected disclosure. This provision, commonly known as 'safe space', would enable NHS staff to share their experience of a patient safety incident without fear of reprisal. Importantly, it would not prevent HSIB from sharing information with families, regulators or organisations about an incident or to address immediate risks to patient safety. Health Service Safety Investigations Bill has not yet been introduced to Parliament.

78. Investigations into, and NHS learning from, serious incidents is essential to helping ensure that the circumstances leading to avoidable deaths do not reoccur. It is heartening to hear from the Care Quality Commission that some trusts are establishing more robust practices for investigating and learning from deaths but such change must be made throughout the whole of the NHS. Cultural change is essential to achieve this. We believe the Care Quality Commission's inspections provide one way for the NHS to determine the progress it is making in culture change; namely the shift from a closed and defensive blame culture to one of openness, willingness to hear and tell the truth, and to learning from mistakes to avoid future harm to patients. It is essential that the NHS moves from a culture which falls into short-term reputation management to one which facilitates open learning and longer-term improvements to service provision. The NHS should further consider how it can assess the progress it is making in changing the culture surrounding investigations and learning. Such cultural change must be regarded as a high priority.

⁹³ Sixth Report of the Public Administration Select Committee, Session 2014–15, *Investigating clinical incidents in the NHS*, HC 886.

⁹⁴ https://www.hsib.org.uk/

⁹⁵ Healthcare Safety Investigation Branch, IDF0018;. See the full framework attached in annex to their evidence.

⁹⁶ Report of the Joint Committee, *Draft Health Service Safety Investigations Bill: A new capability for investigating patient safety incidents*, Session 2017–19, HL Paper 180 HC 1064.

⁹⁷ https://www.hsib.org.uk/

79. We welcome the initial work of Healthcare Safety Investigation Branch (HSIB) in investigating the causes of clinical incidents without attributing blame and in order to disseminate learning for the future and the seven-point "framework for professionalising safety investigations in the NHS". We call on the Government to introduce the Health Service Safety Investigations Bill as soon as possible in order to provide HSIB with statutory powers and independence, and to enable it to provide a statutory 'safe space' for clinicians and patients and their families to speak freely, like other safety investigation bodies.

Final conclusions and 7 recommendations

80. There is evidence of a lot of work that has been taken forward by several organisations in response to the PHSO's report, which we welcome, but it is clear from our conclusions and the evidence quoted above that sufficient progress in the area of eating disorders has not yet been made. While we have received a large amount of evidence about what various organisations plan to do, this has for the most part not yet resulted in concrete deliverables. In relation to the PHSO Delivery Group, Dr Kendall remarked to us:

> Rather naively, I now feel, I thought that we would have a limited time period, possibly a year, perhaps two, to get this whole thing going and make sure each of the bodies involved knew their responsibilities and had programmes underway. We now, on reflection, think that we need to keep this group going until we are very clearly getting eating disorders established within curricula, within doctors' training, and so on. 98

- 81. Welcome steps are being made in response to the PHSO's report, but sufficient progress has not yet been made in response to the PHSO's report. We agree with Dr Kendall's assessment that the PHSO Delivery Group needs to continue to meet. It is essential that there is a delivery body that has responsibility for ensuring these recommendations are taken forward. We recommend that the PHSO Delivery Group not be disbanded until it can report with confidence that all the recommendations have been implemented.
- 82. In oral evidence to us, the Parliamentary Under Secretary of State for Mental Health, Inequalities and Suicide Prevention, told us:

The recommendations are sitting with various aspects of the system but ultimately, as the Minister, it is my job to make sure that everyone steps up to the plate. I am happy to take on that challenge99 ... In terms of the levers that I can bring, I think that ability to have good, constructive engagement with those responsible for delivery and the ability to challenge other partners and those responsible is where I can really use my influence. 100

83. We are encouraged by the Minister's and the Department of Health and Social Care's interest in this subject. They can play a critical leadership role in providing impetus to ensure timely progress is made on the PHSO's recommendations. A number of steps have been set out in the evidence we have received but we do not think there is enough urgency. Such urgency must reflect the fact that lives will continue to be lost under the status quo. There must accordingly be a clear picture of what actions will be delivered under each recommendation, what funding will be assigned to delivering those actions and by what timeframe those actions will be complete. In its response to this report the Government should produce a timeline against each of the PHSO's recommendations; what steps have been taken, what further steps will be taken under each recommendation and what funding will be allocated. These actions should have clear responsible owners and deadlines for completion.

84. Once proceedings in court are finished, we plan to consider the PHSO's investigation of Averil Hart's case in greater depth. At that time, we will return to the PHSO's wider recommendations to assess what progress has been made.

Conclusions and recommendations

Training of doctors and other medical professionals

- 1. We conclude that there is a serious lack of training for doctors about eating disorders and the treatment of eating disorder patients, as evidenced, for example, by GPs relying on BMI as a sole indicator of whether people can access treatment for eating disorders, contrary to published guidance. This is particularly important because preventing patients from receiving treatment for eating disorders by reference to single measures such as BMI prevents the access to early treatment which can help prevent a patient from becoming seriously ill. While the number of hours spent in training does not on its own determine the competence of clinicians, two hours of training on such a complicated topic is insufficient. (Paragraph 16)
- 2. The steps taken by the General Medical Council (GMC) in support of the PHSO's recommendation are welcome. While we acknowledge the limits of the GMC's powers, the GMC has a strong influencing role to play, which would recognise the urgency of taking this work forward. We look forward to receiving a summary from the General Medical Council of the responses they have received from medical schools about the way eating disorders are taught. We recommend the GMC acts on this information and uses the responses received from medical schools to identify examples where education has not been effective, to share best practice where it is identified and overall use its influence to ensure that medical schools improve outcomes in relation to eating disorders. We recommend that the GMC undertakes to write again to medical schools after one year to find out what changes to medical student training have been implemented. (Paragraph 28)
- 3. We recognise that for eating disorder training to improve postgraduate training is also critical. We agree with witnesses who identified the need for greater cross-college working to ensure eating disorders are included in relevant curricula and support the Academy of Medical Royal Colleges' work in coordinating a discussion between relevant specialties and colleges on sharing resources. We note that participants in the informal seminar highlighted the importance of training for General Practitioners in this context. We recommend that the Academy should also coordinate the necessary actions arising from this work and report on how the learning from these discussions are implemented. (Paragraph 29)
- 4. There must be wider take up of the Management of Really Sick Patients with Anorexia Nervosa (MARSIPAN) guidelines. They are a vital tool to promote active communication and consultation between psychiatric services, including eating disorder and liaison psychiatry, and medical services and includes for quick reference an all-age checklist for use by clinicians. These guidelines are lifesaving for people who have anorexia nervosa. We recommend that Health Education England should work with NHS England to improve uptake of the MARSIPAN guidance by practitioners, particularly practitioners who are not specialists in eating disorders, and the Care Quality Commission should ensure that the MARSIPAN guidelines are being adopted at all levels in NHS England. (Paragraph 32)

The quality and availability of adult services, and the transition from child to adult services

- 5. We welcome the increased funding for mental health within the NHS long term plan but we recommend that NHS England set out how much of this funding will be specifically allocated to adult eating disorder services. but we recommend that NHS England set out how much of this funding will be specifically allocated to adult eating disorder services (Paragraph 45)
- 6. We support NHS England's plans to transfer investment from inpatient services to community care which has the potential to deliver greater value for money. Better community service provision is essential not only to help prevent people from becoming so ill that they need hospitalisation but also to support people who are discharged from hospital, to avoid relapsing and therefore requiring further hospitalisation. Although we accordingly welcome greater funding for community services, NHS England must also ensure that there is adequate inpatient capacity. (Paragraph 46)
- 7. In our informal seminar with people who had lived experience of eating disorders, we were told there was potential for more involvement of family or carer support in adult eating disorder services. Though we recognise this is a complicated matter, such support can be extremely important for people with eating disorders. (Paragraph 47)
- 8. We welcome the steps that have already been taken and that the NHS is piloting the introduction of a four-week waiting time target for adult and older adult community mental health teams, which has the potential to improve the provision of services for patients. We hope this will be transformed from a pilot to an appropriately funded business as usual target. (Paragraph 49)
- 9. Although there are a number of welcome ambitions to improve quality and availability of adult eating disorder services, it is clear that there has not yet been delivery of substantive improvements in that provision. Accordingly we find it disturbing that the Government claims that the PHSO's recommendation on achieving parity of adult eating disorder services with child and adolescent services has been implemented, when this it is clear that this is not the case. This work must be done and this should be championed by the PHSO Delivery Group. As part of its work under this PHSO recommendation, we recommend the NHS have particular regard to ensuring the needs of autistic patients are met. (Paragraph 50)
- 10. NHS England established an Adult Eating Disorder Expert Reference Group, chaired by Professor Tim Kendall and Jess Griffiths, an expert by experience, to help review the data and modelling for the NHS Long Term Plan. We Commend NHS England for establishing the Adult Eating Disorder Expert Reference Group to help review data and modelling for the NHS Long Term Plan but the Government must publish the Expert Reference Group's report as soon as possible. If the Group's report has not been published by the time the Government publishes its response to our report, the Government should provide a timeline for the publication of the Expert Reference's Group's report in that response. (Paragraph 53)

11. A lack of precise information on the prevalence of eating disorders is shocking, given the claims that up to 1.25m people are suffering from eating disorders and the fact that eating disorders have the highest mortality rate of mental illnesses. This vagueness limits the ability of NHS commissioners to gauge what services need to be provided and encourages them to devote resources to better recorded diseases and conditions. We welcome the inclusion of SCOFF (the eating disorder screening tool) in the 2019 Health Survey England to improve this information about the prevalence of eating disorders but recommend as a matter for urgent action that NHS England commissions a national population-based study to accurately assess the number of people who have eating disorders. It is essential such research does not simply look at the numbers of people who have been diagnosed with eating disorders, the evidence we have heard suggests that eating disorders are under-reported and are inherently secretive conditions. (Paragraph 57)

Coordination of services

12. We welcome the inclusion of coordination in the new NICE quality standard on eating disorders but further work is necessary to embed those standards. We recommend that the PHSO Delivery Group, as part of its work, commission an audit of the extent of implementation of the NICE guidelines. This could be completed over the next few months (before we report again on this topic - see paragraph 84 below). (Paragraph 62)

User training to address gaps in provision of eating disorder specialists

- 13. All junior doctors should complete a four-month psychiatry placement and we welcome the Minister's support for this proposal. Such placements should include exposure to eating disorders. We recommend Health Education England take this recommendation forward and assess whether it is possible to ensure each such placement includes exposure to patients with eating disorders. (Paragraph 68)
- 14. We welcome the efforts of Health Education England to develop competency within the wider workforce in relation to eating disorders. People with eating disorders can present in a variety of circumstances and through a number of different pathways, therefore improving the wider workforce's knowledge of eating disorders can significantly improve the early detection and provision of support for people with eating disorders. This work should specifically consider the provision of training to nurses and nurse practitioners. Health Education England should take steps to facilitate the delivery of such training by people who have lived experience of eating disorders. In circumstances where that is not viable, solutions such as online training should be pursued. (Paragraph 69)

Improving investigation and learning, in particular from serious incident investigations

15. Investigations into, and NHS learning from, serious incidents is essential to helping ensure that the circumstances leading to avoidable deaths do not reoccur. It is heartening to hear from the Care Quality Commission that some trusts are establishing more robust practices for investigating and learning from deaths but

such change must be made throughout the whole of the NHS. Cultural change is essential to achieve this. We believe the Care Quality Commission's inspections provide one way for the NHS to determine the progress it is making in culture change; namely the shift from a closed and defensive blame culture to one of openness, willingness to hear and tell the truth, and to learning from mistakes to avoid future harm to patients. It is essential that the NHS moves from a culture which falls into short-term reputation management to one which facilitates open learning and longer-term improvements to service provision. The NHS should further consider how it can assess the progress it is making in changing the culture surrounding investigations and learning. Such cultural change must be regarded as a high priority. (Paragraph 78)

16. We welcome the initial work of Healthcare Safety Investigation Branch (HSIB) in investigating the causes of clinical incidents without attributing blame and in order to disseminate learning for the future and the seven-point "framework for professionalising safety investigations in the NHS. We call on the Government to introduce the Health Service Safety Investigations Bill as soon as possible in order to provide HSIB with statutory powers and independence, and to enable it to provide a statutory 'safe space' for clinicians and patients and their families to speak freely, like other safety investigation bodies. (Paragraph 79)

Final conclusions and recommendations

- 17. Welcome steps are being made in response to the PHSO's report, but sufficient progress has not yet been made in response to the PHSO's report. We agree with Dr Kendall's assessment that the PHSO Delivery Group needs to continue to meet. It is essential that there is a delivery body that has responsibility for ensuring these recommendations are taken forward. We recommend that the PHSO Delivery Group not be disbanded until it can report with confidence that all the recommendations have been implemented. (Paragraph 81)
- 18. We are encouraged by the Minister's and the Department of Health and Social Care's interest in this subject. They can play a critical leadership role in providing impetus to ensure timely progress is made on the PHSO's recommendations. A number of steps have been set out in the evidence we have received but we do not think there is enough urgency. Such urgency must reflect the fact that lives will continue to be lost under the status quo. There must accordingly be a clear picture of what actions will be delivered under each recommendation, what funding will be assigned to delivering those actions and by what timeframe those actions will be complete. In its response to this report the Government should produce a timeline against each of the PHSO's recommendations; what steps have been taken, what further steps will be taken under each recommendation and what funding will be allocated. These actions should have clear responsible owners and deadlines for completion. (Paragraph 83)
- 19. Once proceedings in court are finished, we plan to consider the PHSO's investigation of Averil Hart's case in greater depth. At that time, we will return to the PHSO's wider recommendations to assess what progress has been made. (Paragraph 84)

Formal minutes

Tuesday 11 June 2019

Members Present

Sir Bernard Jenkin, in the Chair

Ronnie Cowan Dr Rupa Huq
Dame Cheryl Gillan Mr David Jones
Kelvin Hopkins Eleanor Smith

Draft Report (*Ignoring the Alarms follow-up: Too many avoidable deaths from eating disorders*), proposed by the Chair, brought up and read.

Ordered, That the draft Report be read a second time, paragraph by paragraph.

Paragraphs 1 to 84 read and agreed to.

Summary agreed to.

Resolved, That the Report be the Seventeenth Report of the Committee to the House.

Ordered, That the Chair make the Report to the House.

Ordered, That embargoed copies of the Report be made available, in accordance with the provisions of Standing Order 134.

[Adjourned till Tuesday 18 June 2019 at 09.30am

Witnesses

The following witnesses gave evidence. Transcripts can be viewed on the <u>inquiry publications</u> <u>page</u> of the Committee's website.

Tuesday 14 May 2019

| Andrew Radford, Chief Executive , BEAT Eating Disorders and Dr Dasha Nicholls , Chair, Faculty of Eating Disorders, Royal College of Psychiatrists | <u>Q1-44</u> |
|--|--------------|
| Professor Lisa Bayliss-Pratt , Chief Nurse, Health Education England and and Professor Colin Melville , Director of Education and Standards, General Medical Council | Q45-92 |
| Jackie Doyle-Price MP, Minister for Mental Health, DHSC and Professor Tim Kendall, National Clinical Director for Mental Health, NHS England and NHS Improvement | Q93–169 |

Published written evidence

The following written evidence was received and can be viewed on the $\frac{\text{inquiry publications}}{\text{page}}$ of the Committee's website.

IDF numbers are generated by the evidence processing system and so may not be complete.

- 1 A1 (IDF0013)
- 2 Autistica (IDF0001)
- 3 Beat (IDF0012)
- 4 Care Quality Commission (IDF0009)
- Department of Health and Social Care and National Institute for Care Excellence (IDF0017)
- 6 Eating Disorders Health Integration Team, Bristol. (IDF0008)
- 7 Family Mental Wealth (IDF0004)
- 8 General Medical Council (IDF0015)
- 9 Hart, Mr Nic (IDF0007)
- 10 Hart, Mr Nic (IDF0016)
- 11 HSIB (ID00018)
- 12 Parliamentary and Health Service Ombudsman (IDF0010)
- 13 Patient Experience Library (IDF0006)
- 14 Rethink Mental Illness (IDF0003)
- 15 Royal College of Psychiatrists (IDF0011)
- 16 Virgo, Miss Hope (IDF0005)
- 17 YoungMinds (IDF0014)

List of Reports from the Committee during the current Parliament

All publications from the Committee are available on the <u>publications page</u> of the Committee's website.

Session 2017-19

| First Report | Devolution and Exiting the EU and Clause 11 of the European Union (Withdrawal) Bill: Issues for Consideration | HC 484 |
|----------------------|---|----------------------|
| Second Report | Parliamentary Boundary Reviews: What Next? | HC 559 (HC 1072) |
| Third Report | PHSO Annual Scrutiny 2016–17 | HC 492 (HC 1479) |
| Fourth Report | Ensuring Proper Process for Key Government Decisions: Lessons Still to be Learned from the Chilcot Report | HC 854 (HC 1555) |
| Fifth Report | The Minister and the Official: The Fulcrum of Whitehall Effectiveness | HC 497 (HC 1977) |
| Sixth Report | Accounting for Democracy Revisited: The Government Response and Proposed Review | HC 1197 |
| Seventh Report | After Carillion: Public sector outsourcing and contracting | HC 748 (HC 1685) |
| Eighth Report | Devolution and Exiting the EU: reconciling differences and building strong relationships | HC 1485 (HC 1574) |
| Ninth Report | Appointment of Lord Bew as Chair of the House of Lords Appointments Commission | HC 1142 |
| Tenth Report | Pre-Appointment Hearings: Promoting Best Practice | HC 909 (HC 1773) |
| Eleventh Report | Appointment of Mr Harry Rich as Registrar of Consultant Lobbyists | HC 1249 |
| Twelfth Report | Appointment of Lord Evans of Weardale as Chair of the Committee on Standards in Public Life | HC 930 (HC 1773) |
| Thirteenth Report | A smaller House of Lords: The report of the Lord Speaker's committee on the size of the House | HC 662 (HC 2005) |
| Fourteenth Report | The Role of Parliament in the UK Constitution Interim Report The Status and Effect of Confidence Motions and the Fixed-term Parliaments Act 2011 | HC 1813 (HC 2065) |
| Fifteenth Report | Status of Resolutions of the House of Commons | HC 1587 (HC 2066) |
| Sixteenth Report | PHSO Annual Scrutiny 2017/18: Towards a Modern and Effective Ombudsman Service | HC 1855 |
| First Special Report | Will the NHS never learn? Follow-up to PHSO report 'Learning from Mistakes' on the NHS in England: Government Response to the Committee's Seventh Report of Session 2016–17 | HC 441 |

| Second Special Report | The Future of the Union, part two: Inter-institutional relations in the UK: Government Response to the Sixth Report from the Committee, Session 2016–17 | HC 442 |
|------------------------------|--|---------|
| Third Special Report | Lessons still to be learned from the Chilcot inquiry: Government Response to the Committee's Tenth Report of Session 2016–17 | HC 708 |
| Fourth Special Report | Government Response to the Committee's Thirteenth Report of Session 2016–7: Managing Ministers' and officials' conflicts of interest: time for clearer values, principles and action | HC 731 |
| Fifth Special Report | Parliamentary Boundary Reviews: What Next?: Government Response to the Committee's Second Report | HC 1072 |
| Sixth Special Report | PHSO Annual Scrutiny 2016–17: Government and PHSO Response to the Committee's Third Report | HC 1479 |
| Seventh Special Report | Ensuring Proper Process for Key Government Decisions: Lessons Still to be Learned from the Chilcot Report: Government Response to the Committee's Fourth Report | HC 1555 |
| Eighth Special Report | Government Response to the Committee's Eighth Report: Devolution and Exiting the EU: reconciling differences and building strong relationships | HC 1574 |
| Ninth Special Report | Government Response to the Committee's Seventh Report: After Carillion: Public sector outsourcing and contracting | HC 1685 |
| Tenth Special Report | Government Response to the Committee's Tenth Report: Pre-Appointment Hearings: Promoting Best Practice, and to the Committee's Twelfth Report: Appointment of Lord Evans of Weardale as Chair of the Committee on Standards in Public Life | HC 1773 |
| Eleventh Special Report | Government Response to the Committee's Fifth Report: The Minister and the Official: The Fulcrum of Whitehall Effectiveness | HC 1977 |
| Twelfth Special Report | Government Response to the Committee's Thirteenth report: A smaller House of Lords: The report of the Lord Speaker's committee on the size of the House | HC 2005 |
| Thirteenth Special Report | Government Response to the Committee's Fourteenth Report: The Role of Parliament in the UK Constitution Interim Report The Status and Effect of Confidence Motions and the Fixed-term Parliaments Act 2011 | HC 2065 |
| Fourteenth Special Report | Government Response to the Committee's Fifteenth Report: Status of Resolutions of the House of Commons | HC 2066 |