Parliamentary and Health Service Ombudsman

PHSO submission: PACAC's follow-up to PHSO report 'Ignoring the Alarms' Inquiry

1. Introduction

1.1 The PHSO published *Ignoring the alarms: How NHS eating disorder services* are failing patients in December 2017. The families who brought their complaints to us helped us uncover serious issues that require national attention. We welcome the opportunity to make this submission to the Committee's follow up Inquiry into our report.

1.2 Ignoring the alarms contained an in-depth focus on our investigation into the case of a young woman, Averil Hart, who suffered from anorexia nervosa and died on 15 December 2012, aged only 19, following a series of failures that involved every NHS organisation that should have cared for her. The report also includes additional casework examples that reflect similar failings to those experienced by Averil.

1.3 The failings catalogued in the report highlight a systemic set of problems in relation to identifying, treating and monitoring eating disorders that require a systemic response. This encompasses raising awareness among clinicians, building greater specialist capability and ensuring adult eating disorder services achieve parity with child and adolescent services.

1.4 This submission provides an overview of the report's systemic findings and the responses we have seen to the systemic recommendations we made to date. Beyond the brief summary provided below, it does not cover in detail the findings or recommendations we made in the individual case of Averil Hart, as her death remains the subject of a pending coronial investigation.

2. Key findings from our casework

2.1 We found that Averil Hart's tragic death from anorexia nervosa would have been avoided if the NHS had cared for her appropriately. All four NHS organisations involved in Averil's care and treatment failed her in some way and all missed opportunities to prevent the deterioration which ultimately led to her death.

2.2 The key contributory factors we identified included a general lack of awareness about eating disorders among clinicians, a lack of eating disorder

specialists, poor transition between child and adolescent to adult services and poor co-ordination between different services.

2.3 Averil's family also had to fight to get answers from organisations that had failed to work together to establish what had happened and provide a co-ordinated response to the family. The organisations were defensive and protective of themselves, rather than taking responsibility.

2.4 As the report notes, we all too often see the burden of getting a response from different bodies involved across a care pathway falling to patients and families. The Committee will also be aware that the need to improve the quality of patient safety investigations has been the subject of several previous PHSO reports[1] and PACAC/PASC inquiries[2].

2.5 As reflected in the other casework examples in the report, the failures in Averil's care and treatment were not unique. In one case we investigated, Miss E, a severely ill woman with suicidal thoughts was inappropriately discharged from hospital. Her care plan was inadequate and did not meet her care needs. As a result, nobody spotted the signs of deterioration in time and she died from a heart attack, triggered by starvation.

2.6 Miss B, another seriously ill woman, with a history of vomiting and binge eating was referred to an Eating Disorder Service that was dangerously short-staffed. Again, there was no care plan in place and therapy sessions were inconsistent and unhelpful. Sadly, her condition deteriorated and she died of heart failure after taking an overdose, leaving a young child behind.

2.7 Our conversations with system leaders and experts reinforced the findings in our casework. In the words of one eating disorder specialist we spoke to: "it is a miracle we don't have more tragedies". To address the issues these cases highlighted we therefore made a series of systemic recommendations to improve Eating Disorder Services.

2.8 We also made a wider recommendation to improve the co-ordination and oversight of investigations in to serious incidents and complaints related to them.

2.9 Following the publication of *Ignoring the alarms*, we have not completed any investigations into complaints about eating disorder services with such tragic outcomes. While we cannot discuss open cases due to our requirement to investigate in private, we will continue to monitor our casework in this important area and provide individual remedies for any injustice suffered. However, it is important that the more systemic approach we outlined in *Ignoring the alarms*

[1] PHSO, Review into the quality of NHS complaints investigations where serious or avoidable harm has been alleged (2015); PHSO, Learning from mistakes- An investigation report into how the NHS failed to properly investigate the death of a three-year old child (2016).

[2] PASC, Investigating clinical incidents in the NHS, Sixth Report of Session, 2014-15; PACAC, PHSO Review: Quality of NHS Complaint Investigations, First Report of Session 2016-17; PACAC, Will the NHS never learn? Follow-up to PHSO report 'Learning from Mistakes' on the NHS in England, Seventh Report of Session 2016-17.

delivers the real change in the national approach to treating eating disorders that is needed.

3. Recommendations

We set out below the response we have had to the recommendations in *Ignoring the alarms* to date.

3.1 Awareness

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

Rationale: According to the latest estimates from eating disorder charity BEAT, eating disorders affect approximately 1.25 million people in the UK[3]. Yet training for most doctors on this complex and serious mental illness is limited to just a few hours amongst many years of training. Our experience of investigating the casework we highlighted in our report shows this is not enough. 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.

Response: The GMC told us that responsibility for curricula content lies with medical schools (undergraduate) and the Royal Colleges (post graduate foundation training and specialisms). The GMC's regulatory role in this area is to approve curricula to ensure they meet the requirements set out in their broad outcome and professional capabilities frameworks. These include the following:

- Generic professional capabilities (GPC) framework – the professional knowledge and skills all doctors need to demonstrate, applied to all medical specialties.
- Outcomes for graduates which incorporates the GPC.
- Excellence by design – standards for the development of postgraduate curricula.

The GMC told us these overarching frameworks are intentionally generic and therefore do not necessarily specify knowledge of specific conditions such as eating disorders. They highlighted some aspects of the Outcomes for Graduates framework that are relevant to the issues raised in our report. These include sections on safeguarding vulnerable patients, leadership and team working, as well as applying psychological principles.

The GMC also pointed to the post graduate Foundation programme curriculum, developed by the Academy of Medical Royal Colleges, which requires all Foundation year 2 doctors to "*recognise eating disorders, seek senior input and refer to local specialist service*". The GMC also provided us with examples from

[3] https://www.beateatingdisorders.org.uk/how-many-people-eating-disorder-uk

post graduate speciality curricula in psychiatry and paediatrics which make explicit reference to identifying and treating eating disorders.

The GMC also acknowledged, however, that with no single organisation holding overarching authority the landscape of medical training is complex. They said that our report had helped bring in to sharp focus some of the issues around medical education and training on eating disorders. In particular, it is challenging to get a clear picture of the extent of training in undergraduate curricula and ultimate decisions on course content at this level rest with the medical schools.

To explore these issues in more detail the GMC convened a round table in March 2019, chaired by Baroness Parminter and attended by a range of Parliamentarians, health education organisations and regulators, medical schools, membership bodies and charities. Following the roundtable, the GMC have committed to writing to medical schools across the UK seeking information about: 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 are also asking 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 will also coordinate a discussion between relevant specialities and colleges on sharing resources and best practice.

We welcome the work the GMC have done to date to bring together the various organisations involved across the complex landscape of medical education and training. However, from the information we have seen, the medical and education training sector have yet to articulate a shared view on whether eating disorders are sufficiently covered in their course offerings and curricula.

It will be particularly important to see what assessment is made following the GMC's call for information from medical schools and Royal Colleges. The most comprehensive research on this topic to date found that the average teaching and assessment time on eating disorders in undergraduate courses amounts to just 1.8 hours, and one in five medical schools do not offer any training on eating disorders at all[4]. The authors of this research concluded that "given the risk of mortality and multimorbidity associated with these disorders, this needs to be urgently reviewed to improve patient safety".

As part of its inquiry, the Committee may wish to explore what assessment the GMC makes of the sufficiency of education and training on eating disorders and

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

what plans it has to work with others to address any gaps to ensure all doctors are equipped with the right knowledge and skills.

3.2 Transition

Recommendation: *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. In addition to CQUIN indicators [5]and new NICE guidance on eating disorders, NHS England and the Department of Health should consider the possibility of developing benchmarking guidance for adult eating disorder services and appropriate measures of success for this. Any guidance should take account of any funding earmarked within the Five Year Forward View for Mental Health for adult eating disorder services and the availability of resources locally so that standards are achievable.*

Rationale: Moving between services is a particularly challenging time for people with eating disorders. These transitions between services in different geographical locations, or from child and adolescent eating disorder services to adult ones are recognised as high-risk, with students moving to university being identified as particularly vulnerable. Child and adolescent eating disorder services have received specific focus in recent years, including increased funding and guidance. However, for good quality transitions to be the norm there needs to be dual focus on the quality and availability of adult eating disorder services, particularly given how frequently these conditions continue into adulthood.

Response: In a recent edition of Radio Ombudsman, our regular podcast, Claire Murdoch, NHS England's National Mental Health Director, told the Ombudsman that *Ignoring the Alarms* was "*a really searing, independent insight to things we must fix, things we must address, and things we must do better*" (see Annex A). In the discussion she also highlighted that the NHS England Board scrutinised the report carefully and asked her to develop a clear action plan to respond to the recommendations that would also involve the other bodies named in the report. This led to the establishment of a working group with NHS Improvement, Health Education England, the Department of Health and Social Care and other bodies identified in the report to co-ordinate the actions being taken in response to the recommendations. The working group was chaired by Professor Tim Kendall, National Clinical Director for Mental Health and aimed to inform the Long Term Plan for NHS England.

NHS England also commissioned a benchmarking study to collect data on the current levels of provision across community and inpatient services for adults with an eating disorder. This work reported to NHS England in 2018 and a modelling exercise has taken place to establish a baseline, help understand the issues with

[5] Commissioning for Quality and Innovation Framework., https://www.england.nhs.uk/nhs-standard-contract/cquin/cquin-17-19/

geographical variation, and the cost and workforce required to achieve parity with children and young people's eating disorder services.

Furthermore, in July 2018, NHS England established an Adult Eating Disorder Expert Reference Group, chaired by Professor Tim Kendall and Jess Griffiths, Expert by Experience, to help review the data and modelling for the NHS Long Term Plan. The group includes representation from experts by experience, parents/carers, clinicians, academics, charity leaders, service and provider leads and commissioners.

NHS England then commissioned the National Collaborating Centre for Mental Health (NCCMH) at the Royal College of Psychiatrists to work with the Adult Eating Disorder ERG to:

- develop guidance and helpful resources on effective models and costs of delivery;
- the staffing skill-mix required;
- quality measures and data metrics to demonstrate outcomes and test potential waiting time standards that will address inequity and create parity with CYP ED.

The work and outputs developed by the PHSO Delivery Group and the Adult Eating Disorder Expert Reference Group will inform a revision of service standards used to assess quality of care by CQC and the Eating Disorder Quality Network run by the Royal College of Psychiatrists.

Published on 7 January 2019, the NHS Long Term Plan sets out NHS England's vision and priorities for the next decade. With respect to eating disorder services, the Plan states that the waiting time standards for children and young people "*are being achieved or are on track for delivery in 2020/21*". The Plan goes on to state that:

> *"Alongside work to explore the effectiveness of different approaches to integrated delivery with primary care, we will test four-week waiting times for adult and older adult community mental health teams, with selected local areas. This will help build our understanding of how best to introduce ambitious but achievable improvements in access, quality of care and outcomes. We will then set clear standards for patients requiring access to community mental health treatment and roll them out across the NHS over the next decade"*

NHS England have subsequently told us that as part of the above commitment, in 2019-20 they will start to fund new models of services for adults with eating disorders across the country. These will aim to maximise access and minimise waits, and to generate learning about how to achieve greater levels of parity with Children and Young Peoples' eating disorder services over the course of the Long Term Plan.

To support the ambitions within the Long Term Plan the NHS has made a renewed

commitment that mental health services will grow faster than the overall NHS budget, creating a new ringfenced local investment fund worth at least £2.3 billion a year by 2023/24. The recently-published 'Guidance for operational and activity plans: assurance statements' to accompany the NHS Planning Guidance for 2019/20 makes clear that these services include services for adults with eating disorders.

We welcome the leadership NHS England has shown to date on responding to the recommendations in *Ignoring the alarms*. We hope this will set the groundwork for achieving tangible improvements in the quality and availability of adult eating disorder services. As part of its inquiry, the Committee may wish to explore in more detail how both the eating disorders working group and bench marking study will inform the development and refinement of the commitments in the NHS Long Term Plan, how improvements in access and quality will be funded and how progress will be measured over time.

3.3 Coordination

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

Rationale: Poor co-ordination was a common issue in all of the cases in the report. 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.

Response: At the time the report was published, NICE were consulting on a draft Quality Standard for Eating Disorders. In response to the recommendation, NICE revised the draft to give greater emphasis on co-ordinated care across services.

The final version of the Eating Disorders Quality Standard was published in September 2018 and contains a specific Quality statement on co-ordination of care across services, including measures for assessing quality in this area.

We are particularly pleased that NICE responded so directly to our recommendation and that they were able to translate it into clear guidance and measurable outcomes for frontline services.

To support implementation of the quality standard NICE is working with the following national partners:

- 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.
- Health Education England (HEE): NICE is supporting HEE to deliver our recommendation (see 4. below) to review current training education and training to identify any gaps to ensure the findings align with NICE guidance and quality standards.

- Beat Eating Disorders, the Royal College of General Practitioners, and the 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.

3.4 Access to specialists

Recommendation: *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.*

Rationale: Another challenge in achieving good coordination of care for people with eating disorders is the scarcity of specialists. This often means 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. In Averil's case, this meant that the only person available to act as her care coordinator was someone with no experience of looking after people with anorexia nervosa. In Miss B's case, the Eating Disorder Service had not been properly commissioned, meaning that staffing levels were too low and clinical supervision and multidisciplinary input was not available.

Response: HEE's National Mental Health Programme has undertaken a project to scope eating disorder training nationally, mapping what currently exists in order to understand existing training and professional presence/skills across the Eating Disorders pathway. The project has found that the pathway varies greatly across the country and has therefore conducted a mapping exercise to understand the patient journey, the professionals involved and the training in place. This will also include scoping of education and training on eating disorders for those working in healthcare settings outside of mental health where people with an eating disorder are likely to initially present.

This project commenced in January 2019 and is due to conclude and report findings in June. This report will inform future decisions and commissioning of training in the field of eating disorders.

HEE have told us they are also working closely with NHS England to better understand the current provision of eating disorder services and how these are currently staffed. This links in with work which HEE are already undertaking around developing new roles and on how existing staff can expand their current skill-set to better meet future patient need.

As part of its inquiry, the Committee may wish to explore the range of action HEE are considering to address any gaps that emerge from the scoping work they are currently undertaking, and how they might work with others in the field of education and training, such the GMC and Royal Colleges, to achieve this.

3.5 Investigations and Learning

Recommendation: *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.*

Rationale: We noted that in the cases we investigate we too often see organisations failing to work together to understand what has happened and why, and to learn and improve. The burden of establishing what has happened all too often falls to patients and their families. Commissioners are key to ensuring that effective co-ordination take place when care spans multiple organisations but system leaders also have a crucial role to play in proving the necessary oversight so that these complex investigations can be carried out successfully.

Response: At the time *Ignoring the alarms* was published NHS Improvement led on patient safety, although this function has previously sat within NHS England. During 2018, NHS Improvement conducted an engagement programme to inform revision of the Serious Incident Framework (SIF). Following our report, this included a specific focus on supporting cross system investigation. The engagement also explored other issues limiting good quality incident management including: oversight and assurance, supporting staff, patients and families, ensuring appropriate time and expertise and the core principles for patient safety investigations.

NHS Improvement told us that that the feedback they received highlighted the need for a fundamentally different approach to the management of serious incidents. While this is still being finalised, this is likely to support the development of broader systems, processes, skills and behaviours that enable an appropriate response to patient safety incidents (not just 'Serious Incidents'). This will encourage the use of a range of tools including but not limited to systems-based patient safety investigation as part of a system focused on learning and improvement.

NHS Improvement informed us that the new framework is likely to include clearer roles for the newly aligned NHS England and NHS Improvement regional teams to support co-ordination of cross-setting investigation at a local level were required. The new framework is also expected to clarify the approach to both independent and/or regionally co-ordinated investigation by:

- Describing roles and responsibilities within commissioning systems (or Sustainability Transformation Plans/Integrated Care Systems where these have developed) to support coordination of cross setting investigation at a local level.
- Establishing a more inclusive set of criteria for regionally commissioned investigations to support investigation of complex cross-system incidents where required.
- Endorsing the development and expansion of the expertise and role of the regional Independent Investigation Review Groups over time to support investigation of wider, cross system issues– these are currently focussed primarily on mental health homicide investigations.

While we await the publication of the revised framework, we welcome the direction of travel that NHS Improvement shared with us. Beyond the specific recommendations in *Ignoring the Alarms*, we have previously called for common standards for investigations and greater support for, and involvement of, those affected. We are therefore also encouraged to hear that the revised framework will be accompanied by national investigation standards and templates, and set out clearer expectations on support and involvement of those affected - including patients, families, carers and staff.

In addition to clear roles and responsibilities for system leaders and investigation standards, a key challenge is to enhance the capability and capacity of frontline services to identify, investigate and learn from mistakes. In relation to this, we note that NHS Improvement have recently consulted on a new patient safety strategy. This included several important proposals that have the potential to improve the infrastructure of patient safety, including: a new patient safety curriculum; a network of senior patient safety specialists; new patient advocates for safety; and a dedicated patient safety support team to support organisations that are struggling in this area.

Going forward, it is vital these ambitious proposals are matched with clear funding and timescales for implementation and we anticipate that the Committee will want to look at these issues in particular as part of its inquiry.

April 2018

Annex A: Radio Ombudsman Transcript

Excerpt of transcript of a conversation between Ombudsman Rob Behrens and Claire Murdoch on Radio Ombudsman , 16 November 2019

Rob Behrens: You've eloquently catalogued the transition and the revolution that's taken place, but we shouldn't underestimate the real challenges that are still there. While paying tribute to those who give their public service to working in mental health, we know that there is structural underfunding of mental health in comparison to other health provision.

As a relatively new ombudsman, I have been hugely impressed in the visits that I've made to mental health provision.

Two of our insight reports were fairly critical of current provision, while appreciating the public service that goes into it.

The 2017 report we did into anorexia provision demonstrated a lack of willingness to learn from mistakes that are made in the provision, particularly to young people, the lack of training that is given, and the weaknesses in some of the curricula that are provided to those dealing with anorexia. NHS England has agreed to look at this and set up a taskforce. Is there anything you can tell us about how that's going?

Claire Murdoch: Yes. Look, first of all, I do just want to say that we've come a long way in 35 years. I say to anyone and everyone who will listen to me, and every staff induction at the Trust I make the same point: "We've got at least as far again to go but we haven't got the luxury of 35 years." We need now to move much faster to make the sorts of improvements that your insight reports have rightly pointed to.

I think the first thing to say is that, particularly with the anorexia report that you're talking about here, I've been impressed with a) the report. I thought it was fair. It's painful reading. These are the sorts of things that I, and probably other professionals who care passionately, feel hurt by – but not hurt in a wounded way, hurt because we probably recognise it as a really searing, independent insight to things we must fix, things we must address, things we must do better.

I've also been impressed because the NHS England board, I know, scrutinised that report really carefully, required of myself and my colleagues a very clear action plan about what we would do – not only NHS England but with NHSI. You mentioned training and education: HEE, Health Education England; NICE, the National Institute for Clinical Excellence, and also the Department of Health.

I've seen the mobilisation of your report and your findings of those bodies, those arms-length bodies, all of whom have a role to play in making the improvements you rightly pointed to.

We asked Professor Tim Kendall, our Clinical Advisor, to chair that working group. We've been busily working this last year or so with that working group, who also

have people with lived experience on it. So, I think it's really important that the family and patient or service-user voice that you bring to life so eloquently in your reports, and so vividly, also informs our taskforce. The sorts of work-

The sorts of work that we've been doing have been, firstly, we've been rolling out, as you may know, as part of the 'Five Year Forward View', 72 new community-facing eating disorder services for children and young people.

The last 18 months has seen very significant investment in community-facing eating disorder services.
They're achieving two things at the moment. One is access and treatment of youngsters with an eating disorder. We've seen some of the first ever access and waiting-time standards for eating disorders, or mental health as a whole, so one-week referral to treatment for urgent referrals, and four-week for routine referrals.

Our goal is to, by 2021, have 95% of all referrals meeting those two standards. At the moment, our routine referrals, 81% of them are being seen within four weeks within those new services, and something like 72% are being seen within a week. So I would say we're well on track to hit those rather exacting but important standards by 2021. These new teams really are seeing more people differently and intervening earlier.

I spoke to two families not long ago at the launch of one of these new community services. One of the families had a daughter who had, if you like, missed: had become an adult and had missed the existence of such services. They described her care and treatment, and it had so many echoes of what your report found.
I then spoke to a current father and his daughter, talking about their current experience with the new service.

What they pointed to, actually, was a school who'd become concerned about this young woman – child – a family that hadn't realised that their daughter had eating disorder issues. They went to the GP together because school contacted family. The GP said, "There's this team. I'm referring you." They were seen within a week.

That team have worked with school, the family, the acute hospital, because BMI was lower than anyone had realised. Really, what the father talked about was how rapid the intervention and intense it was, and how his daughter was back at school. The first family, the daughter missed years of schooling, was in and out of hospital. I don't say yet that we're there everywhere, but by 2021 we'll have made those improvements.

The second role of those specialist teams is to do some more of the work that you've pointed to in your report. So it's to work with the wider system on training and education, on early identification, ongoing into the GP practice or the acute hospital and giving talks and lectures, disseminating information, being available to help the wider system.

Other things we've done, in addition to setting up those services, is we've commissioned a piece of work which has been ongoing over these last several months with the NHS Benchmarking Club. We've asked them to look at adult

services for eating disorder, the activity, the funding, and the outcomes, and to report on the state of play currently.

We've also had, through this taskforce, input from people with lived experience and others, really helping us understand the scale and extent of existing problems. We hope to take the findings from that work, which was ongoing from about April until July of this year, into our long-term plan. Obviously, yesterday the Chancellor made a big announcement about mental health funding, but we will be using that to inform our proposals around what next.

In a way, I make no apology, in a world of finite funds, for commencing with child and adolescent eating disorders, because we can change, we hope, the trajectory for those youngsters and their families for good. But it really is high time now that we take the learning from the last year and your report, and take it into our long-term plan. We're hoping, of course, to make some further announcements about the long-term plan and which services we're developing next, within the next four to six weeks.

Also, the only other thing I'd add is that NICE have, in September, so the National Institute for Clinical Excellence, as part of the work over the last year, were asked to look at your report and your recommendations, look at best evidence base, and reissue the eating disorder guidelines to the system, which they did in September.

Rob Behrens: Yes, good.

Claire Murdoch: So, quite a lot of work has been mobilised by your report.