

## Written evidence A1 (PHO06)

### Public Administration and Constitutional Affairs Committee Parliamentary and Health Service Ombudsman Scrutiny 2020-21 inquiry

#### Context

This is our fourth PACAC submission regarding PHSO handling of a (2016) NHS related complaint.

#### Chronology

- August 2016 – PHSO complaint submitted regarding one (driving force) NHS Trust
- October 2016 - PHSO declined to investigate and instructed us to submit complaints to two other NHS Trusts who were implicated in the original complaint
- April 2017 – Further PHSO complaint submitted (implicating all 3 NHS Trusts as instructed)
- April 2017 – January 2019 - PHSO assessment and investigation:
  - Poor PHSO communication e.g. Just x2 short telephone conversations in 18 months
  - Deeply offensive, factually inaccurate and authority biased PHSO report produced
- January 2019 - DPA SAR submitted to PHSO
  - March 2019 – Information released by PHSO (one month later than usual expectation)
- May 2019 – Complainant Review Request submitted (PHSO agreed to extend deadline)
- February 2020 – Complainant approached the Patients Association due to lack of PHSO progress
- March 2020 – PHSO Review completed
- April 2020 – Mr Behrens refused to quash the flawed 2019 PHSO report
- April 2020 – Mr Behrens’ proposal for a new investigation was reluctantly agreed to
- May 2021 – The ‘new’ PHSO investigation began – email contact only (no telephone contact)
- September 2021 – Two emails sent to Mr Behrens to request the PHSO end the investigation
- October 2021 – Complainant still awaiting PHSO decision.

#### Summary of Concerns

Eating Disorder treatment will never be effective whilst cooccurring conditions such as autism and food allergies, are not accommodated. As someone with a relevant professional background I was horrified to discover the extent of authority bias the PHSO demonstrated in favour of the NHS during its 2017-2019 investigation; and the true degree to which our family were victimised by NHS staff in connection with the concerns we had dared to raise during our daughters eating disorder treatment.

**1. The 2019 PHSO report unfairly criticised us as a family but found no fault with NHS staff who had:**

- a) Offered no specialist eating disorder therapeutic support in 10 weeks community treatment
- b) Made unlawful 'best interest' decisions for our daughter, an adult with capacity, who was not subject to any treatment under the Mental Health Act (MHA) or through any guardianship order
- c) Ignored the professional opinions of two NHS doctors: an A&E doctor who examined our daughter and saw no reason to admit her to a medical ward, and a Consultant Cardiologist who confirmed to her GP that an ECG result at his surgery was not a cause for concern
- d) Surreptitiously arranged her admission to an acute ward (just 10 weeks after a questionable eating disorder diagnosis) by means of unethical pharmacological manipulation and psychological coercive control, unfair trickery, physical entrapment on a locked ward, and by using the visual threat of MHA detainment to raise her anxiety and put her under pressure to 'consent' to immediate inpatient treatment they knew she did not want (or arguably, even need)
- e) Put an unlawful plan in place to detain her under s5 MHA if she did not agree to immediate admission at the outpatient appointment on a locked ward even though there was no clinical evidence that the Trusts care pathway criteria for inpatient treatment (BMI <13 or medically unstable) was met, and this plan would involve two hospital transitions for an autistic person
- f) Put her under unnegotiable and medically unnecessary 1:1, 24/7 agency RMN observation for 12 days following her unexpected admission to a gastroenterology ward for daily ECG's though she has no history of self-harm or violence
- g) Failed to adhere to the documented admission plan for daily ECGs (the alleged reason for the admission under a gastroenterologist) despite her subsequent (unprecedented) inpatient treatment weight loss (1.6kg) which caused medical instability for the first time and put her at high risk (as documented in their own records) of sudden heart seizure or death
- h) Failed to accommodate her lifelong (NHS Consultant Immunologist diagnosed) food allergies (at either hospital) causing us worry, inconvenience, and expense through having to have to purchase and provide all the allergen free food items she required throughout her 15-week inpatient treatment (until she felt safe enough to self-discharge herself without being sectioned)
- i) Denied our daughter, an informal patient, the right to family life by refusing to give her permission to spend over 4 days on a UK family holiday with us even though she was medically stable and her BMI>18
- j) Created false paper trails to imply our daughter was at medical risk, that she was consuming known allergens without ill effect, that we were being unreasonable as a family, and to try to deflect responsibility for unethical and medically unnecessary decisions onto other professionals.
- k) Penalised her (refused to allow her to join the once a day group walk in the grounds of the hospital, expelled her from the jam making group, and by moving her from the 'self serve' table to a higher observation table) because she had refused to eat halloumi cheese (a known allergen that RMNs told her she must eat because it was not dairy produce even though it was not on her menu plan) in a burger at an external BBQ; and (to avoid

confrontation with staff) she had removed and tried to hide the cheese (before being seen and reported by another patient).

## 2. PHSO Failure to Apply Relevant Standards – Evidence of PHSO Conscious Bias in investigation

It was particularly noteworthy that the PHSO and Clinical Advisor failed to apply the clinical and professional standards in place in 2016. The failure to do so strategically concealed the existence of the widespread NHS fault that has caused our family to suffer so much ongoing distress and injustice

For example, none of the following clinical standards were applied:

- a) The **NHS Constitution** explicitly emphasises the right of individuals to be involved in treatment plans and decisions and the right of individuals to refuse recommended NHS treatment:

*You have the right to be involved in planning and making decisions about your health and care with your care provider or providers...*

*You have the right to accept or refuse treatment that is offered to you, and not to be given any physical examination or treatment unless you have given valid consent...*

[The NHS Constitution for England - GOV.UK \(www.gov.uk\)](http://www.gov.uk)

- b) **The Mental Health Act (MHA) Code of Practice** emphasises that the use of coercion invalidates consent, that acquiescence is not consent, that the views of families/carers are important, and that where possible autistic people should be treated in community settings:

*14.17 The threat of detention must not be used to coerce a patient to consent to admission to hospital or to treatment (and is likely to invalidate any apparent consent).*

*20.20 Compulsory treatment in a hospital setting is rarely likely to be helpful for a person with autism*

*20.36 Consideration should be given to whether there are alternative means of providing the care and treatment which the patient requires before it is decided that admission to hospital is necessary. Alternatives to detention under the Act should always be considered (see paragraphs 14.11 – 14.13).*

*20.39 All those involved in examining, assessing, treating or taking other decisions in relation to people with learning disabilities or autism should bear particular risks in mind in relation to people with learning disabilities or autism including:*

- incorrect assumptions that they do not have capacity to make decisions for themselves and a tendency to be over-protective. city to make decisions for themselves and a tendency to be over-protective. The MCA makes clear that a person must be assumed to have capacity unless it is established that they do not*
- incorrect assumptions that a tendency to acquiesce is the same as informed consent*

• *failing to consult or fully listen to carers who, as ‘experts by experience’, can play an important role in providing relevant information about the person’s past, or about effective communication methods*

[Mental Health Act 1983 \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/270202/mental-health-act-1983.pdf)

c) **Statutory Guidance on the Adult Autism Strategy** reiterated:

***7.2. People with autism should be assessed, treated and cared for in the community wherever possible,***

[Statutory guidance for Local Authorities and NHS organisations to support implementation of the Adult Autism Strategy \(publishing.service.gov.uk\)](https://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/270202/mental-health-act-1983.pdf)

d) **NICE Eating Disorder Guidance** in place in 2016 (NG9) confirms our expectation for more than 10 weeks community-based eating disorder treatment was entirely legitimate, and the pharmacologic circumstances behind our daughter’s admission to an acute ward were highly questionable:

***1.2.2.4 Most people with anorexia nervosa should be managed on an outpatient basis, with psychological treatment (with physical monitoring) provided by a healthcare professional competent to give it and to assess the physical risk of people with eating disorders.***

***1.2.2.5 Outpatient psychological treatment for anorexia nervosa should normally be of at least 6 months’ duration***

***1.2.3.4 Healthcare professionals should be aware of the risk of drugs that prolong the QTc interval on the ECG;***

<https://www.oxfordhealth.nhs.uk/cotswoldhouse/wp-content/uploads/sites/7/2013/04/NICE-Guidelines-for-Eating-Disorders.pdf>

e) If the PHSO had followed due process and applied either the Trusts own **Care Pathway criteria for inpatient eating disorder treatment** (BMI<13 or medically unstable) or the national clinical standard of the Royal College of Psychiatrists (**MARSIPAN Risk Assessment Checklist** [MARSIPAN-.pdf \(stgeorges.nhs.uk\)](https://www.stgeorges.nhs.uk/marsipan/)) this would have revealed that as our daughter was medically stable and weight maintained for 9 weeks she was not at high risk: She did not meet the criteria for admission. There was no reason she could not have been supported within the community if the local eating disorder team had been willing to produce a care plan (they never did) and to provide specialist therapeutic support in line with the NICE guidance (NG9) in place at the time.

f) Despite our daughters significant and lifelong clinical history, NICE Guidance on the Management of food allergy in children and young people aged under 19 [Food allergy in children and young people \(nice.org.uk\)](https://www.nice.org.uk/guidance/TA69) was also completely ignored as was long established food allergy advice from WHO

*“The only way for allergic individuals to manage food allergies is to avoid eating the food that causes the allergy”.*

[International Food Safety Authorities Network \(INFOSAN\) \(who.int\)](https://www.who.int/infodis/news/2013/04/20130401-allergy)

It is clear from NHS records that the eating disorder staff we encountered, and the Clinical Advisors the PHSO engaged, were prejudiced against people who have food allergies and that, if inpatient eating disorder treatment had ever been necessary, given our daughters lifelong clinical history, a more appropriate referral should have been made i.e. to a NHS hospital that was willing to accommodate individual dietary requirements:

*“If you have any special dietary requirements, for example, dairy free, gluten free, vegan or specific cultural or religious needs these can all be arranged.”* [Cicz7bSbZp \(dpt.nhs.uk\)](https://dpt.nhs.uk)

### 3. Current Concerns

A year after Mr Behrens directed a new Investigation (April 2020) the new investigation began (May 2021). By September we had lost what little confidence we had as, following information we submitted in response to a PHSO request (July 2021) for examples of inaccuracies in NHS records the email response we received from the Caseworker was as follows:

*“I’m not intending to go through multiple emails and letters to challenge the accuracy of things that have been said”.*

*PHSO Senior Complaint Investigator email  
dated 1.9.2021*

It is impossible to have confidence in an administrative justice system that requests specific examples of information and then makes it clear that these will be ignored.

There is already evidence of predetermination in the ‘new’ PHSO investigation: Far from being a new and impartial investigation as we had been led to believe, it is quite obviously a rehash of the previous one. We have been clearly told that previous NHS submissions will be relied upon and that (unspecified) clinical advice obtained during the previous investigation is also being used. No explanation has been offered regarding this and we have not been provided with any copies of these records (NB we did not receive all the clinical advice previously obtained – even through the subsequent DPA SAR we submitted).

The PHSO recently told us our expectations need to be managed. This is a deflection argument. Our expectations are legitimate as they are governed by existing rules, policies, and legislative frameworks. They therefore do not need to be ‘managed’. The PHSO is the decision maker but has consistently failed to explain why relevant clinical and professional standards were not applied during the first investigation and seemingly will not be applied again. This failure to apply standards demonstrates the continuance of conscious authority bias by PHSO Officials.

We have no confidence in the ability of the PHSO to act fairly, to scrutinise NHS submissions, or to challenge NHS staff or Clinical Advisors.

On 5.9.2021 and 19.9.2021 as Mr Behrens directed a new investigation 18 months previously, we emailed him to request the investigation cease immediately.

He did not reply.

## **Personal Impact Statement**

Our adult daughter suffered an unfair de facto detainment for which the NHS was responsible. The admission to an acute ward was punitive and we believe it was retaliation following the complaint we submitted. She had done nothing wrong: Quite the contrary she had proactively sought help when she realised she was developing an eating disorder.

Inpatient treatment was unhelpful. It caused her more harm (psychological and physical) than good. She was denied the right to a family life, her views were ignored, and she was accused of lying. She was so anxious about being observed using the wc that she ate/drank less and she became very unwell. She spent five weeks in hospital before she regained the weight she lost on the acute ward. There was no benefit to acute treatment: she was under constant observation, there was no menu plan in place, she was prescribed food supplements she could not have, and she ended up being nasogastric tube fed. This was hugely distressing not just for her (and us as parents) but for her three younger sisters (two of whom were doing their GCSE's).

The PHSO should have said at the outset that its caseworkers do not have the necessary emotional intelligence or professional skillset to investigate NHS related complaints: we would have understood this. But they didn't and instead we have been stuck in the PHSO quagmire for over five years and they are still dragging things out. Five years represents over a fifth of our daughter's life.

The level of NHS lies, bullying, disability discrimination, coercive control, and malpractice we encountered is truly shocking and we never thought for a minute that the PHSO would collude with it. We expected the caseworker to quickly secure the reasonable outcomes we sought (apology and service improvements) but he dragged his feet, he ignored our correspondence, and he strategically concealed NHS fault by not applying the correct clinical standards. For example, he applied 20117 NICE Eating Disorder standards to events that happened in 2016.

Far from experiencing administrative justice, what we experienced was PHSO authority bias and character assassination. To have discovered, through a DPA SAR to the PHSO nearly three years later, that we were reported to the Local Authority Safeguarding Team is totally humiliating, particularly given my professional background. As no s42 Care Act Adult Safeguarding Enquiry ever took place, one must wonder what the true purpose of processing this sensitive personal data to the PHSO really was given the fact that (as we did not know about the secret accusations) they did not form any part of our complaint to the PHSO (and it still doesn't as we have no desire to have any further contact with any of these Trusts again).

We believe Mr Behrens' decision not to quash the flawed 2019 report is misguided and cruel: we worry every day that the continued existence of the January 2019 report will have fatal consequences if our daughter were admitted under the MHA because the PHSO report would be used to justify force feeding her allergens and to legally displace us as her Nearest relative because the PHSO inaccurately stated her dietary needs would have been accommodated if they had been medically necessary, and the PHSO completely slated us as a family. We can never forgive the PHSO.

## **Conclusion**

The PHSO does not represent value for money: It takes far too long to deal with simple complaints.

Nor is it an effective means of administrative justice for those of us with no wish to take legal action.

*October 2021*