

Engagement Report: *Adult Eating Disorder* *Inpatient Service Specification*

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1. Summary:

This report summarises the engagement that the national Specialised Commissioning Mental Health Team, NHS England has undertaken on the refreshed Adult Eating Disorder Inpatient service specification. It details the actions taken and how the feedback gathered has been incorporated into the refreshed service specification. The experiences and views of patients, families and carers has been sought through a range of engagement methods.

These findings inform the refresh of this service specification. Engagement with current providers and clinicians within Adult Eating Disorders teams has directly informed each step of this service specification refresh, which represents a clarified and strengthened version of the original service specification. No changes have been made to the eligibility criteria, service model, or contracting approach. Rather, the voices of system stakeholders have been heard and acted upon to ensure the refreshed service specification:

- Responds comprehensively to potential health inequalities within the adult eating disorder population.
- Strengthens transitions for students and young adults, particularly those moving across geographical areas, ensuring continuity of care.
- Protects equity of access for marginalised groups, including men and transgender individuals, within specialist intensive treatment services.
- Clarifies and reinforces the alignment of specialist eating disorder services with community and acute medical services to ensure a seamless care pathway.
- Recognises and supports the unique, multidisciplinary role that specialist eating disorder teams play within evolving Integrated Care Systems, with a focus on collaboration and co-production.
- Enhances the understanding and integration of sensory needs and reasonable adjustments for neurodivergent individuals within treatment plans.
- Introduces a commitment to an annual review of outcome and quality metrics to ensure continuous improvement and accountability.
- Prioritises person-centred care planning that includes social, physical, and mental health needs, with a core focus on improving quality of life and meaningful engagement.

2. Background:

Rationale for service specification refresh

The NHS Long Term Plan sets a clear ambition that by 2023/24, all appropriate specialised mental health services will be managed through NHS-led Provider Collaboratives (PCs). For specialist Adult Eating Disorder (AED) inpatient services, this vision is already being realised, with 14 NHS-Led AED PCs now delivering specialist services across the country. These PCs will transition to the oversight of the new statutory commissioning bodies in England—NHS Integrated Care Boards (ICBs)—starting from 1st April 2025.

These ICBs will assume leadership, decision-making, and future commissioning responsibilities for Eating Disorders services in England, marking a significant transformation in the delivery and management of these services. In light of this transition and to support continuous service improvement, it became imperative to refresh and re-publish the national minimum service specification for AED inpatient services before the 1st April 2025 deadline.

This review and revision were also necessitated by several critical issues identified in the 2013/2014 service specification, which highlighted limitations and areas requiring substantial improvement.

- Outdated Specification: The previous specification did not reflect the latest best practices and evidence-based approaches for treating Adult Eating Disorders (AED), potentially compromising the quality and effectiveness of patient care. It also failed to align with the new commissioner/provider landscape within which AED services are currently delivered, leading to possible misalignment with current operational frameworks.
- Limited Scope and Accessibility: The old specification was overly focused on inpatient and day patient care, lacking a continuum of care across different levels of severity and stages of recovery. This limited scope resulted in an over-reliance on inpatient beds, which are not always necessary or the most effective form of care for all patients. Furthermore, the exclusion of intensive community treatments limited accessible and less invasive care options closer to patients' homes.
- Insufficient Inclusion of Co-Morbidities: The previous specification inadequately addressed the frequent co-occurrence of eating disorders with other complex mental health conditions, such as autism and personality disorders. This omission highlighted the need for more integrated, multidisciplinary approaches to ensure holistic and effective care, consistent with NICE guidelines that emphasise the treatment of co-occurring conditions where possible.
- Outdated Diagnostic and Treatment Approaches: Over the past decade, significant advancements have been made in the understanding and treatment of eating disorders. The old specification did not reflect these developments, potentially resulting in outdated or suboptimal treatment practices. Advocacy groups like BEAT have stressed the necessity of continuous updates to treatment protocols to incorporate the latest evidence-based practices.
- Lack of Quality Outcome Metrics: The original service specification lacked robust, up-to-date quality outcome and metric indicators necessary to measure the effectiveness and efficiency of the services provided. Implementing standardised outcome metrics, as recommended by the NHS and other health organisations, is crucial for continuous quality improvement and was a critical factor driving the need for revision.

3. Engagement Process & Results:

Early Engagement

The Stakeholder Working Group (SWG) employed a collaborative engagement approach to revise the Adult Eating Disorder Inpatient service specification. This approach is highly valued in complex and sensitive areas such as eating disorder services because it ensures that diverse perspectives and expertise are included in the decision-making process. The SWG included professionals with extensive backgrounds in adult eating disorders from various fields and, crucially, experts by experience (EbyE) who had recent lived experience with eating disorders in different capacities (patients, family members, and carers).

Key Elements of the Collaborative Approach:

- Inclusivity: The approach ensured that a wide range of perspectives, including those from EbyE and clinical experts, were incorporated. This diversity led to a more balanced and comprehensive specification.
- Transparency: By engaging stakeholders directly, the process remained transparent, building trust and credibility among those involved. This was particularly important in addressing contentious issues where transparency helps in managing expectations and fostering support.
- Quality of Feedback: The direct engagement allowed for more detailed, nuanced, and actionable feedback compared to other forms such as surveys. Stakeholders could provide immediate input on the draft specification, which facilitated more effective revisions.
- Collaboration and Buy-In: Engaging stakeholders in the review process increased their sense of ownership and commitment to the final specification. This is crucial for smoother implementation and greater acceptance of the new standards.
- Responsiveness: The method allowed for real-time dialogue and adjustments, ensuring that the specification remained relevant and responsive to stakeholders' needs and concerns.

Overall, this robust collaborative engagement approach significantly enhanced the quality, acceptance, and completion of the final draft of the Adult Eating Disorder Inpatient service specification. It leveraged the collective knowledge and experience of both clinical professionals and those with lived experience, resulting in a specification that was well-rounded and reflective of the needs of all stakeholders.

Stakeholder Testing and Feedback

Following the collaborative engagement approach, the revised service specification underwent formal stakeholder testing from October 30, 2023, to November 27, 2023. The extension of the testing period allowed for additional feedback from key national bodies, such as the Royal College of Psychiatry, BEAT (the UK's leading eating disorder charity), and the National Experts by Experience Network (NEbEN).

Stakeholder Testing Process:

- Diverse Feedback Sources: The SWG received 28 formal responses during the stakeholder testing period. These responses came from a wide array of

contributors, including experts by experience, consultant psychologists, clinical leads of existing services, operational managers, regional commissioners, and representatives of national organisations. This broad range of feedback ensured that the revised specification was evaluated from multiple perspectives, leading to a more comprehensive and inclusive final document.

- Thematic Analysis: A simple thematic analysis of the feedback was conducted to identify key themes and areas that needed to be addressed in the specification. This analysis helped distinguish issues that could be resolved within the scope of the specification and those that required broader, cross-sectoral approaches.

Key themes from feedback:

The engagement process uncovered several critical themes and insights, each reflecting the concerns and priorities of various stakeholders involved in the Adult Eating Disorder (AED) Inpatient Service. These findings highlight the areas where the current service specification needed refinement and have directly informed the updates in the revised specification, these themes were as follows:

1. Inclusion Criteria Clarification
2. Strengthening the response to Inequalities and Health Inequalities, including the service response to neurodiversity.
3. Pro-Active Family Involvement
4. Annual Review of Metrics
5. Collaboration with other Clinical Services
6. Training Needs
7. Training Resources

Changes made to specification from feedback:

1. Inclusion Criteria:

Stakeholders consistently emphasised the importance of having clear and comprehensive inclusion criteria for conditions such as Avoidant/Restrictive Food Intake Disorder (ARFID) and Binge Eating Disorder (BED). These conditions, although significant, have historically been underrepresented in treatment protocols. Feedback indicated that without explicit inclusion criteria, there was a risk of patients with these disorders being inappropriately excluded from receiving necessary inpatient care. Stakeholders expressed concern that the lack of clarity could lead to inconsistent application of the criteria across different service providers, potentially resulting in disparities in patient access to care.

In response, the revised specification has incorporated detailed guidelines that define the inclusion criteria for these disorders. This includes specifying the clinical presentations and severity levels that warrant inpatient care, ensuring that patients with ARFID and BED are adequately recognised and appropriately managed. The aim is to standardise admissions criteria across the board, reducing variability in patient treatment and ensuring that all individuals who meet the criteria receive the care they need.

2. Strengthening the Response to Inequalities and Health Inequalities, including the Service Response to Neurodiversity:

A critical area of concern raised during the engagement process was the need to address inequalities and health inequalities within the AED inpatient services, particularly in relation to neurodiversity. Stakeholders highlighted those individuals from marginalised communities, as well as those with neurodiverse conditions such as autism spectrum disorders (ASD), often face significant barriers in accessing and receiving appropriate care. These barriers can include stigma, lack of awareness, and insufficient accommodations within healthcare settings.

The revised specification places a strong emphasis on ensuring equitable access to care for all patients, regardless of their background or neurodiverse status. It includes specific provisions to enhance the service response to neurodiversity, such as implementing accommodations and support tailored to the needs of neurodiverse patients. This includes ensuring that clinical environments are sensory-friendly, that communication is clear and accessible, and that care plans are individualised to reflect the unique needs of neurodiverse patients.

3. Family and Carer Involvement:

The engagement process underscored the critical role that families and carers play in the treatment and recovery of individuals with eating disorders. Stakeholders, particularly those with lived experience, stressed the need for their active involvement in the treatment process. They noted that families and carers often provide essential support and insights that can significantly impact the success of treatment. However, they also pointed out that their involvement is not always systematically integrated into the care process.

To address this, the revised specification includes clear requirements for the involvement of families and carers in Multi-Disciplinary Team (MDT) meetings and treatment planning. This ensures that their perspectives and contributions are considered in the decision-making process. The specification also advocates for regular communication between healthcare providers and families, fostering a collaborative environment that supports the patient's recovery journey. By formalising this involvement, the specification aims to enhance the overall effectiveness of treatment and improve patient satisfaction.

4. Data Collection and Outcome Measures

Stakeholders highlighted the need for robust data collection and outcome measures to monitor and evaluate the effectiveness of the treatments provided within AED inpatient services. The lack of standardised metrics was seen as a significant gap in the current service specification, leading to difficulties in assessing the quality and outcomes of care across different providers. Stakeholders argued that without reliable data, it is challenging to identify areas for improvement or to ensure accountability within the service.

The revised specification addresses this concern by introducing standardised metrics for data collection and outcome measurement. These metrics will enable continuous monitoring of treatment effectiveness, patient progress, and service efficiency. The specification also includes provisions for an annual review of these metrics, ensuring that they remain relevant and reflective of the latest clinical evidence and best

practices. This approach will facilitate ongoing improvements in service delivery and help ensure that all patients receive high-quality care.

5. Collaboration with Other Clinical Services

The necessity of a multidisciplinary approach, particularly for patients with co-morbid conditions, was a recurring theme in the feedback. Stakeholders pointed out that individuals with eating disorders often have complex health needs that extend beyond the scope of a single specialty. For example, many patients may have co-occurring mental health conditions, such as anxiety, depression, or personality disorders, or physical health issues like diabetes or cardiovascular problems. Effective treatment, therefore, requires close collaboration between different clinical services to provide holistic care.

The revised specification strongly advocates for enhanced collaboration between AED services and other relevant clinical services. It emphasises the importance of coordinated care plans that involve multiple specialties, ensuring that all aspects of a patient's health are addressed comprehensively. This multidisciplinary approach is designed to improve the overall quality of care, reduce the risk of fragmented or incomplete treatment, and ultimately lead to better health outcomes for patients with eating disorders.

6. Training Needs

Another prominent theme that emerged was the strong demand for additional training resources for healthcare staff, particularly in relation to ARFID and autism. Stakeholders highlighted that staff often feel underprepared to manage the complexities associated with these conditions. ARFID, for example, presents unique challenges that differ significantly from other eating disorders, requiring specialised knowledge and skills to address effectively. Similarly, patients with autism may have specific needs and behaviours that require tailored approaches, which many staff members currently lack training in.

The revised specification addresses this by mandating the provision of targeted training programs for all staff involved in the treatment of eating disorders. These programs will cover the latest evidence-based practices for managing ARFID and autism, ensuring that healthcare professionals are equipped with the necessary skills and knowledge. This will not only improve the quality of care but also increase staff confidence in handling complex cases, leading to better patient outcomes.

7. Training Resources and Expectations

In addition to the identified training needs, stakeholders also emphasised the importance of making accessible and comprehensive training resources available to healthcare providers. The management of ARFID and autism spectrum disorders (autism) requires specific expertise that goes beyond general eating disorder treatment protocols. Stakeholders pointed out that without proper training resources, staff might struggle to implement the revised inclusion criteria and treatment plans effectively, which could undermine the quality of care provided.

In response, the specification was updated to include explicit references to available training resources that staff and providers can access directly. These resources are designed to provide healthcare providers with the necessary tools and knowledge to

address the complex needs of patients with these conditions. By ensuring that staff have access to these resources, the revised specification supports a higher standard of care and promotes a more consistent approach to treatment across different service providers.

Furthermore, the updated specification outlines clear expectations for ongoing professional development. It encourages healthcare providers to engage in continuous learning and training to stay updated on the latest developments in managing eating disorders, particularly those that involve comorbid conditions such as autism. This proactive approach to training and resource availability is intended to empower staff, reduce variability in care, and enhance patient outcomes across the AED inpatient services.

Engagement Process Summary

The feedback process was instrumental in refining the specification, ensuring it was aligned with the latest clinical guidelines, best practices, and the needs of both patients and providers. Despite the challenges and diverse opinions, the SWG was able to incorporate meaningful changes that enhanced the specification's clarity, inclusivity, and effectiveness.

By involving a broad spectrum of stakeholders and rigorously analysing their feedback, the revised Adult Eating Disorder Inpatient service specification was strengthened to better meet the needs of those it serves. This process highlights the importance of stakeholder engagement in shaping healthcare policies and ensures that the final specification is practical, forward-thinking, and capable of delivering high-quality, patient-centred care.

4. Representations to PPVAG:

During the representations to the Patient and Public Voice Assurance Group (PPVAG) regarding the Adult Eating Disorder Inpatient service specification, the group recognises the significant effort that has gone into the engagement process.

PPVAG members particularly praise the comprehensive clinical engagement and the structured approach taken to develop the specification. The collaborative engagement process, which includes feedback from various stakeholders such as clinical experts, service providers, and organisations, is acknowledged as thorough and well-executed.

However, the PPVAG expresses concern that, despite these extensive efforts, the stakeholder testing phase does not yield enough direct or individual responses from former service users, carers, and members of the public. This observation is made even though it is noted that many of the responding bodies have likely consulted their own networks of experts by experience or similar groups when formulating their feedback.

Considering these concerns, the PPVAG recommends that the specification be subjected to a further 30-day public consultation. The objective of this additional consultation period is to ensure broader and more direct input from individuals with

lived experience, their families, and the wider public. The goal is to enhance the robustness of the engagement process and ensure that the final specification is reflective of a diverse range of voices, particularly those who have been directly affected by eating disorders.

The PPVAG's decision underscores NHS England's commitment to the importance of direct public involvement in the development of healthcare specifications, ensuring that the voices of those most impacted by these services are heard and integrated into the final document.

5. Next Steps:

The newly revised Adult Eating Disorder Inpatient service specification will now enter a formal 30-day public consultation process. This consultation phase is a critical step to ensure that the specification receives comprehensive input from a wider audience, including individuals with lived experience, their families, carers, and the public.

This process will be overseen by NHS England's Specialised Commissioning Communications & Engagement Team, who will manage the consultation activities, gather feedback, and ensure that all relevant voices are heard. The team's oversight will help maintain transparency and ensure that the consultation is conducted in a fair and inclusive manner.

The outcomes from this public consultation will be carefully reviewed and considered, with the goal of refining and finalising the specification to better meet the needs of those affected by eating disorders.