

# Lives at risk:

## The state of NHS adult community eating disorder services in England

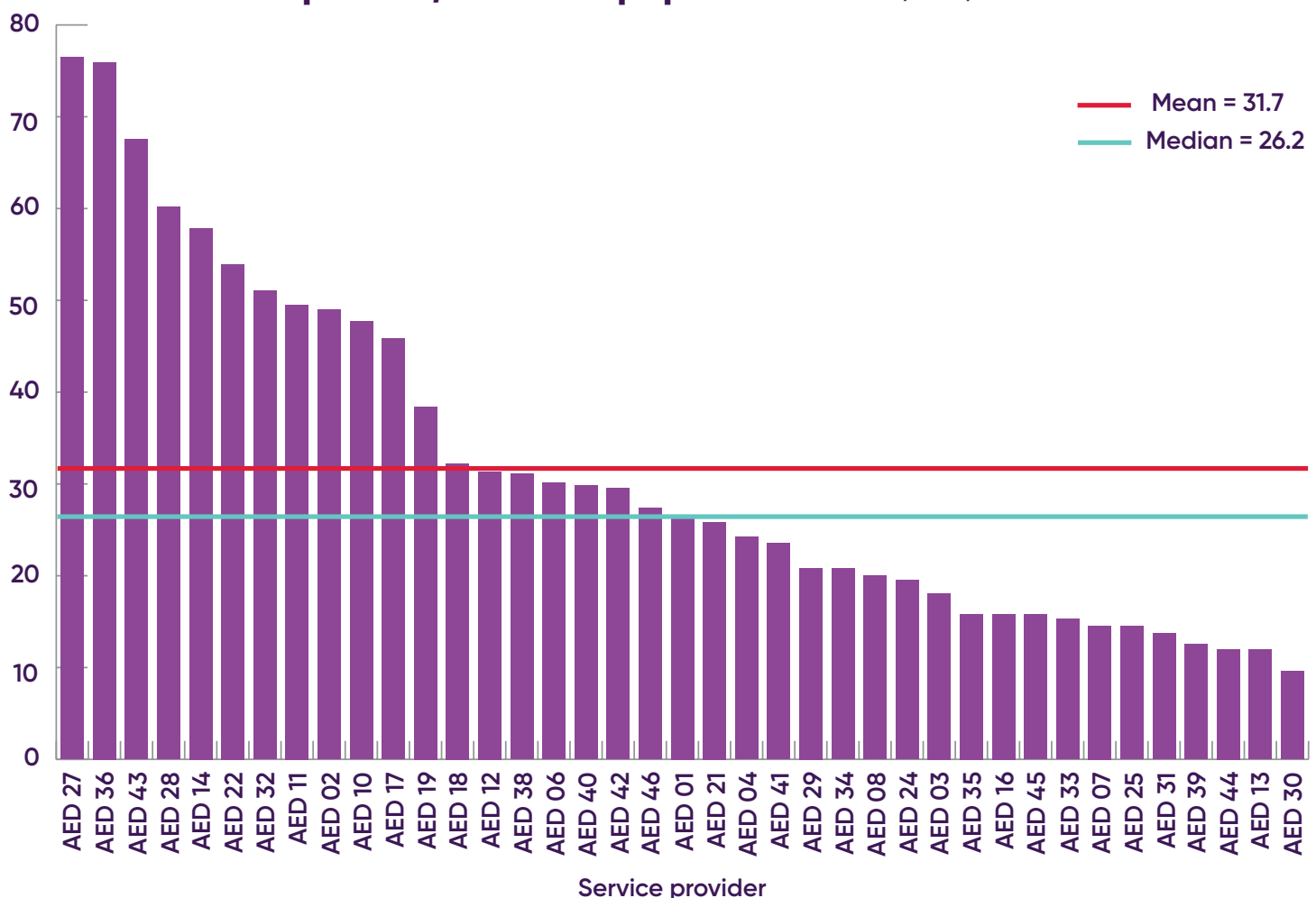


In 2018/2019 Beat conducted research into access, waiting times and staffing levels at NHS adult community eating disorder services in England. We submitted a Freedom of Information request to service providers and conducted eight in-depth interviews with people with lived experience focusing on the impacts of long waiting times. **The findings demonstrate alarming discrepancies in access to specialist treatment, waiting times and staffing levels at adult eating disorder services in England.** This briefing outlines the key findings and our recommendations for Government and the NHS in England.

### Access

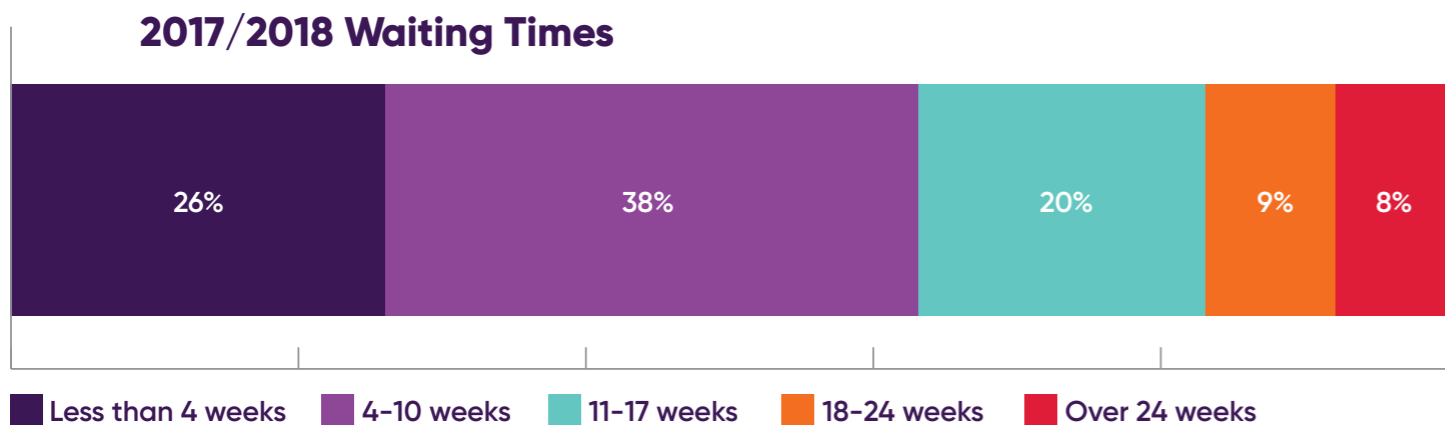
Adults with eating disorders often face high thresholds to access treatment and complex referral pathways. After accounting for the differences in the size of the populations served, there was an eight-fold difference between service providers in the size of caseloads (number of patients receiving treatment). This is shown in the graph below.

**Caseload per 100,000 local population at 31/03/18**



## Waiting times

Many adults referred to specialist treatment face very long waiting times. The waiting times to access adult eating disorder services in England in 2017/2018 are shown in the graphic below.

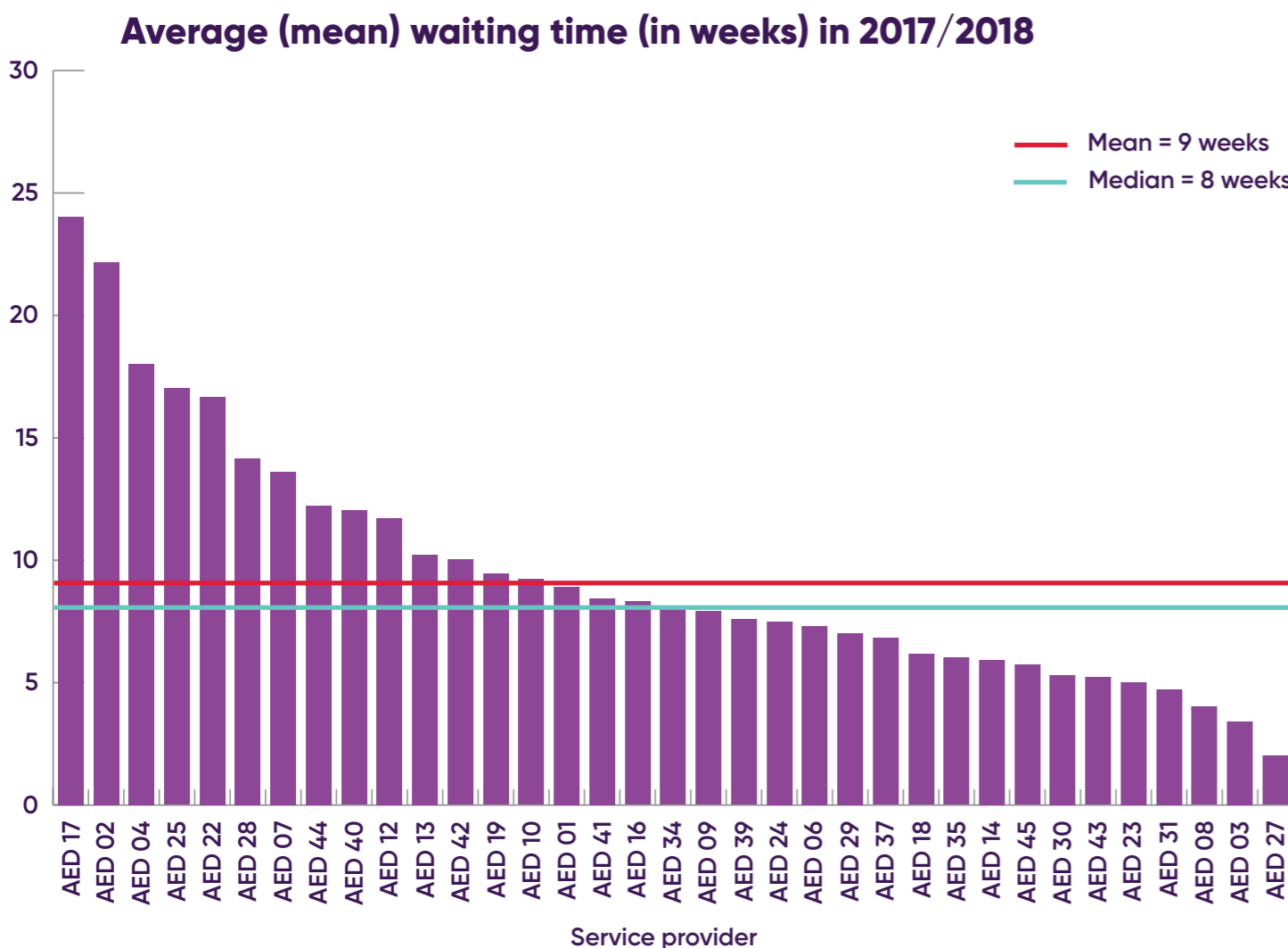


Only 26% of adults started treatment within four weeks. In contrast in the same year 81% of routine referrals for under-18s started treatment within four weeks<sup>1</sup>.

The average waiting time in 2017/2018 was nine weeks. But waiting times from referral to the start of treatment vary significantly between service

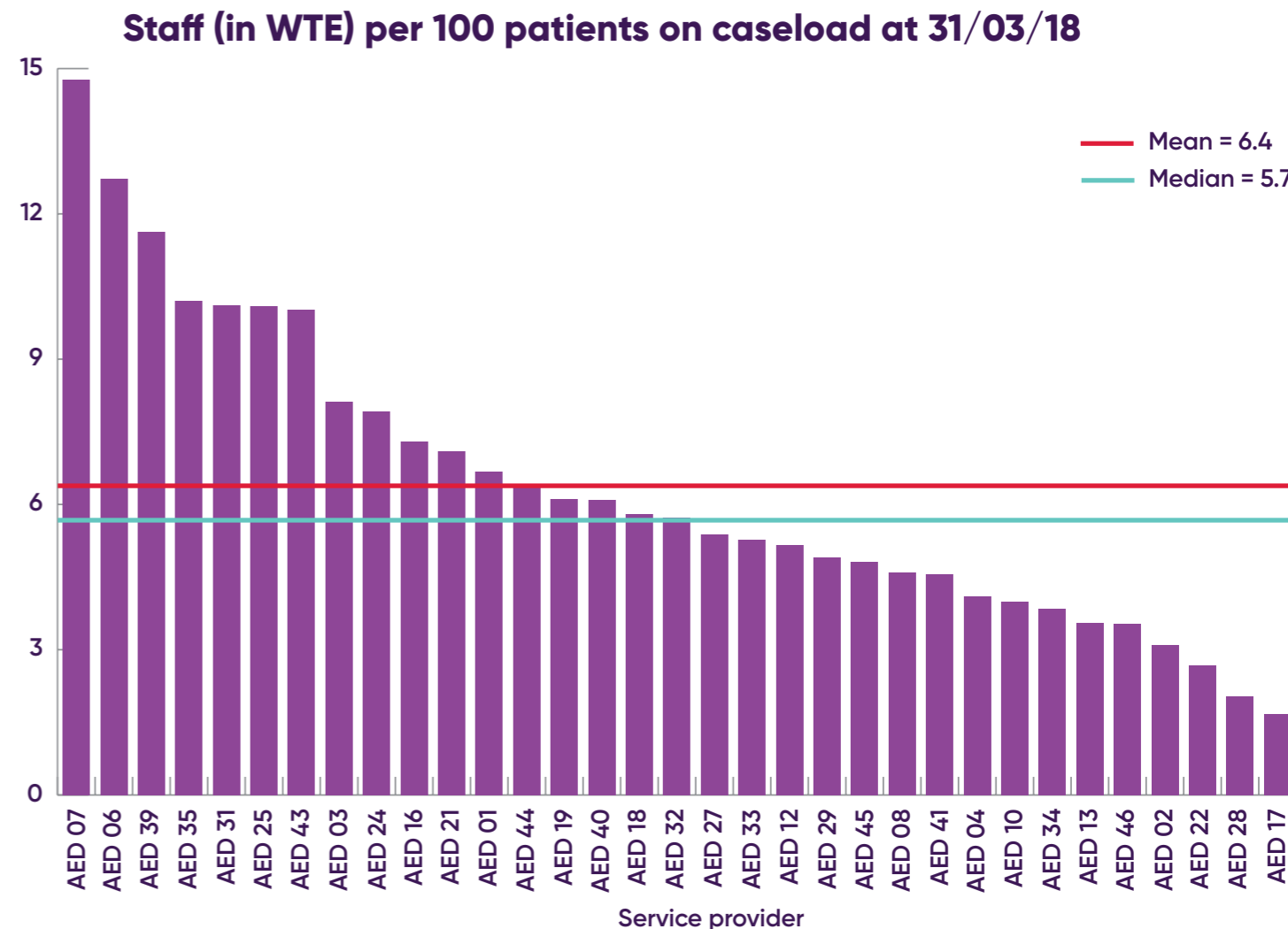
providers. There was a 12-fold difference between the shortest and longest average waiting time. This is illustrated in the graph below, which also shows the longest average wait was 24 weeks (5.5 months).

Generally, services with shorter waiting times had smaller caseloads and vice versa.



## Staffing levels

After accounting for differences in the numbers of patients treated, staffing levels varied widely between service providers. There was a nine-fold difference between the highest and lowest staff per patient ratios. This is shown in the graph below.



## Impacts of long waiting times

The in-depth interviews found long waiting times can have severe impacts on the welfare and safety of patients. The participants reported the following key impacts:

- Declining health and quality of life:** Participants discussed how they became more severely ill as they waited, with some feeling this led to them needing longer or more intensive treatment.
- Incentive to maintain or attempt to increase severity of illness:** Many explained how the long waiting time influenced their perceptions of the criteria required to access treatment. They described having attempted to become more unwell or abandoning self-help efforts to try to access treatment more quickly.

- Doubts about whether they are deserving of treatment:** Participants reported having questioned whether they deserved to access or continue treatment, out of concerns about the needs of other patients on the waiting list, whom they worried might need treatment more than they did.
- Risks to patient safety:** During the wait, medical and psychological risk was often not adequately monitored.

## Conclusions

The findings demonstrate that adults with eating disorders in England face a postcode lottery in terms of access to specialist treatment, waiting times and staffing levels at adult eating disorder services in England. Many adults face long waits to start treatment. Long waiting times can have severe impacts on patients' efforts to recover and their safety. The service providers with the shortest waiting times generally treat relatively small numbers of patients, which is suggestive of higher thresholds to access these services.

## Recommendations to Government and the NHS in England

- **The Department for Health and Social Care, NHS England and other arm's length bodies to prioritise the introduction of an Access and Waiting Time Standard for adult community eating disorder services, supported by sufficient funding and workforce planning.** This would be a major step towards an NHS where all adults with an eating disorder can benefit from timely access to evidence-based treatment.
- **NHS England, NHS Improvement and NHS Digital to ensure collection and publication of data concerning NHS adult community eating disorder services.**
- **Sustainability and Transformation Partnerships (STPs)/Integrated Care Systems (ICSs) to include a specific focus on transforming adult community eating disorder services in their five-year plans.**
- **Commissioners and providers to assess their services against the NICE Quality Standard<sup>2</sup>.**
- **NHS adult community eating disorder services to review the way they manage their waiting lists and their communication with patients after referral and assessment to ensure communications and procedures are patient-centred.**

**Please note:** The full report is available on the Beat website: [beateatingdisorders.org.uk/lives-at-risk](https://beateatingdisorders.org.uk/lives-at-risk)

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Briefing created with support  
from the Maudsley Charity.



<sup>1</sup> NHS England (2019) Children and Young People with an Eating Disorder Waiting Times. Available at: <https://www.england.nhs.uk/statistics/statistical-work-areas/cyped-waiting-times/>. Retrieved: 28/01/2020.

<sup>2</sup> National Institute for Health and Care Excellence (2018). Eating disorders (NICE Quality Standard No. 175). Available at: <https://www.nice.org.uk/guidance/qs175>. Retrieved: 28/01/2020.