# When do eating disorders start?

## An investigation into two large UK samples

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## Aim

To describe the age at onset of clinically relevant symptoms of eating disorders in two large UK research studies for 8,945 participants reporting a lifetime diagnosis of an eating disorder.

## Background

The age at which an eating disorder begins to develop, known as 'age at onset', is important to consider in terms of its implication for the design of services and the targeting of clinical interventions. A recent global study on the age at onset of various psychiatric disorders - the first completely epidemiological and largest meta-analysis conducted on this topic thus far - identified 192 studies suitable for inclusion[1]. Of these 192 studies, three looked at age at first anorexia nervosa symptom[2–4], two at age at first binge-eating disorder symptom[2, 4], and three at age at first bulimia nervosa symptom[2–4].

In anorexia nervosa, the meta-analysis reported a median age of 16 for first symptoms of anorexia, with 20.4% of participants reporting onset by age 14, 59.9% by age 18, and 89% by the age of 25[1]. For bulimia nervosa, the median age at onset was 18 years, with 16% of participants reporting onset at age 14 years, 45.3% at 18 years, and 82.9% at 25 years[1]. A median age of 20 years was identified for first symptoms of binge-eating disorder, with 15.5% of participants reporting onset by age 14, 31.4% by age 18, and 70.4% by the age of 25[1].

Thus, the literature strongly suggests that anorexia nervosa, bulimia nervosa, and binge-eating disorder have a median age at onset during the transitional period from adolescence into young adulthood. This supports the delivery of early intervention with the promotion of good mental health facilitated through primary and secondary schools, and higher education settings[1]. However, there were no UK samples included in this comprehensive meta-analysis of eating disorders age at onset studies.

## Methods

In this report, we explored the age at onset of regular episodes of binge eating (n = 6,634), low weight (n = 5,570), and purging behaviour (n = 6,223) in a total sample of 8,945 UK participants in the UK Eating Disorders Genetics Initiative (EDGI UK) and the Genetic Links to Anxiety and Depression (GLAD) Study. The vast majority of participants were female with 6.5% being male (using assigned sex at birth). These symptoms were chosen because of their direct relevance to diagnoses of binge-eating disorder (regular binge eating), bulimia nervosa (regular binge eating; purging behaviour) and anorexia nervosa (low weight).

### The EDGI UK and GLAD studies

EDGI UK aims to establish a re-contactable databank of participants with experience of an eating disorder with information on clinical symptoms/history, environmental risks, and genetics. EDGI UK is a partnership between King's College London and Beat. In parallel, researchers at King's College London also are running the GLAD Study, which launched in September 2018 and aims to collect the same data from 40,000 people who have experienced anxiety and/or depression, and which currently includes >5,000 participants with eating disorders. The benefit of including GLAD eating disorders cases is that it increases the representation of binge-eating disorder.

### Deriving eating disorder diagnosis

Table 1 below demonstrates the distribution of eating disorder diagnoses in our total sample (n = 8,945). Diagnoses for all eating disorders shown in Table 1 were based on responses to questions in the Mental Health Diagnosis (MHD) questionnaire, adapted from the UK Biobank Questionnaire(*5*), such as "*Have you ever been diagnosed with one or more of the following eating disorders by a professional, even if you don't have it currently? By professional we mean: any doctor, nurse or person with a specialist training. Please include disorders even if you did not need treatment for them or if you did not agree with the diagnosis*", as well as responses to the optional ED100K screener question included in GLAD, *"Which of the following eating disorders did you/do you currently have? If you have not received a diagnosis and are not sure which of the following may apply to you please select 'Don't know'".* Additionally, diagnostic algorithms for anorexia nervosa, bulimia nervosa, and binge-eating disorder were developed based on the DSM-5 criteria and utilised participants' responses to the ED100K questionnaire(*6*).

**Table 1.** Table indicating the spread of self-report and/or algorithm-derived lifetime eating disorder diagnoses in our sample of 8,945 participants from the GLAD Study or EDGI UK. Note that some participants will have experienced more than one lifetime diagnosis.

| Eating Disorder | Percentage | Frequency |
|---|---|---|
| Anorexia nervosa | 45.2% | 4041 |
| Bulimia nervosa | 53.2% | 4757 |
| Binge-eating disorder | 43.3% | 3871 |
| Atypical anorexia nervosa | 8.4% | 753 |
| Atypical bulimia nervosa | 1.5% | 136 |
| Atypical binge-eating disorder | 0.7% | 60 |
| Purging disorder | 5.4% | 480 |
| Night-eating syndrome | 3.4% | 305 |
| Pica | 0.8% | 69 |
| Avoidant/Restrictive Food Intake Disorder | 10.6% | 945 |
| Rumination disorder | 0.6% | 58 |
| OSFED/EDNOS | 5.7% | 514 |
| Other | 4.0% | 357 |

**Age at onset**

To assess age at onset of binge eating, the participants who previously indicated that they have experienced binge eating were asked, "*Roughly how old were you when you began having regular episodes of binge eating?*". To assess the age at onset of low weight, the participants who answered "*Yes*" to the question "*Have you ever had a period of time when you weighed much less than other people thought you ought to weigh?*" were asked "*How old were you then?*". To assess the age at onset of purging behaviours, participants who endorsed "*Made yourself vomit*", "*Used laxatives*" or "*Used diuretics*" to the question *"Have you ever used any of the following to control your body shape or weight?"* were subsequently asked their age at onset for each purging behaviour, for example, "*How old were you when you used laxatives for the first time?*". We took the lowest data entry for participants who reported their age at onset for more than one purging behaviour. These questions form the basis of our analysis. Answers below the age of 3 and above the age of 118 were eliminated due to implausibility, as were answers that were higher than the participant's age at the time of filling in the questionnaire. Participants could belong in more than one group.

**Exclusion criteria**

Participants who did not self-report their sex and/or did not have a self-reported or algorithm-derived eating disorder diagnosis were excluded from our analyses. Participants with missing data for all age at onset variables were also excluded.

*Figure 1* shows the spread of the age at onset of low weight.
*Figure 2* shows the spread of the age at onset of binge eating.
*Figure 3* shows the spread of the age at onset of purging behaviour.
*Table 1* describes the sample split into four age at onset categories: 1) under 10 years, 2) 10-15 years, 3) 16-24 years, 4) 25+ years.
*Table 2* describes the sample split into two age at onset categories: 1) under 18 years, 2) over 18 years.
*Table 3* describes the sample split into two age at onset categories: 1) under 16 years, 2) over 16 years.

**Table 1.** Table describing the percentages of age at onset (under 10 years; 10-15 years; 16-24 years; 25+ years) of the sample split by phenotype (low weight; binge eating; purging behaviour) and by sex (male; female) . Note that 'sex' is assigned sex at birth.

| | Low weight | | | Binge eating | | | Purging behaviour | | |
|---|---|---|---|---|---|---|---|---|---|
| | **Male**<br>**(n = 208)** | **Female**<br>**(n = 5362)** | **Total**<br>**(n = 5570)** | **Male**<br>**(n = 421)** | **Female**<br>**(n = 6213)** | **Total**<br>**(n = 6634)** | **Male**<br>**(n = 196)** | **Female**<br>**(n = 6027)** | **Total**<br>**(n = 6223)** |
| **<10 years** | 2.9%<br>(6/208) | 0.3%<br>(14/5362) | 0.4%<br>(20/5570) | 2.6%<br>(11/421) | 3.2%<br>(198/6213) | 3.1%<br>(209/6634) | 0.5%<br>(1/196) | 1.2%<br>(74/6027) | 1.2%<br>(75/6223) |
| **10-15 years** | 10.1%<br>(21/208) | 20.6%<br>(1106/5362) | 20.2%<br>(1127/5570) | 20.2%<br>(85/421) | 29.8%<br>(1852/6213) | 29.2%<br>(1937/6634) | 23.0%<br>(45/196) | 40.7%<br>(2450/6027) | 40.1%<br>(2495/6223) |
| **16-24 years** | 53.8%<br>(112/208) | 61.5%<br>(3300/5362) | 61.3%<br>(3412/5570) | 35.9%<br>(151/421) | 48.6%<br>(3019/6213) | 47.8%<br>(3170/6634) | 47.4%<br>(93/196) | 47.8%<br>(2880/6027) | 47.8%<br>(2973/6223) |
| **25+ years** | 33.2%<br>(69/208) | 17.6%<br>(942/5362) | 18.2%<br>(1011/5570) | 41.3%<br>(174/421) | 18.4%<br>(1144/6213) | 19.9%<br>(1318/6634) | 29.1%<br>(57/196) | 10.3%<br>(623/6027) | 10.9%<br>(680/6223) |

**Table 2.** Table describing the percentages of age at onset (under 18 years; 18+ years) of the sample split by phenotype (low weight; binge eating; purging behaviour) and by sex (male; female) . Note that 'sex' is assigned sex at birth.

| | Low weight | | | Binge eating | | | Purging behaviour | | |
|---|---|---|---|---|---|---|---|---|---|
| | Male (n = 208) | Female (n = 5362) | Total (n = 5570) | Male (n = 421) | Female (n = 6213) | Total (n = 6634) | Male (n = 196) | Female (n = 6027) | Total (n = 6223) |
| <18 years | 22.1% (46/208) | 43.3% (2322/5362) | 42.5% (2368/5570) | 32.8% (138/421) | 48.3% (2998/6213) | 47.3% (3136/6634) | 38.3% (75/196) | 61.4% (3703/6027) | 60.7% (3778/6223) |
| 18+ years | 77.9% (162/208) | 56.7% (3040/5362) | 57.5% (3202/5570) | 67.2% (283/421) | 51.7% (3215/6213) | 52.7% (3498/6634) | 61.7% (121/196) | 38.6% (2324/6027) | 39.3% (2445/6223) |

**Table 3.** Table describing the percentages of age at onset (under 16 years; 16+ years) of the sample split by phenotype (low weight; binge eating; purging behaviour) and by sex (male; female) . Note that 'sex' is assigned sex at birth.

| | Low weight | | | Binge eating | | | Purging behaviour | | |
|---|---|---|---|---|---|---|---|---|---|
| | **Male (n = 208)** | **Female (n = 5362)** | **Total (n = 5570)** | **Male (n = 421)** | **Female (n = 6213)** | **Total (n = 6634)** | **Male (n = 196)** | **Female (n = 6027)** | **Total (n = 6223)** |
| <16 years | 13.0% (27/208) | 20.9% (1120/5362) | 20.6% (1147/5570) | 22.8% (96/421) | 33.0% (2050/6213) | 32.3% (2146/6634) | 23.5% (46/196) | 41.9% (2524/6027) | 41.3% (2570/6223) |
| 16+ years | 87.0% (181/208) | 79.1% (4242/5362) | 79.4% (4423/5570 | 77.2% (325/421) | 67.0% (4163/6213) | 67.7% (4488/6634) | 76.5% (150/196) | 58.1% (3503/6027) | 58.7% (3653/6223) |
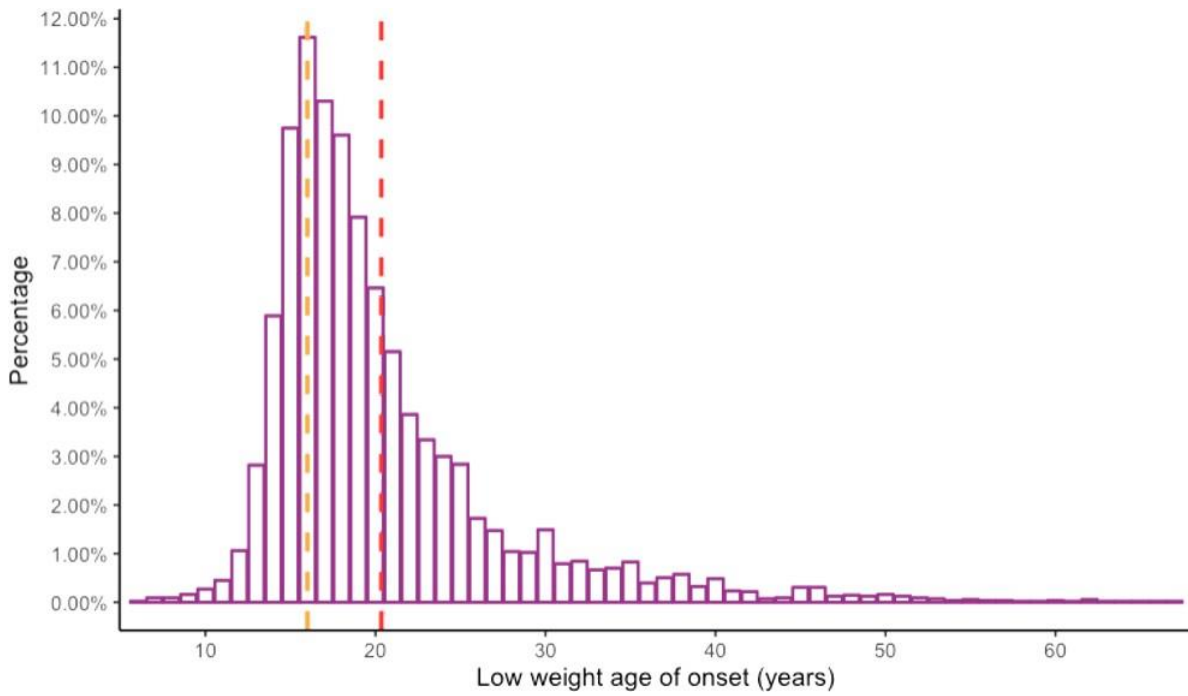
**Figure 1.** Histogram indicating the spread of age at onset of low weight in the GLAD Study and EDGI UK participants (n = 5,570). The red line represents the mean, and the orange line represents the median.
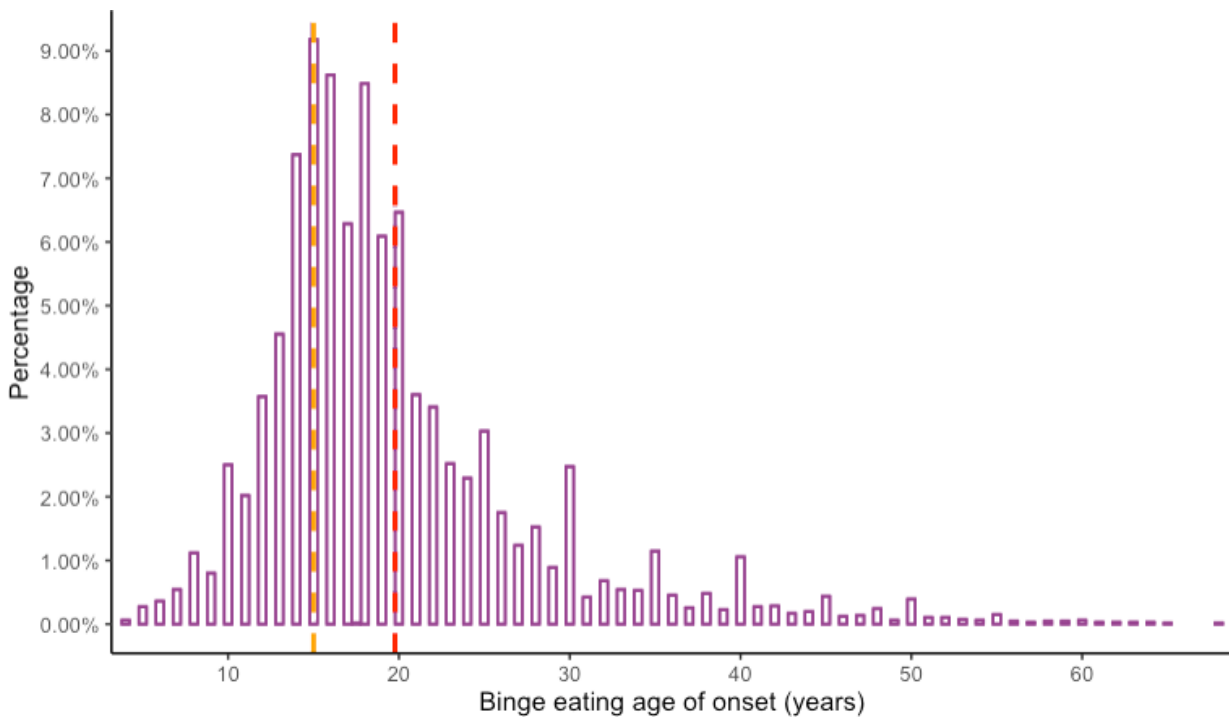


**Figure 2.** Histogram indicating the spread of age at onset of binge eating in the GLAD Study and EDGI UK participants (n = 6,634). The red line represents the mean, and the orange line represents the median
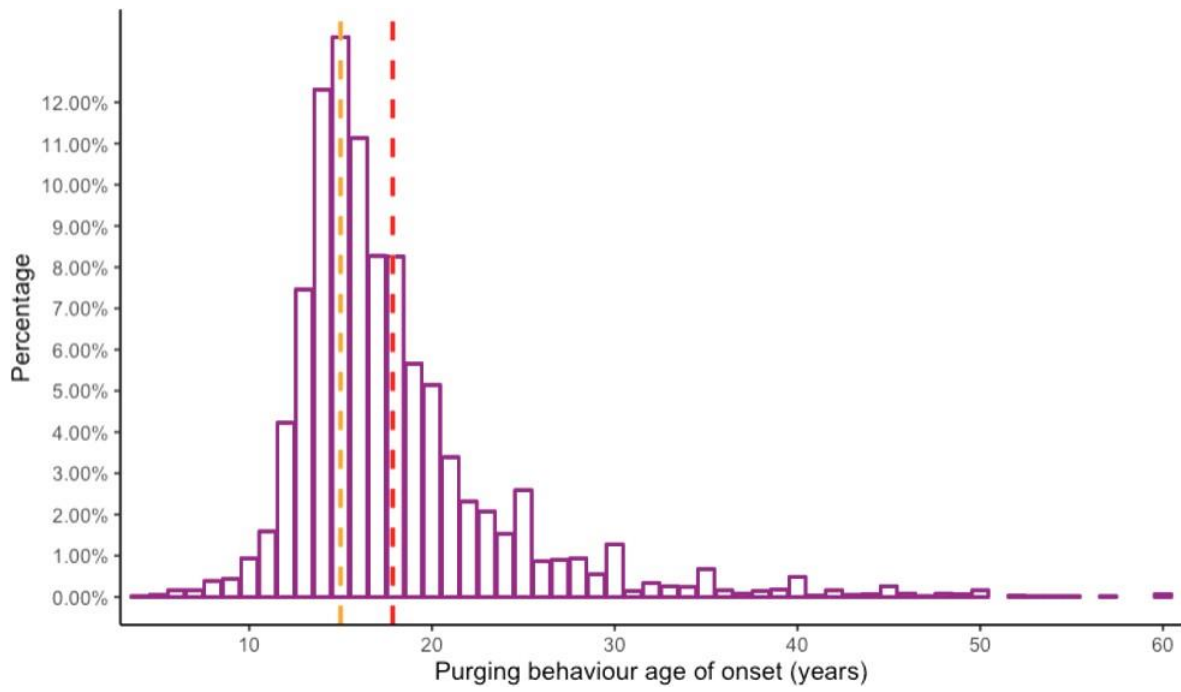
**Figure 3.** Histogram indicating the spread of age at onset of purging behaviour in the GLAD Study and EDGI UKparticipants (n = 6,223). The red line represents the mean, and the orange line represents the median.

## Conclusions and summary

The age at onset of anorexia nervosa, bulimia nervosa, and binge-eating disorder symptoms in these two studies from the UK population largely replicates the international studies' estimates. However, our analyses show two clear findings:

1. A majority of cases experience their first serious episodes of either low weight (57.5%) or regular binge eating (52.7%) when they are >18 years of age. For purging behaviours, this was not a majority but was a still substantial 39.3%. This highlights the necessity for more adult clinical services.

2. Male cases are always a minority but, compared to female cases, proportionally more males experienced adult onset (i.e., over 25 years) low weight, regular episodes of binge eating, and purging behaviour. Also, proportionally more males reported very early, prepubertal onset of low weight (i.e., under the age of 10). This suggests that there also needs to be more provision for male cases/beds at those ages.

Limitations of our study include that we relied on retrospective self-report of symptom onset and that participants were from volunteer/convenience samples. For example, the proportion of male cases shown does not necessarily correspond to the true male/female ratio in the community, as males may be less likely to self-identify with disordered eating and to sign up to take part in such studies.

## Policy recommendations

Our analyses support the following policy recommendations:

- The UK Government and NHS England should ensure that every area of England is served by an Adult (or All-age) community eating disorder service.

- The UK Government, NHS England, and Integrated Care Systems (ICSs) should ensure sufficient investment reaches Adult eating disorder services to enable them to deliver the standards of care outlined in NHS England's '*Adult Eating Disorders: Community, Inpatient and Intensive Day Patient Care Guidance for commissioners and providers'(7)*.

- The UK Government and NHS Digital should ensure that the methodology of the Adult Psychiatric Morbidity Survey (APMS) 2022 will enable the first-ever evidence-based assessment of the population prevalence of eating disorders in English adults.

- The Governments of Scotland, Wales and Northern Ireland, NHS Scotland, NHS Wales and Health and Social Care Northern Ireland (HSCNI) should, as part of implementing the recommendations of recent national reviews of eating disorder services(*8 - 10*), significantly expand access to evidence-based treatment for adults with eating disorders. Timescales and dedicated funding must be allocated to this work to ensure that it is prioritised.

- Governments and the NHS in all parts of the UK should publish data on Adult eating disorder services to help drive much-needed investment in these services.

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