

## BRITISH PAEDIATRIC SURVEILLANCE UNIT

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### Early onset eating disorders (under 13 years of age)

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**Abstract** Epidemiological studies suggest that the incidence of eating disorders, including anorexia nervosa, has been increasing in adolescents over the last 50 years although others suggest patients may simply be getting younger with no increase in numbers. However, there are no good estimates of the incidence in children under 13 years of age, who often fall across both paediatric and mental health services. This study will quantify the problem but also will examine the circumstances surrounding onset and examine current management regimens. A one-year follow up will assess short-term outcomes.

**Principal Investigators**

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**Coverage** United Kingdom and Ireland

**Duration** March 2005 – March 2006 (inclusive)

**Background** Early-onset eating disorders (EOED: defined as onset before 13 years of age) are equally as likely to present to paediatricians as child psychiatrists in the UK(1) Management of these frequently extremely ill children is complicated by a lack of knowledge of the breadth of the problem, difficulties with recognition of eating disorders in this age group(2) and ongoing debate over the role of paediatricians versus mental health professionals. Nevertheless, clinical experience suggests that children with EOED are very frequently admitted to paediatric wards before referral to child mental health services.

Epidemiological studies suggest that the incidence of eating disorders, including anorexia nervosa (AN), has been increasing in adolescents over the last 50 years(3) Specialist services have recognised they are seeing increasing numbers of EOED cases, yet no incidence estimates are available for this specific age group. The most recent incidence data for eating disorders in the UK were obtained from a GP register study of all age groups undertaken in the early 1990s. Incidence of AN was estimated as 17.5/100,000 in 10-19 year olds, and 0.3/100,000 in 0-9 year olds. For bulimia nervosa the rates are 20.5/100,000 and 0/100,000 respectively (4). Retrospective studies from the US and Denmark have suggested higher figures, e.g. 9-27 per 100,000 10-14 year girls and 3.7 per 100,000 for boys (5;6).

The ambiguous position of EOED between paediatrics and mental health, overseas perhaps more than in the UK, has led to significant gaps in knowledge about the extent of this problem. The recent Department of Health National Inpatient Child & Adolescent Psychiatric survey (NICAPS)(7) showed that eating disorders were the commonest diagnosis amongst psychiatric inpatients, and that 9.2% of these (12 patients) were under 13 years. Notably these figures did not include children on paediatric wards, and there is no information on the scale of paediatric resource use by this patient group. A recent national survey of child psychiatrists showed that when a young person with an EOED needed admission, it is common for this to be to a paediatric ward in the first instance. (Dasha Nicholls, unpublished data).

The recently published National Institute of Clinical Effectiveness (NICE) guidelines on the treatment of eating disorders highlight the lack of quality evidence regarding the epidemiology and treatment of EOED and the importance of greater coordination between professionals involved in their care. This study will, amongst other things, provide insight into how care is provided for EOED across the UK and Ireland.

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**Case Definition** Please report any child aged under 13 years, newly diagnosed with early onset eating disorder which is defined as:

**TWO OR MORE OF THE FOLLOWING**

- weight loss or failure to gain weight during a period of expected growth, not due to any identifiable organic cause
- determined food avoidance
- fear of weight gain
- preoccupation with body weight or energy intake
- self induced vomiting
- excessive exercising<sup>1</sup>
- recurrent episodes of binge eating or abuse of laxatives

<sup>1</sup>Exercise may be considered to be excessive when it significantly interferes with important activities, when it occurs at inappropriate times or in inappropriate settings, or when the individual continues to exercise despite injury or other medical complications." (American Psychiatric Association. DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revision. Washington, D.C.: American Psychiatric Association; 2004; pp. 590-591.) This definition has been included in the questionnaire.

**Research Questions**

1. To estimate the incidence of early onset eating disorders in children in the British Isles
2. To describe the age, sex and family history
3. To describe the range of clinical features at presentation including other psychiatric illness
4. To delineate patterns of professional involvement (paediatric & child mental health)
5. To characterise the range of acute medical complications experienced by children with early onset eating disorders
6. To identify the range of therapeutic interventions used in management.

**Methods** Consultant paediatricians and child & adolescent psychiatrists will be asked on a monthly basis to report all cases meeting the case definition, through the orange card system. In order that maximum information is obtained and cases not missed, reporting by more than one clinician is encouraged where applicable. Clinicians reporting a case will be sent a questionnaire seeking demographic details and clinical features. For all valid cases a second questionnaire will be sent to the reporting clinician a year after the case was first reported.

**Reporting Instructions** Please report any new cases meeting the surveillance definition seen by you for the first time even if you believe the case may have been reported from elsewhere.

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**Ethics Approval** All studies undertaken through the BPSU use anonymised patient details and have been approved by a MREC as not requiring patient consent. The London MREC has approved this study.

**References**

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