Surveillance Study of Anorexia Nervosa in the UK & Republic of Ireland

Background
Anorexia nervosa is a serious eating disorder and a long-term mental health condition which can be fatal. It is an expensive illness to treat, often involving lengthy hospital stays and readmission is common. Evidence suggests specialist eating disorder services are better at preventing hospital admissions, more effective and more acceptable to users and carers than general child and adolescent mental health services. Despite this, specialist services are patchy or absent in many areas of the UK and Republic of Ireland. This study aims to assess whether increased investment in community-based specialist eating disorder services would benefit young people and their families and would provide good value for money to the NHS.

Principal Investigator
Sarah Byford, Professor of Health Economics, Centre for the Economics of Mental and Physical Health, King’s College London, De Crespigny Park, London SE5 8AF; s.byford@kcl.ac.uk

Co-investigators
Professor Ivan Eisler, King’s College London; Dr Dasha Nicholls, Great Ormond Street Hospital; Professor Simon Gowers, University of Liverpool; Dr Barbara Barrett, King’s College London; Susan Ringwood, Beat (Beating Eating Disorders); Professor Geraldine Macdonald, Queen’s University, Belfast; Professor Fiona McNicholas, Our Lady’s Children’s Hospital, Dublin; Professor Tamsin Ford, University of Exeter; Dr Mima Simic, South London and Maudsley NHS Trust; Dr Robin Glaze, Abergale Hospital; Jo Fletcher, South London and Maudsley NHS Trust

Protocol
Available from http://www.nets.nihr.ac.uk/projects/hsdr/11102317

Coverage
United Kingdom and Republic of Ireland

Surveillance period
1 February 2015 – 1 February 2016 (12 months maximum)
Research questions

1) To identify all new incident cases of children and young people (aged 8-17 years and 11 months) with DSM5 anorexia nervosa in the British Isles

2) To classify the model of community-based care provided to each case identified and map models of care across the British Isles

3) To estimate the cost and cost-effectiveness of different models of care

4) To explore the impact on cost and cost-effectiveness of potential changes to the provision of specialist community-based services using decision modelling.

Case Definition

ONE bullet point criterion from EACH GROUP below should be fulfilled.

Group A

- Restriction of food, low body weight, or
- Weight less than expected for age

Group B

- Fear of gaining weight, or
- Fear of becoming fat, or
- Behaviour that interferes with weight gain, for example excessive exercising, self-induced vomiting, use of laxatives and diuretics

Group C

- Body image disturbance
- Persistent lack of recognition of the seriousness of the current low body weight.

Exclusions

- Patients who are not underweight
- Patients with bulimia nervosa, binge eating disorder, avoidant restrictive food intake disorder or other failure to thrive presentations.

Reporting instructions

Please report any child/young person aged 8 to 17 years and 11 months inclusive, who meets the case definition criteria above for the first time in the last month.

Methods

Questionnaire completed by reporting clinicians at baseline, 6 and 12-month follow up, to collect information on services used by the young people and their outcomes.

Ethics approval

The study has been approved by King’s College London Research Ethics Committee [PNM/13/14-105] and the Health Research Authority Confidentiality Advisory Group [CAG 4-03(PR1)/2014] under Section 251.

Funding

National Institute for Health Research (NIHR) Health Services and Delivery Research Programme (11/1023/17)