IMPERIAL

Eating Disorders in Children and Young People - What have we learnt from CAPSS studies?

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RC PSYCH ROYAL COLLEGE OF PSYCHIATRISTS

CAPSS
CHILD AND ADOLESCENT PSYCHIATRY SURVEILLANCE SYSTEM

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RCPCH

Eating Disorders in Children Under 13

Clinical Profiles from a British National Surveillance Study

Dasha Nicholls, Richard Lynn, Russell Viner
Institute of Child Health, London and the Royal College of Paediatrics and Child Health Research Unit

The child first and always

Great Ormond Street Hospital and the Institute of Child Health

UCL

Christmas
2000 - 2001

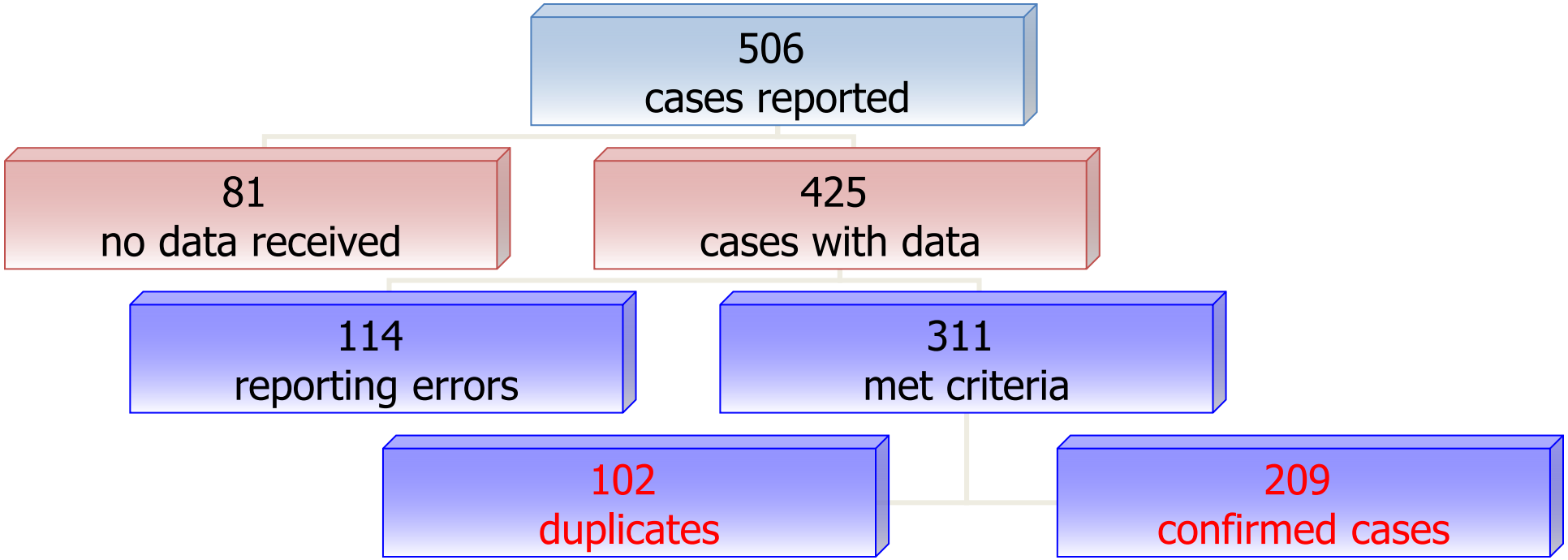
Process

- EOED study used BPSU and also developed a separate system for surveillance of C&A psychiatrists
- During the study…..
  - 90% of child psychiatrists thought it was good idea
  - 84% of returned their cards (once opt outs excluded)
  - 80% of sent back questionnaires

(Lynn, Nicholls and Viner 2012)

What happened next

- Findings presented at CPRS Nov 06
- MHRN funding obtained to establish a Clinical Research Group 2007
- Conversion disorder study started Oct 2008
- Bipolar disorder study
  - first study to run on CAPSS alone
  - CAPSS launched in 2009

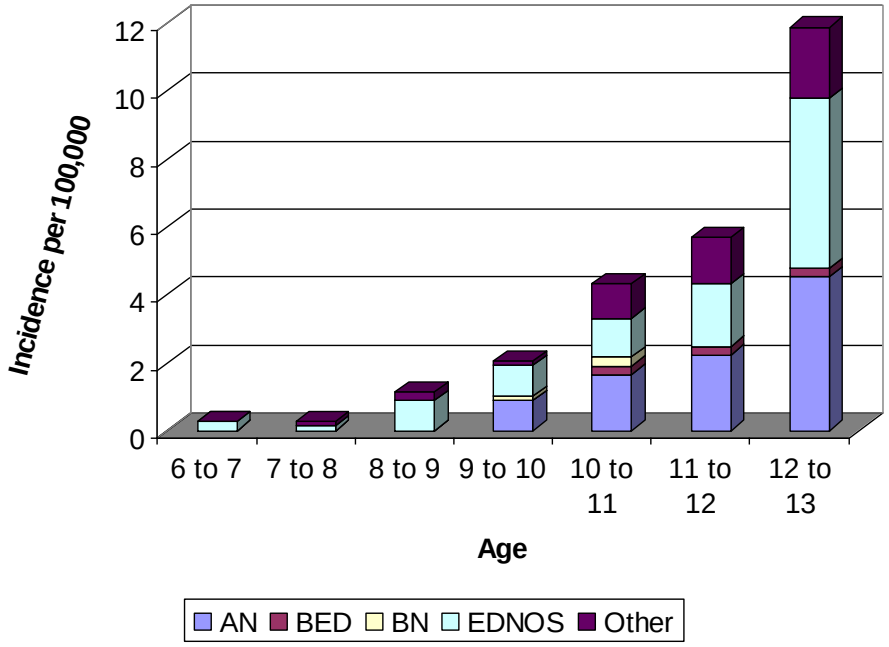


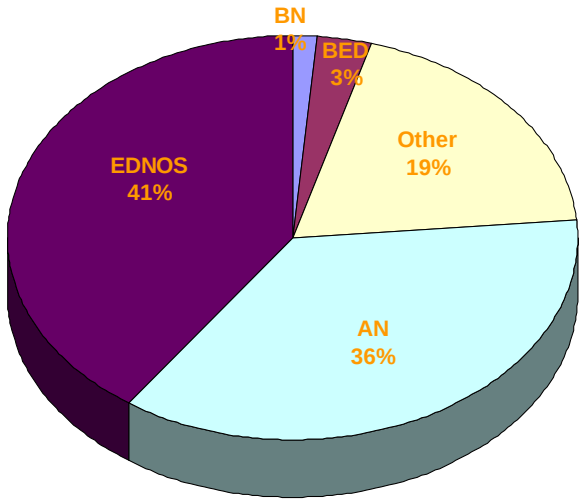
75% reported by psychiatrists and 25% by paediatricians

Nicholls, Lynn, Viner. BJPsych 2011;
Hudson, Nicholls. Lynn, Viner. Arch Dis Ch 2012

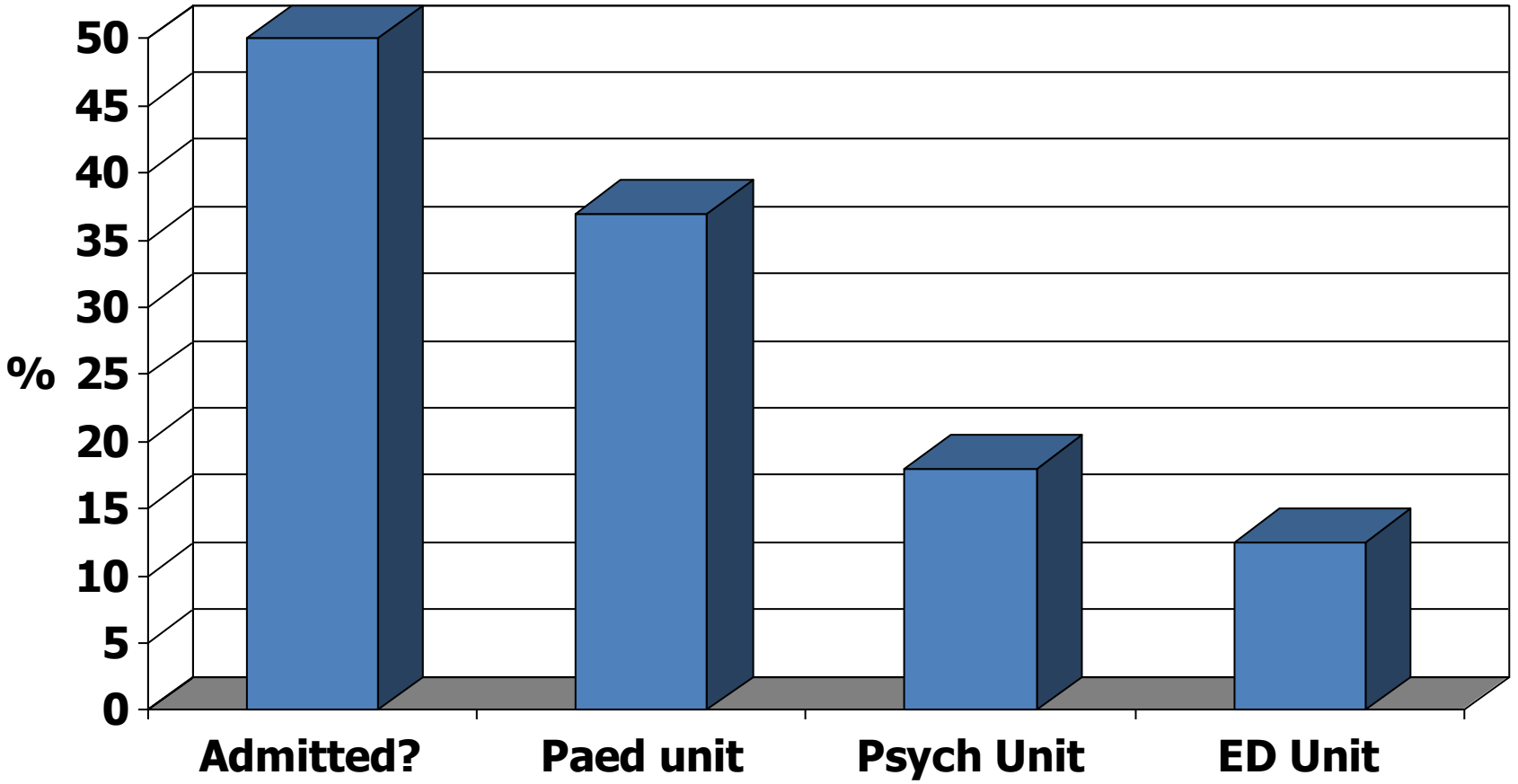
Demographics

- Mean age 11.5 years (SD 1.3)
- Mean duration of illness prior to presentation 8.3 months
- 86% white British
- 64% of females premenarcheal
- 13% males





Management



11% were NG tube fed; 13% received psychotropic medication

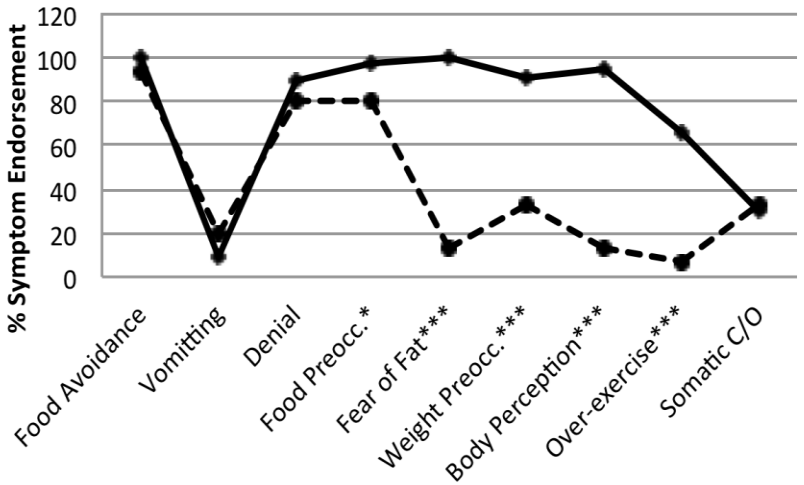
Eating Disorders in Children - A three country comparison

	Australia	Canada	UK
Sample size	100	161	208
Mean age	11.8 (±1.9)	11.3 (±1.5)	11.5(± 1.3)
Duration (wks)	25.3(±25.9)	27.7(+28.0)	34.5 (+ 29.7)
females/males	76/24(3:1)	138/22 (6:1)	171/37 (5:1)

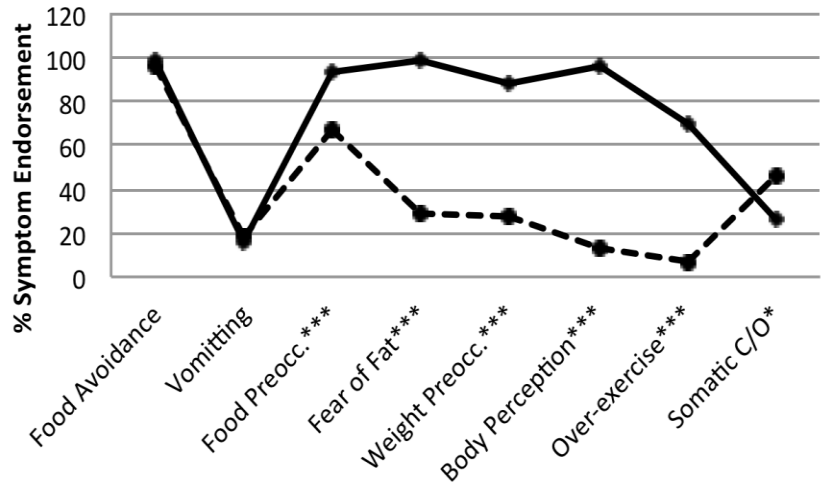
Leora Pinhas (Canada), Sloane Madden (Australia), Dasha Nicholls (UK)

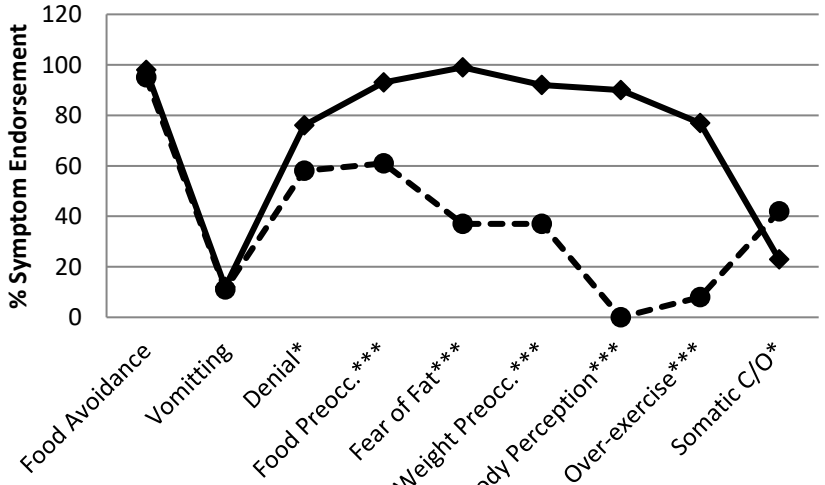
Figure 1: Differences in eating disorder symptom endorsement between the two clusters identified by latent class analysis for A) Australia (n=59), B) Canada (n=131), and C) the United Kingdom (n=162). Cluster 1, solid line; Cluster 2 dashed line. *p<0.05; **p<0.01; ***p<0.001.

A)



C)





Impact of the EOED studies

- Demonstrated clinical characteristics specific to children
  - Higher rates of males
  - Majority of children with EDs not recognised until medical complications became severe.
- Added impetus to change the diagnostic criteria in the DSM-5

Impact 2

- Influenced the training agenda for pediatricians and child mental clinicians.
- Stimulated guideline development (Junior MARSIPAN, now MEED)
- Like all PSU studies, increased awareness and familiarity of the condition

Impact 3

- Fostered closer collaboration between pediatricians and psychiatrists in the care of YP with EDs
- Taken as a model for research in other areas of child mental health, other CAPSS studies and specifically the cost effectiveness study for AN (COSTED)

Cost-effectiveness of models of care for young people with eating disorders – CostED

Sarah Byford
Ivan Eisler & Mima Simic
Dasha Nicholls
Geraldine McDonald
Fiona McNicholas
Tamsin Ford
BEAT (Jonathon Kelly)
Susan Ringwood
Jo Fletcher
Robin Glaze

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KING'S College LONDON

Design

Objective:

- To evaluate the cost and the cost-effectiveness of alternative community-based models of service provision for young people with anorexia nervosa

Design:

- Surveillance study using the Child and Adolescent Psychiatry Surveillance System (CAPSS) for a period of eight months in 2015

Setting:

- Community-based secondary or tertiary CAMHS in the UK or Republic of Ireland

Participants:

- Young people aged 8 to 17, in contact with CAMHS for a first episode of anorexia nervosa according to DSM-5

Interventions:

- Specialist eating disorders services and generic CAMHS

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CAMHS
Child and Adolescent Mental Health Services

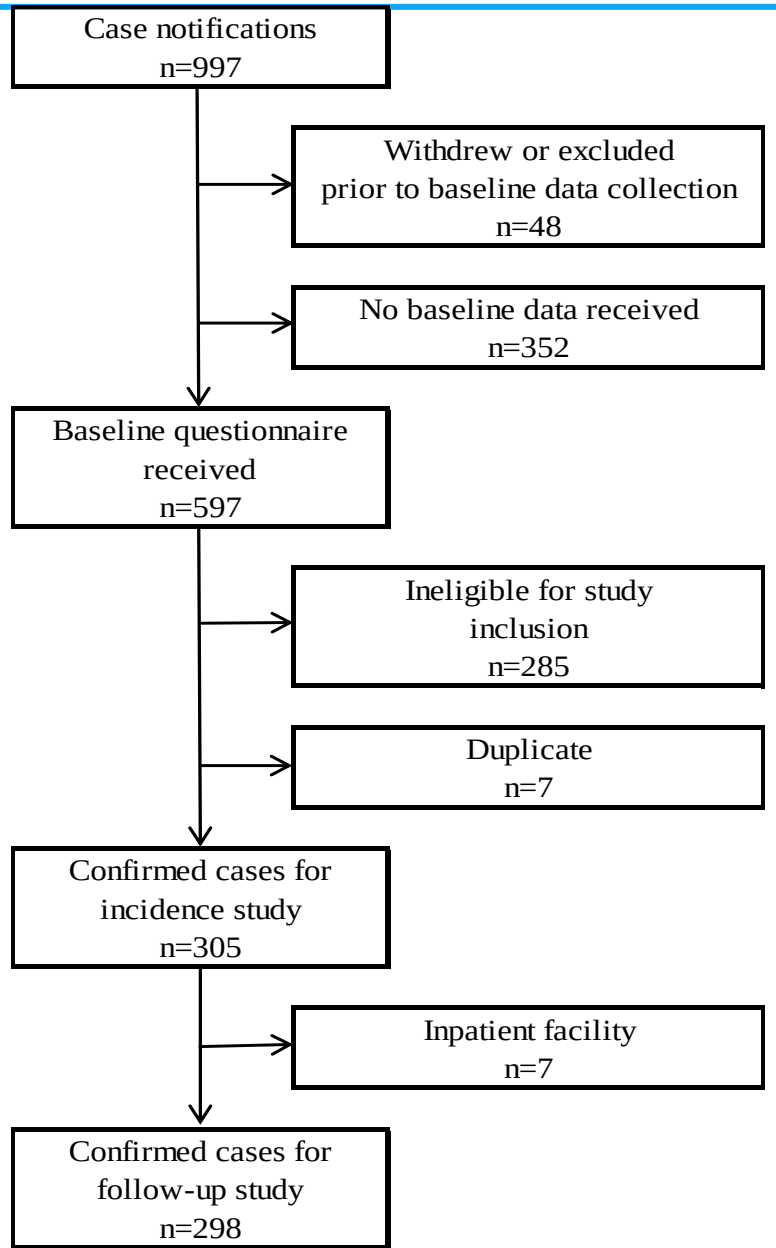
Data

- **Data sources**:
- Data collected by clinicians from clinical records
- Data collected at baseline, 6 and 12-months

- **Data included**:
- Service characteristics
- YP socio-demographic characteristics
- YP clinical characteristics
- YP use of inpatient, outpatient & daypatient services

- **Outcomes measured**:
- Children's Global Assessment Scale (CGAS)
- Percentage of median expected body mass index for age and gender (%mBMI)

Sample


Case notifications
n=997
Withdrew or excluded
prior to baseline data collection
n=48
No baseline data received
n=352
Baseline questionnaire
received
n=597
Ineligible for study
inclusion
n=285
Duplicate
n=7
Confirmed cases for
incidence study
n=305
Inpatient facility
n=7
Confirmed cases for
follow-up study
n=298

Characteristics of cases

	Mean (SD) or %
Age – mean	14.56 (1.66)
Age – category	
Children (8 to 12 years)	11.80%
Adolescents (13 to 17 years)	88.20%
Gender	
Female	91.48%
Male	8.52%
Ethnicity	
Any White	91.64%
Baseline clinical status	
%mBMI	83.23 (10.99)
CGAS*	44.61 (14.08)

* CGAS score falls within the range for 'obvious problems – moderate impairment in most areas or severe in one area' (41-50) on a scale from 1 to 100

Overview of findings

- **Findings**:
- Baseline measures poorer for those in the specialist compared to generic group
- Follow-up outcomes were similar
- Service use and total costs were similar
- Initial assessment in a specialist service has a higher probability of being cost-effective than initial assessment in generic CAMHS

- **Limitations**:
- Not randomised – but would be impossible given prevalence and still larger than largest RCT in the UK (TOuCAN study)
- Missing data – imputation did not change the results
- Bias in reporting likely to be a problem
- Focus on service in which YP initially assessed

CYP Eating Disorders Transformation

NHS England

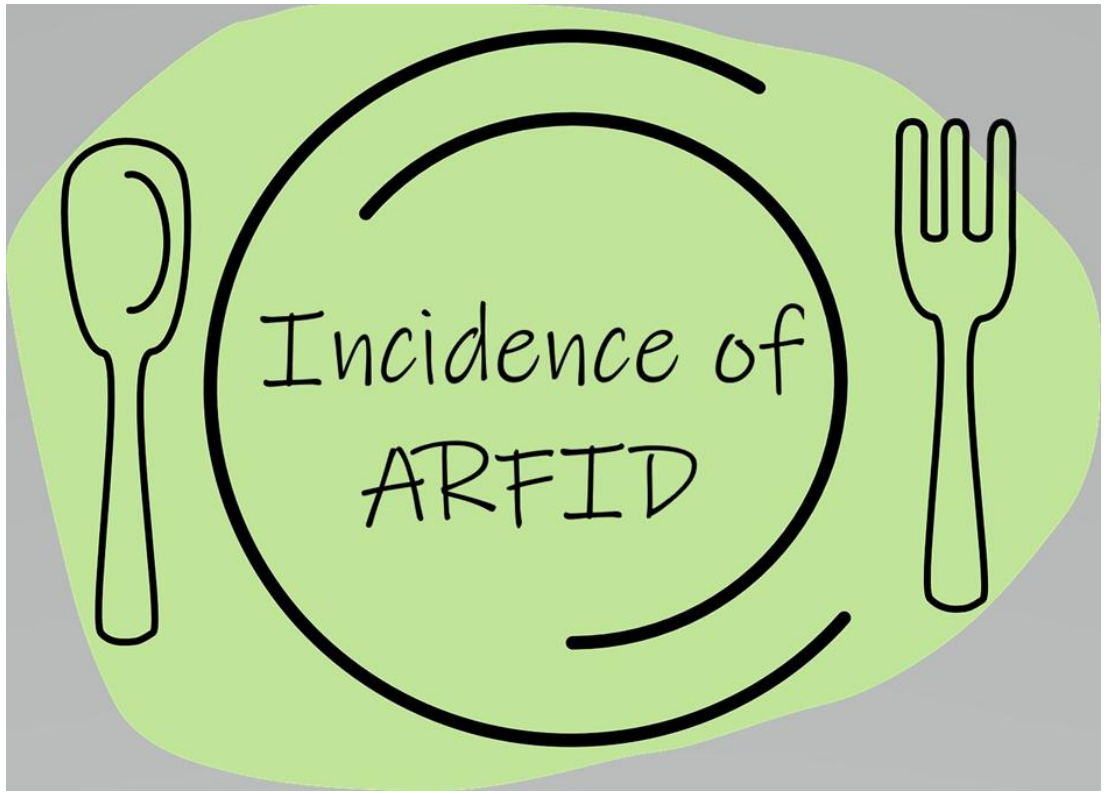
Access and waiting time standard commissioning guidance (2015)

All areas (CCGs) in England should commission a community ED service for children and young people (CYP-CEDS) delivering evidence based early interventions through to level of day care.

Set standards for timely access:
Those referred for assessment or treatment for an eating disorder should receive *NICE concordant treatment within **one week** for urgent cases and within **4 weeks** for every other case.*

Introduced and **monitored** in 2016-17 **via MHSDS and UNIFY data collection**; tolerance levels to be set and **standard implemented** from 2017-18 – **NEW extension for inpatient care-2017**

Aim is **for 95%** of those referred for assessment or treatment receive NICE concordant treatment with the ED standard RTT **by 2020**



Principal Investigator: Professor Dasha Nicholls, Imperial College London

Contributors: Javier Sanchez-Cerezo, Josephine Neale, Richard Lynn, Lee Hudson, Nikita Julius, Ellaha Haidar, Lidushi Nagularaj, Tim Croudace

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Surveillance of Rare Childhood Disease • BPSU •

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UCL GREAT ORMOND STREET INSTITUTE OF CHILD HEALTH

PRIORY

ARFID® AWARENESS UK

autistica

What is ARFID?

- Avoidant/restrictive food intake disorder
- DSM 2013

- No association with concerns about body image, weight or shape

- Excluded from NICE guidelines

- Restricted eating patterns which result in any of:
  - Significant weight loss (or failure to achieve expected weight gain or faltering growth)
  - Significant nutritional deficiency
  - Dependence on enteral feeding or oral nutritional supplements
  - Marked interference with psychosocial functioning

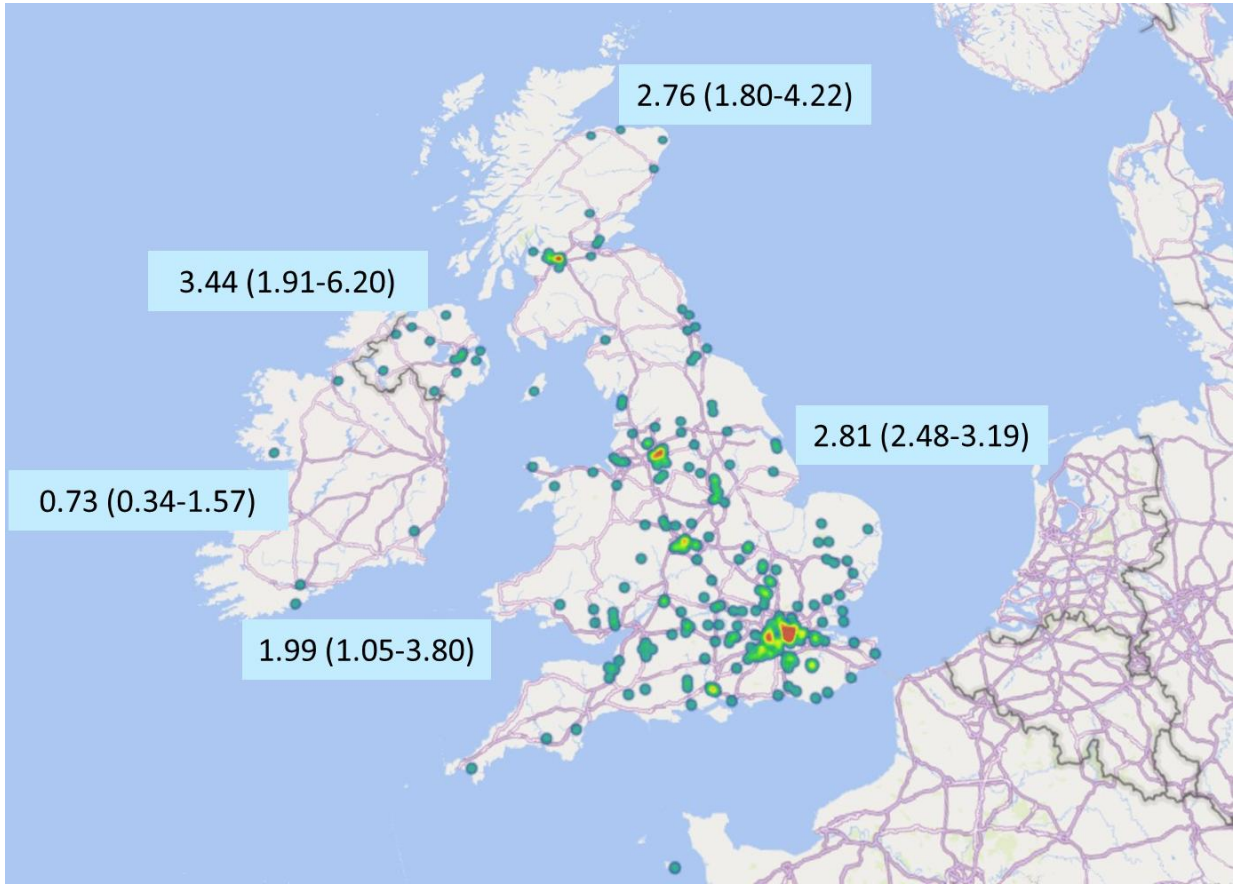
Study Design

- BPSU/CAPSS surveillance study
- Monthly electronic reporting cards
- New cases reported March 2021 – March 2022 in UK and ROI
- Paediatricians and child and adolescent psychiatrists reported newly diagnosed cases of ARFID aged 5-16 or 5-17 years

Incidence

- 319 CYP aged 5-17
- The observed incidence rate in the UK was 2.79 per 100 000 young people

- 174 male (54.5%); 145 female (45.5%)
- Mean age 11.2 yrs (range 5 – 17.99)
- Majority white ethnicity (n = 248; 78%)



Subtypes

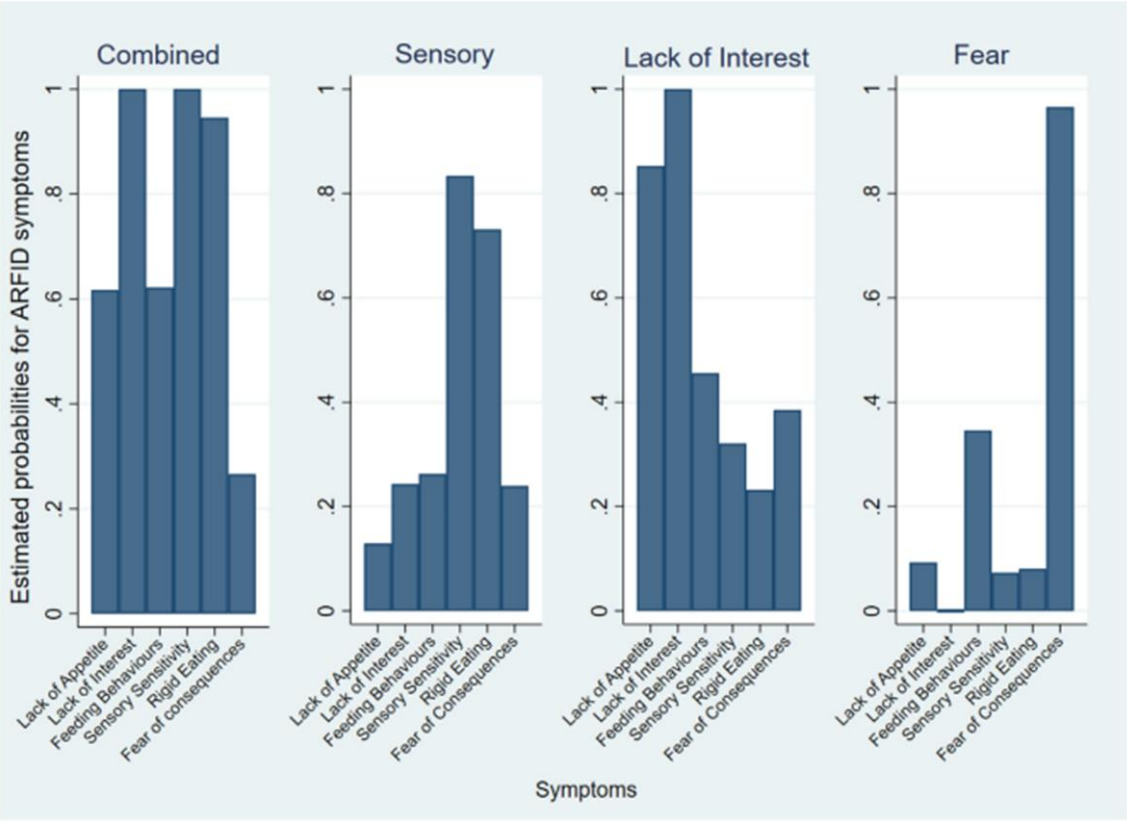


Fig. 2: Estimated item-response probabilities for ARFID symptoms by each latent class.

38% 30% 25% 7%

- LCA revealed four distinct classes
- The Combined subtype, a mixed presentation, was most common

Different presentations by service type

	Paediatricians	Psychiatrists
Age	9.8 years	13.7 years
Males	**62.4%**	43.1%
Chronic symptoms	**80.4%**	67%
Selective eating	**63.7%**	46.6%
Fear of aversive consequences	3.2%	**13.1%**
Weight loss	65.0%	**76.7%**
Comorbid autism	**67.6%**	50.0%
Comorbid anxiety	47.4%	**78.2%**

1 year follow-up

- 109 males (55.3%) and 88 females (44.7%) at follow up
- According to clinicians' overall clinical impression
  - 19 cases (9.6%) improved without treatment,
  - 89 cases (45.2%) improved with treatment,
  - 5 cases (2.5%) changed in presentation,
  - 46 cases (23.4%) persisted unchanged,
  - 6 cases (3%) worsened
  - for 32 cases (16.2%) outcome was unknown

- Comparing paediatrics and psychiatry, at follow-up, both cohorts improved in nutritional status.

- However, the psychiatric cohort improved more regarding disordered eating behaviours.

Implications

- ARFID is not a single presentation
- ARFID is rare but not that rare
- Presentation and management differs by age and sector
  - Needs integrated care pathways and joined up commissioning

Conclusion

- CAPSS has provided a central tool for providing evidence to support policy and transformation of clinical services for children and young people

Publications from the EOED study

- Nicholls D, Lynn R, Viner R. (2011) Childhood eating disorders: British national surveillance study British Journal of Psychiatry 198:295-301;
- Lynn RM, Viner RM, Nicholls DE (2011) Ascertainment of Early Onset Eating Disorders: A Pilot for Developing a National Child Psychiatric Surveillance System. Child and Adolescent Mental Health Published online: 1 July
- Hudson LD, Nicholls DE, Lynn RM, Viner RM. (2012). Medical instability and growth of children and adolescents with early onset eating disorders. Arch Dis Child. Sep;97(9):779-84.
- Katzman D, Madden S, Nicholls D, Mawjee K, Norris M. (2016) From Questions To Answers: Examining The Role Of Pediatric Surveillance Units In Eating Disorder Research. IJED.
- Pinhas L, Nicholls D, Crosby R, Morris A, Lynn R, Madden S. (2017) Classification of Childhood Onset Eating Disorders: A latent class analysis. IJED.

Publications from the COSTED study

- Byford S, Petkova H, Barrett B, Ford T, Nicholls D, Simic M, Gowers S, Macdonald G, Stuart R, Livingstone N, Kelly G, Kelly J, Joshi K, Smith H, Eisler I. Cost-effectiveness of specialist eating disorders services for children and adolescents with anorexia nervosa: a national surveillance study. J Eat Disord. 2021 Jun 26;9(1):76.
- Petkova H, Simic M, Nicholls D, Ford T, Prina AM, Stuart R, Livingstone N, Kelly G, Macdonald G, Eisler I, Gowers S, Barrett BM, Byford S. Incidence of anorexia nervosa in young people in the UK and Ireland: a national surveillance study. BMJ Open. 2019 Oct 22;9(10)
- Byford S, Petkova H, Stuart R, Nicholls D, Simic M, Ford T, Macdonald G, Gowers S, Roberts S, Barrett B, Kelly J, Kelly G, Livingstone N, Joshi K, Smith H, Eisler I. Alternative community-based models of care for young people with anorexia nervosa: the CostED national surveillance study. Southampton (UK): NIHR Journals Library; 2019 Oct.
- Mitrofan O, Petkova H, Janssens A, Kelly J, Edwards E, Nicholls D, McNicholas F, Simic M, Eisler I, Ford T, Byford S. Care experiences of young people with eating disorders and their parents: qualitative study. BJPsych Open. 2019 Jan;5(1):e6.

Publications from the ARFID study

- Sanchez-Cerezo J, Neale J, Julius N, Lynn RM, Hudson L, Nicholls D. Incidence of avoidant/restrictive food intake disorder in children and adolescents across the UK and Ireland: a BPSU and CAPSS surveillance study. BMJ Open. 2024 Nov 27;14(11)
- Sanchez-Cerezo J, Neale J, Julius N, Croudace T, Lynn RM, Hudson LD, Nicholls D. Subtypes of avoidant/restrictive food intake disorder in children and adolescents: a latent class analysis. EClinicalMedicine. 2024 Feb 1;68:102440.
- Haidar E, Sanchez-Cerezo J, Neale J, Julius N, Lynn RM, Hudson LD, Nicholls D. Comparison of clinical presentation and management of children and adolescents with ARFID between paediatrics and child and adolescent psychiatry: a prospective surveillance study. Arch Dis Child. 2025 Jan 24;110(2):144-150.
- Sanchez-Cerezo J, Nagularaj L, Gledhill J, Nicholls D. What do we know about the epidemiology of avoidant/restrictive food intake disorder in children and adolescents? A systematic review of the literature. Eur Eat Disord Rev. 2023 Mar;31(2):226-246.