

BMJ Open Incidence of avoidant/restrictive food intake disorder in children and adolescents across the UK and Ireland: a BPSU and CAPSS surveillance study

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ABSTRACT

Objective We aimed to estimate the incidence of avoidant/restrictive food intake disorder (ARFID) in children and adolescents (CA) presenting to secondary care in the UK and Republic of Ireland (ROI).

Design This observational surveillance study used the British Paediatric Surveillance Unit and the Child and Adolescent Psychiatry Surveillance System. Monthly electronic reports were submitted by consultant paediatricians and child and adolescent psychiatrists from 1 March 2021 to 31 March 2022, with outcomes assessed at a 1-year follow-up.

Setting The UK and ROI.

Participants Clinician-reported data on children and young people aged 5–17 (inclusive) in contact with paediatric services or CA mental health services for a new diagnosis of ARFID.

Primary outcome measures Annual incidence rates (IRs) estimated as confirmed new cases per 100 000 population at risk.

Results 319 newly diagnosed cases of ARFID were reported over the 13-month surveillance period and assessed as eligible for inclusion. The mean age of the sample was 11.2 years (SD=3.8). The sample consisted of 145 females (45.5%). Most cases were of white British ethnicity (71.2%). The observed IR (IRO) in the UK was 2.79 per 100 000 CA (95% CI 2.48 to 3.13), with a higher IRO in males (2.98 per 100 000 CA (95% CI 2.55 to 3.49)) than in females (2.58 per 100 000 CA (95% CI 2.18 to 3.07)). Comorbidity was common in this sample with anxiety and autism spectrum disorder. At follow-up, 54.8% of cases had improved according to clinicians' clinical impression.

Conclusions We conducted the first study reporting estimates of incidence of ARFID in CA in the UK and ROI presenting to secondary care. Our finding that ARFID is a disorder of relatively low incidence in CA should help inform service planning and resource allocation, as well as the development of evidence-based interventions.

INTRODUCTION

Avoidant/restrictive food intake disorder (ARFID) is defined by a persistent disturbance in feeding or eating, that results in at least one of the following: weight loss or insufficient weight gain; nutritional deficiencies; reliance

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study used national paediatric surveillance methodology.
- ⇒ The study benefits from a large, nationally representative sample from across the UK and Ireland and from data on the outcomes at 1-year follow-up.
- ⇒ Surveillance methodology is limited to cases seen in teams that have a consultant paediatrician or child and adolescent psychiatrist, so young people with avoidant/restrictive food intake disorder treated in primary care or in psychology or dietetic-led services will not be included and so does not provide accurate data on community prevalence.
- ⇒ The findings of this study will influence service planning and resource allocation, as well as the development of evidence-based interventions.

on enteral feeding or nutritional supplements; or substantial impact on psychosocial functioning. ARFID was first introduced as a distinct diagnosis in the Diagnostic and Statistical Manual of Mental Disorders (5th ed.; DSM-5) in 2013,¹ and it has since been included in the International Classification of Diseases 11th Revision.² Prior to its inclusion in the DSM5, people with ARFID, depending on their age and presentation, were diagnosed with Feeding Disorder of Infancy and Early Childhood, Eating Disorder Not Otherwise Specified or other terminology (eg, selective eating, food avoidance emotional disorder, functional dysphagia) that were not formally diagnoses.^{3 4} The DSM-5 describes that food restriction in ARFID can stem from heightened sensitivity to sensory characteristics of food—such as its texture, colour or temperature; from a lack of interest in eating or food; or from anxiety related to food, including fears of negative experiences like choking or vomiting.¹ These three presentations are not mutually exclusive, and a combined

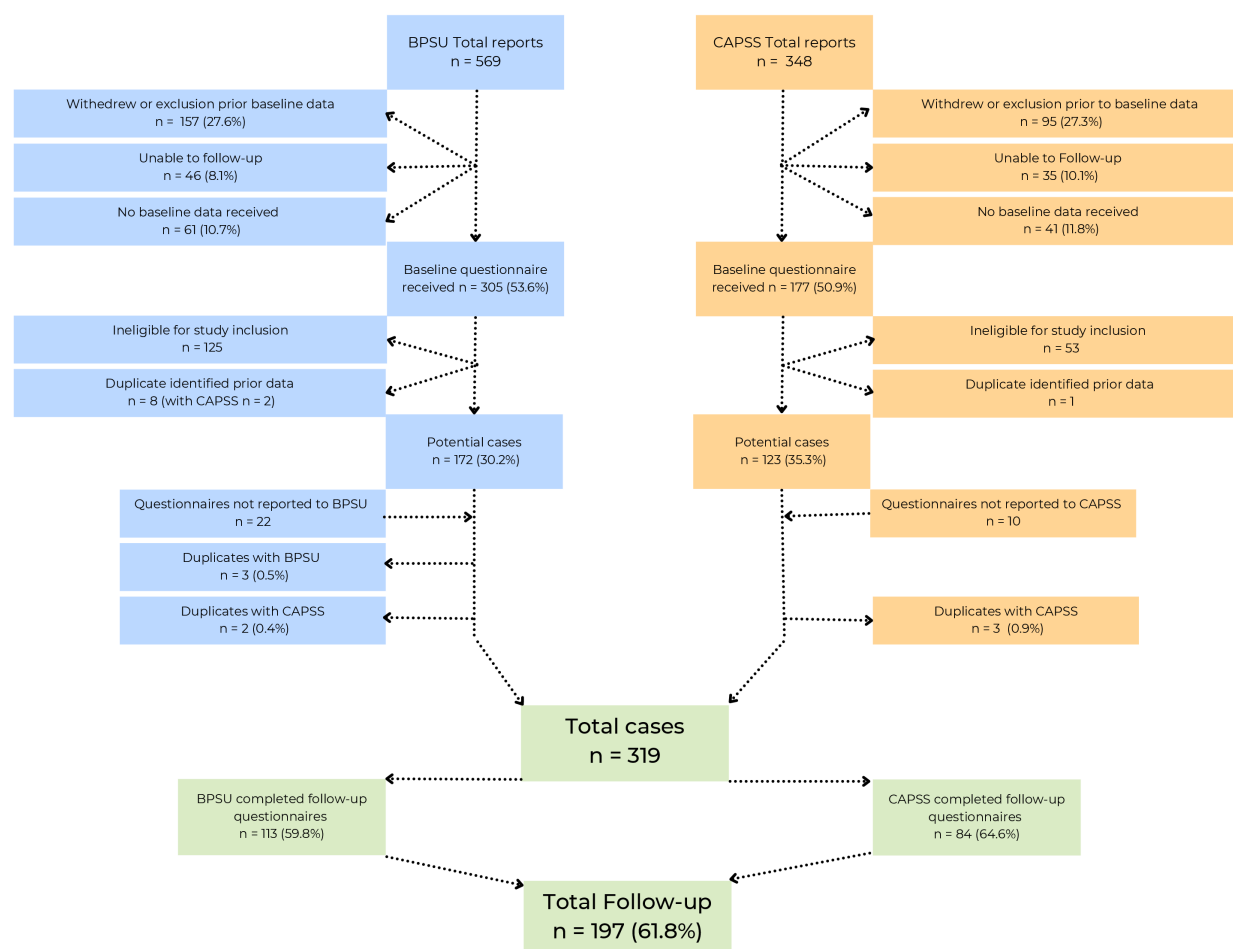


Figure 1 Flow diagram of case ascertainment. Figure 1 shows the flow of individuals from notification to case validation: after reporting a case to BPSU or CAPSS, clinicians were contacted to complete a questionnaire. Reporting errors (such as prevalent cases or confirmed diagnosis of anorexia nervosa) were excluded prior to baseline questionnaire completion after contacting the clinician. Unable to follow-up cases were those excluded due to clinicians stating that they did not wish to be included in the study (due to retirement, shortage of reporting capacity and so on). Cases were excluded if no response was obtained after multiple attempts to contact the notifying clinician or their team (no baseline data received). Completed questionnaires by reporting clinicians were examined to confirm cases were eligible for inclusion. Duplicates were identified and excluded. Additional cases from other sources that met inclusion criteria were added (ie, cases from consultants that did not report the case to the surveillance units but contacted the research team and completed the questionnaire). A 1-year follow-up questionnaire was sent to clinicians reporting confirmed cases. BPSU, British Paediatric Surveillance Unit; CAPSS, Child and Adolescent Psychiatry Surveillance System.

presentation is more common than one specific subtype in some settings.^{5–7}

Understanding the epidemiology of a disorder is essential for assessing clinical service needs and identifying at-risk populations. A recent systematic review found that epidemiological studies on ARFID in children and adolescents (CAs) vary widely, with prevalence estimates ranging from 0.3% to 64%, depending on study setting, methodology and sample characteristics.^{8,9} To date, only one study has reported incidence of ARFID, which is more useful than prevalence for predicting clinical care demand. This was a surveillance study from Canada which found that the incidence of ARFID was 2.02 per 100 000 CAs aged 5–18 years presenting to paediatricians.¹⁰

Surveillance methodology has previously proved helpful in the study of paediatric eating disorders and associated issues that need clinical and research focus in order to develop appropriate care.^{8,11} The number of CAs with symptoms of ARFID presenting to secondary care in the UK and Republic of Ireland (ROI) is currently unknown which is problematic with regard to understanding need and planning appropriate care.

We, therefore, conducted a surveillance study to estimate the incidence of ARFID in CAs presenting to secondary care in the UK and ROI; to describe clinical characteristics, psychiatric comorbidities, family history and management plans and to assess outcome at 1 year.

METHODS

Design

We undertook an observational surveillance study in collaboration with the British Paediatric Surveillance Unit (BPSU) and the Child and Adolescent Psychiatry Surveillance System (CAPSS). The BPSU was established in 1986 in the UK and ROI to facilitate the study of rare paediatric conditions.¹² In 2007, this was supplemented with the launch of the CAPSS, the first mental health-specific surveillance system.¹³ These surveillance systems work by sending monthly electronic reporting ecards listing health conditions currently under study to all consultant paediatricians (BPSU) and consultant child and adolescent (CA) psychiatrists (CAPSS) in the UK and ROI. The reporting ecards are returned to the surveillance systems who inform the research team when a clinician reports a case. Reports of no case provide the denominator. A questionnaire is then sent to the reporting clinician for further details about the case. BPSU surveyed 4298 consultant paediatricians and CAPSS surveyed 695 consultant CA psychiatrists during the study period.

Case definition

We developed the surveillance case definition (online supplemental file 1) which was approved by both BPSU and CAPSS committees based on modified DSM-5 diagnostic criteria for ARFID¹ and was included in the monthly ecard sent to consultant paediatricians and CA psychiatrists. This surveillance case definition was purposely broad to ensure that all cases were recognised and reported.¹² We confirmed the cases of ARFID by using the analytic case definition (a more detailed case definition used by the study team) after reporting clinicians completed a questionnaire with details of the case (online supplemental file 2). In any unclear cases, we reached a consensus between the study team on whether the criteria for ARFID had been met. We did not include the identified duplicate case reports in the final dataset.

Data collection

We ascertained newly diagnosed cases of ARFID over a 13-month period (from 1 March 2021 to 31 March 2022), as is customary with surveillance studies. Follow-up took the form of data collection at 12 months after a case of ARFID was reported through a second questionnaire sent to reporting clinicians. We collected and managed study data by using Research Electronic Data Capture^{14 15}, a secure, web-based software platform hosted at Imperial College London. We developed a questionnaire specifically for this study. We asked reporting clinicians to report patients' sex in the questionnaire.

Statistics

We analysed the data in Stata (V.17, StataCorp) and Microsoft Excel. Our analyses were descriptive. Newly diagnosed cases of ARFID were classified into three different age groups: 5–9 years, 10–13 years and 15–17 years.

We calculated the observed incidence rates (IR0), defined as the number of new cases during a specified period of time in a population at risk for developing the disease, as follows: the number of confirmed new cases of ARFID in the 13-month surveillance period converted to 12 months ((N cases over 13 months/13)×12), divided by the population at risk in UK and ROI and multiplied by 100 000 to give the rate per 100 000 young people. We assumed the population at risk as the total population of children and young people. We obtained the data for the total population of children for 2021 aged 5–17 (inclusive) from the Office of National Statistics (UK)¹⁶ and the Central Statistics Office (ROI).¹⁷

$$IR0 = (\text{confirmed new cases converted to 12 months}) / \text{total population} \times 100\,000.$$

For each IR, we calculated the total, age-group-specific and sex-specific annual IRs for ARFID for the year 2021 and 95% CIs.

Public and patient involvement

One adult patient representative and one child patient representative with ARFID contributed to the development and design of the study. We also had feedback from the charities ARFID Awareness UK and Autistica.

Role of the funding source

The funding source had no role in study design, data collection, data analysis, data interpretation or writing of the report.

RESULTS

Case ascertainment can be seen in figure 1. The response rate to the monthly electronic reporting ecards was 78.5% for BPSU and 47.5% for CAPSS. We received 81.2% of the initial questionnaires that were sent to paediatricians (BPSU) reporting positive cases of ARFID and 78.1% of those sent to CA psychiatrists (CAPSS). A total of 917 potential cases of ARFID were reported (569 from BPSU and 348 from CAPSS) over 13 months. Of those, 319 CAs with ARFID aged 5–18 years (mean age=11.2 years; (SD=3.8; range 5.00–17.99); female=45.5%) living in the UK and ROI met the analytic case definition and were included. Only four duplicates between both surveillance units were identified. Most cases were of white British ethnicity (71.2%). Nearly half of the sample (44.1%) was prepubertal and the majority were born at term. We show the demographic characteristics of the incident cases in table 1. We report the proportion of the included sample notified from each region within the UK and ROI in table 2. England notified 83.1% of new ARFID cases; Wales notified 3.1%; Scotland notified 7.2%; Northern Ireland notified 3.8% and the ROI notified 2.2%. Two cases were reported from the Crown Dependencies. 126 cases were included in the 5–9 years group; 100 cases in the 10–13 years group and 93 cases in the 14–17 years group.

Table 1 Demographic characteristics of incident cases

	N	Mean (SD) or %
Age	319	11.2 (3.78)
Sex		
Female	145	45.5
Male	174	54.5
Ethnicity		
White British	227	71.2
Other	72	22.6
Unknown/not reported	20	6.3
Pubertal development		
Prepubertal	141	44.2
In puberty	57	17.9
Fully mature	38	11.9
Unknown/not reported	83	26.0
Gestation		
Preterm (<37 weeks)	18	5.6
Term (≥37 weeks)	193	60.5
Unknown/not reported	108	33.9

Incidence rates

Table 3 shows the IR0 of ARFID by sex and by age group. The cases from the Crown Dependencies were not included in the IR calculation. The IR0 in the UK including all age groups was 2.79 per 100 000 young people (95% CI 2.48 to 3.13), with a higher IR0 in males (2.98 per 100 000 young people (95% CI 2.55 to 3.49)) than in females (2.58 per 100 000 young people (95% CI 2.18 to 3.07)). The highest IR0 for males in the UK was in the group aged 5–9 years (4.22 per 100 000 young people (95% CI 3.41 to 5.21)). The IR0 for females in the UK was higher than for males in the group aged 10–13 years (3.02 per 100 000 young people (95% CI 2.28 to 4.01)) and in the group aged 14–17 years (3.40 per 100 000 young people (95% CI 2.58 to 4.48)). The IR0 in England including all age groups and both sexes was 2.81 per 100

Table 2 Cases by region of the UK and Ireland over 13 months surveillance

Region	Incident cases (N)			%
	BPSU	CAPSS	Total	
England	154	111	265	83.1
Wales	7	3	10	3.1
Scotland	13	10	23	7.2
Northern Ireland	7	5	12	3.8
Republic of Ireland	6	1	7	2.2
Other*	2	0	2	0.6

*Crown Dependencies.

BPSU, British Paediatric Surveillance Unit; CAPSS, Child and Adolescent Psychiatry Surveillance System.

Table 3 Observed annual incidence of ARFID in young people aged 5–18 for 2021, reported per 100 000 young people in the UK and Ireland

Age group	Sex	UK and Republic of Ireland	UK
5–9 years	Female	1.51 (1.06–2.14)	1.59 (1.11–2.26)
	Male	3.88 (3.14–4.80)	4.22 (3.41–5.21)
	Total	2.72 (2.27–3.27)	2.93 (2.44–3.52)
10–13 years	Female	2.87 (2.18–3.79)	3.02 (2.28–4.01)
	Male	2.30 (1.70–3.11)	2.33 (1.70–3.19)
	Total	2.58 (2.10–3.17)	2.67 (2.16–3.29)
14–17 years	Female	3.19 (2.43–4.19)	3.40 (2.58–4.48)
	Male	1.94 (1.38–2.73)	2.11 (1.50–2.96)
	Total	2.55 (2.06–3.15)	2.74 (2.21–3.39)
All age groups (5–17 years)	Female	2.45 (2.06–2.90)	2.58 (2.18–3.07)
	Male	2.80 (2.39–3.26)	2.98 (2.55–3.49)
	Total	2.63 (2.34–2.94)	2.79 (2.48–3.13)

ARFID, avoidant/restrictive food intake disorder.

000 young people (95% CI 2.48 to 3.19). Similarly, the IR0 in Scotland was 2.76 per 100 000 young people (95% CI 1.80 to 4.22). The lowest IR0 across the UK was reported in Wales (1.99 per 100 000 young people (95% CI 1.05 to 3.80)) while the highest was in Northern Ireland (3.44 per 100 000 young people (95% CI 1.91 to 6.20)). The IR0 in the ROI including all age groups and both sexes was 0.73 per 100 000 young people (95% CI 0.34 to 1.57). The IR0 in the total population, including the UK and ROI, was 2.63 (95% CI 2.34 to 2.94).

Psychiatric comorbidities and family history

Table 4 displays the past and present psychiatric comorbidities and psychiatric family history for the included cases. Anxiety (40.8%), deliberate self-harm (DSH) (8.8%), depression (6.3%) and obsessive-compulsive disorder (OCD) (5.6%) were the most common past mental illness comorbidities in the sample. Regarding current comorbidities, anxiety was the most common (43.9%), followed by depression (7.8%) and OCD (5.3%). Comorbidities with neurodevelopmental disorders were common, the highest being with autism spectrum disorder (ASD) (43.9%), followed by learning disabilities (LD) (20.4%) and attention-deficit/hyperactivity disorder (ADHD) (7.2%). 55 cases (17.2%) had both ASD and present anxiety. The most common past and current mental illnesses in the family history were depression (14.7 and 8.5%, respectively), anxiety (13.5 and 11.6%) and OCD (3.1 and 2.2%). Family history of ASD was reported in 13.5% of the sample and ADHD in 5.0%.

Management plans

Regarding the outpatient management of cases, medical outpatient monitoring was used in 211 new cases of ARFID (66.1%), dietetic advice in 246 cases (77.1%), psychoeducation (ie, provision of information about the disorder to the patient and their families) in 165 cases (51.7%), medication in 75 cases (23.5%), tube feeding in 21 cases (6.6%), nutritional supplements in 133 cases (41.7%), individual

Table 4 Psychiatric comorbidities and family history

	Past		Present	
	N	%	N	%
Comorbidities				
Depression	20	6.3	25	7.8
Anxiety	130	40.8	140	43.9
OCD	18	5.6	17	5.3
Alcohol misuse	1	0.3	0	0
Substance misuse	2	0.6	1	0.3
DSH	28	8.8	15	4.7
LD*			65	20.4
ADHD*			23	7.2
ASD*			140	43.9
Family history				
Depression	47	14.7	27	8.5
Anxiety	43	13.5	37	11.6
OCD	10	3.1	7	2.2
Alcohol misuse	4	1.3	4	1.3
Substance misuse	5	1.6	3	0.9
Anorexia nervosa	5	1.6	2	0.6
Bulimia nervosa	2	0.6	0	0
DSH	5	1.6	3	0.9
LD*			9	2.8
ADHD*			16	5.0
ASD*			43	13.5

*Neurodevelopmental disorders (ie., LD, ADHD, and ASD) were only included in the column of present disorders.
ADHD, attention-deficit/hyperactivity disorder; ASD, autism spectrum disorder; DSH, deliberate self-harm; LD, learning difficulties; OCD, obsessive-compulsive disorder.

psychological therapy in 85 cases (26.7%), family therapy in 58 cases (18.2%) and input from another specialty in 94 cases (24.5%). In total, 37 new cases of ARFID (11.6%) were admitted to a paediatric inpatient unit or day care and 12 cases (3.8%) were admitted to a psychiatric inpatient unit or day care. Regarding psychiatric medication, 36 cases (11.3%) were prescribed antidepressants, 8 cases (2.5%) were prescribed antipsychotics, 11 cases (3.5%) were prescribed stimulants, and 31 cases (9.7%) were prescribed melatonin. Regarding the follow-up plans, clinicians reported that 186 cases (58.3%) were going to be followed up with the same clinician that completed the questionnaire, 28 cases (8.8%) were going to be referred to a medical specialist, 67 cases (21.0%) to a psychiatric specialist, 54 cases (16.9%) to a psychologist, 79 (24.8%) to another healthcare provider and 18 cases (5.6%) discharged to primary care.

Outcomes at 1-year follow-up

Follow-up data were available for 197 (61.8%) participants (113 from BPSU and 84 from CAPSS) (figure 1).

At follow-up, the sample consisted of 109 males (55.3%) and 88 females (44.7%). According to the reporting 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 and for 32 cases (16.2%) the reporting clinicians reported that outcome was unknown.

We asked clinicians to report in the follow-up questionnaire if any concurrent mental disorder, neurodevelopmental disorder diagnosis or disability emerged since completion of the baseline questionnaire: 5 cases (2.5%) were diagnosed with depression, 13 cases (6.6%) with anxiety, 2 cases (1.0%) with OCD, 4 cases (2.0%) with ADHD, 1 case with substance misuse (0.5%), 17 cases (8.6%) with ASD, 3 cases (1.5%) with LD, 1 cases (0.5%) with DSH, 2 cases (1.0%) with anorexia nervosa and 4 cases (2.0%) with other eating disorder.

Regarding the management clinicians reported the following in the follow-up questionnaire: medical outpatient monitoring was used in 137 cases of ARFID (69.5%), dietetic advice in 165 cases (83.8%), psychoeducation in 108 cases (54.8%), medication in 52 cases (26.4%), tube feeding 21 cases (10.7%), nutritional supplements in 78 cases (39.6%), individual psychological therapy in 52 cases (26.4%), family therapy in 36 cases (18.3%) and input from another specialty in 47 cases (23.9%). Regarding the follow-up plans, clinicians reported that 186 cases (58.3%) were going to be followed up with the same clinician that completed the questionnaire, 28 cases (8.8%) were going to be referred to a medical specialist, 67 cases (21.0%) to a psychiatric specialist, 54 cases (16.9%) to a psychologist, 79 (24.8%) to another healthcare provider and 18 cases (5.6%) discharged to primary care. In total, 22 cases of ARFID (11.2%) were admitted to a paediatric inpatient unit or day care and 3 cases (1.5%) were admitted to a psychiatric inpatient unit or day care. Regarding the follow-up plans, 95 cases (48.2%) were going to be followed up with the same clinician that completed the questionnaire, 15 cases (7.6%) were going to be referred to a medical specialist, 22 cases (11.2%) to a psychiatric specialist, 23 cases (11.7%) to a psychologist, 27 (13.7%) to another healthcare provider and 62 cases (31.5%) discharged to primary care.

At follow-up, clinicians reported that there was a safeguarding referral in 7 cases (3.6%), other social care support in 12 cases (6.1%), special educational assessment in 8 cases (4.1%), special educational provision (including change of school) in 13 cases (6.6%) and other agencies or referrals in 22 cases (11.2%).

DISCUSSION

This is the first study reporting IRs of ARFID in CAs using paediatric surveillance methodology in the UK and ROI. We found that the IRO of ARFID in the UK was 2.79 per 100 000 young people aged 5–17 years. Our results are similar to those reported by Katzman *et al*¹⁰ who first reported

an IR of ARFID in CAs in Canada of 2.02 per 100 000 young people, a slightly lower rate than in the UK. The methodology used in the Canadian study was very similar to the present study. However, they only surveyed paediatricians while in our study we included cases reported by both paediatricians and CA psychiatrists. A previous surveillance study of childhood eating disorders (using DSM-IV criteria) conducted in the UK and ROI including children aged 5–12 years reported an IR of 3.01 per 100 000.¹⁸ Some of those identified cases would now be diagnosed with ARFID, with the latent class analysis in Pinhas *et al*¹⁹ suggesting a proportion of 34% (55 cases). These differences could be explained by increasing recognition of childhood onset eating disorders, and ARFID specifically, and/or increasing incidence of eating disorders in childhood since these studies were performed.

We found that the IR in males was higher in the youngest age group (aged 5–9 years) with an IR of 4.22 per 100 000 young people than in the other two age groups. In contrast, the IR in females was higher than that of males in the two older age groups. Overall, including all age groups, the IR in the UK of males (2.98 per 100 000) was higher than that of females (2.58 per 100 000). In contrast, the Canadian study¹⁰ found a higher incidence in females (2.54 per 100 000) than among males (1.52 per 100 000). Contrary to the initial ARFID studies that were conducted in specialised eating disorders services,^{20–25} our study had a slightly higher proportion of males (54.5%) than females (45.5%) which is consistent with prior studies using general population samples^{26–28} and supports the idea that ARFID is equally common in boys and girls or even more frequent in boys.⁸ We speculate that the different IRs in our sample between sexes and age groups are related to different drivers of food avoidance or restriction with younger boys having more sensory sensitivities and comorbidity with ASD and older girls having more lack of interest in eating and fear of consequences of eating and comorbid emotional disorders.⁷

The IR in the ROI, 0.73 per 100 000 children and young people, was lower probably due to a lower reporting pattern and might not be due to actual lower IRs. Some prior surveillance studies using the BPSU and CAPSS methodology have used assumptions to account for the incidence among unreturned cards and uncompleted questionnaires.^{29,30} If those assumptions are used, the IRs are considerably higher (we provide the IRs for the UK using similar assumptions in online supplemental file 3. The capture–recapture method³¹ was not applied in this study because it was felt that the potential for paediatricians and CA psychiatrists to see all cases was questionable, given the lack of duplicates between the two.

Regarding accessibility to health services, our study refers to contact with general paediatric services (both acute and community) and mental health services, both of which are widely available but require referral through primary care and health inequalities may occur at both levels of access. However, ethnic minorities have

historically been less likely to receive a diagnosis or treatment for an eating disorder.³² In our study, the cohort reported by paediatricians consisted of a slightly wider range of ethnic minorities (68.3% of the paediatric cohort were individuals identified as white British against 75.4% of the psychiatric). Efforts should be made to reduce any ethnic inequalities in accessing healthcare.

We found that CAs with ARFID often present with a comorbid psychiatric disorder, with anxiety the most common. This is important because the presence of anxiety or other mental disorder indicates that potentially treatable factors may contribute to the presentation, and that assessment for psychological or pharmacological intervention is warranted. In our sample, 39.7% of patients seen in paediatric care were referred to mental health or psychology services. Other common comorbidities were neurodevelopmental disorders, especially ASD and LD. The rate of comorbidity with ASD in our sample was high, with 44% of the sample having a diagnosis of ASD. Other studies conducted in the UK have also reported high comorbidity of ASD and ARFID. For example, in the study by Watts *et al*.³³ 28% of their sample of CAs with ARFID had comorbid ASD and a further 23% had suspected ASD; and in the study by Farag *et al*³⁴ almost 55% of patients with ARFID referred to a tertiary care paediatric feeding clinic had a comorbid diagnosis of ASD. However, in the Canadian surveillance study of ARFID, the rate of ASD was much lower, around 8% of the sample. Overall, our results are consistent with prior literature which describes that usually CA with ARFID present with a psychiatric comorbidity.^{8,35} We found that it is not uncommon that CAs with ARFID have a family history of psychiatric disorders, most commonly past and/or current anxiety and depression, and ASD.

Clinicians reported that management plans for CAs with ARFID most commonly included dietetic advice, medical monitoring and psychoeducation. Almost 60% of cases were going to be followed up by the same clinicians who reported the cases and only 18 cases (5.4%) were going to be discharged to primary care. Among clinicians who reported they would follow up on the case themselves, 75% completed the follow-up questionnaire. The number of cases requiring hospital treatment was low in our sample, with 37 new cases of ARFID (11.6%) being admitted to a paediatric inpatient unit or day care and 12 cases (3.8%) to a psychiatric inpatient unit or day care.

The most commonly used psychiatric medications were selective serotonin reuptake inhibitors, followed by melatonin, stimulants and antipsychotics, which we speculate were likely used to treat the comorbidities. As a new diagnosis, evidence for pharmacological interventions for ARFID is still limited.

According to clinicians' clinical impression, almost half of the cases for which information was available improved with treatment and 10% improved without treatment at follow-up. Most common emergent psychiatric disorders at follow-up were anxiety and ASD. Two cases were diagnosed with anorexia nervosa and four with another eating

disorder (not bulimia nervosa) at follow-up. Further research using a longitudinal design should explore the temporal stability of the ARFID diagnosis and identify factors that predispose to a diagnosis of anorexia nervosa. Reported management and follow-up plans were similar in the baseline and follow-up questionnaire but the proportion of cases discharged to primary care increased almost sixfold at 1-year follow-up.

Strengths and limitations of this study

Using active surveillance methodology enabled ascertainment of national prospective data from paediatricians and CA psychiatrists in the UK and ROI. This large sample included CYP of different ages and geographical areas, ensuring data were representative. Our study is the first to report outcomes at 1 year in a large representative sample of CAs with ARFID. Our results are of relevance primarily to the UK and Ireland but may be of value to other European countries.

It has been suggested that the current ARFID DSM-5 diagnostic criteria may not ensure optimal diagnostic validity to be useful in epidemiological research, given it is an umbrella term encompassing a number of presentations.³⁶ Surveillance methodology is limited to cases seen in teams that have a consultant paediatrician or CA psychiatrist, so ARFID cases treated in primary care or in psychology or dietetic-led services will not be included and so does not provide accurate data on community prevalence. Case ascertainment in surveillance studies also relies on clinicians' ability to make accurate diagnoses. In recent years, clinicians have become more familiar with ARFID, but diagnostic challenges still exist. For example, children with ASD often present with feeding difficulties³⁷ and identifying those that reach the diagnostic threshold for ARFID may be difficult. There might be difficulties when applying the ARFID diagnostic criteria in situations when there are comorbid psychiatric or medical conditions that may cause restrictive eating and food avoidance or selectivity. Another limitation is that we did not include children under 5 years of age. The DSM-5 states that ARFID can be diagnosed across the lifespan¹ but we excluded children under 5 years because CA psychiatrists do not see this population; picky or fussy eating is common in younger children,³⁸ and therefore, may be more difficult to differentiate from cases of ARFID and carries the risk of overreporting in children under 5 years of age; and we also wanted to compare IRs with those reported in Canada.¹⁰

In our study, data were collected using a questionnaire developed by the authors and diagnoses were inferred on the basis of operational criteria. We modelled our definition based on the Canadian surveillance study¹⁰ to allow for comparisons. Diagnoses were not validated using a clinical instrument such as the Pica, ARFID and Rumination Disorder Interview (PARDI).³⁹ The PARDI was not available when the study protocol was designed. Neither were any screening tool such as the Eating Disturbances in Youth-Questionnaire²⁸ or the Nine-Item ARFID Screen

that would have helped to increase diagnostic accuracy.⁴⁰ Sex was reported in the questionnaire by the responsible clinician and it was limited to male or female, which did not allow to report intersex individuals.

The response rate to the initial ecard from CAPSS was lower than in previous studies (47.5%) and the BPSU response rate was also slightly lower than is typical. This may in part be a result of the clinical pressures services experienced during the COVID-19 pandemic. During the COVID-19 pandemic, there was a well-recognised increase observed worldwide with regard to eating disorder psychopathology.⁴¹ However, a recent systematic review has suggested that the increase did not apply to ARFID presentations.⁴²

The lower number of new cases of ARFID in ROI may be due to an actual lower incidence or to a different reporting pattern to the BPSU and CAPSS. In our prospective research design, loss to long-term follow-up may introduce bias in data analysis for longitudinal findings. Due to the nature of the data, we were not able to compensate for missing data in the analyses.

Conclusion

This is the first study reporting estimates of incidence of ARFID in CAs in the UK and ROI using surveillance methodology. Our findings suggest that ARFID is a disorder of relatively low incidence in CAs. Our results show that boys have a higher incidence than girls during childhood while the opposite happens during adolescence. These findings will influence service planning and resource allocation, as well as the development of evidence-based interventions. Further surveillance studies should be conducted including children under 5 years of age what will help to better understand early presentations of ARFID. Future research should also take into account cases seen in primary care and psychology or dietetic-led services to report more accurate IRs and include long-term prospective studies that explore the course and diagnostic stability of ARFID.

X Javier Sanchez-Cerezo @JaviSanCer1

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Competing interests In the past 3 years, JS-C declares a grant funded by the Fundación Alicia Koplowitz. In the past 3 years, DN declares grants or contracts from North West London NIHR applied research collaboration; NIHR SD&O; Rosetrees Foundation; Imperial College BRC; HQIP; Fundación Alicia Koplowitz and NHS England. DN has received royalties from Springer. DN has received honoraria for contribution from MindEd and the British Association of Psychopharmacology. DN has a leadership role in BEAT (Charity) Clinical Advisory Group and as a National Clinical Advisor in NHS England. All other authors have no interest to declare.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

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Provenance and peer review Not commissioned; externally peer reviewed.

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Any child or adolescent aged 5 to 16 (5 to 18 for child and adolescent psychiatrists) years with persistent restriction of quantity and/or range of food intake, associated with one or both of the following:	
- Nutritional deficiency that requires additional clinical investigation or treatment (e.g., anaemia, micronutrient deficiency, weight loss or poor growth, reliance on nutritional supplementation) that is not fully accounted for by poverty or neglect, cultural practice or an existing medical condition or another mental disorder* - Interference with day-to-day functioning due to eating behaviour (e.g., unable to eat at school or with peers, needs to take preferred foods when out of home, extreme and frequent distress about eating).	
Not explained by ANY of the following:	
- Lack of available food (e.g., from poverty, famine, or neglect) - Culturally sanctioned practice (e.g., endorsed religious and cultural practice) - Other known diagnosis - e.g., Allergy to specific food group (e.g., dairy) - Gastrointestinal disorder - Constipation - Swallowing difficulties - Other eating disorder e.g., anorexia nervosa, bulimia nervosa - Other medical or psychiatric disorder that fully explains food restriction (not requiring additional clinical attention) e.g., depression, anxiety, OCD, malignancy, diabetes mellitus, inflammatory bowel disease, thyroid disease.	
*If the eating disturbance occurs in the context of another condition/disorder, then to meet case definition for ARFID, the severity of eating disturbance should exceed that routinely associated with the particular condition/disorder - and warrant additional clinical attention.	

Supplementary table 1. Instructions to clinicians for notification of potential cases:

Supplementary table 2. Analytic criteria for inclusion or exclusion of cases:

Any child or adolescent aged 5 to 18 years with persistent restriction of quantity and/or range of food intake, associated with one (or more) of the following:	
Lack of appetite Lack of interest in food Logistics of feeding/eating behaviour not consistent with age and development (e.g., small bites/slow eating) Limited variety of food intake Rigid eating behaviour (e.g., brand-specific, food items on a plate cannot touch) Unfounded fear of aversive consequences of eating (e.g., fear of choking/vomiting)	
And resulting in ANY one or more of the following bullet points:	
Anthropometric evidence of significant weight loss or growth impairment	As evidenced by any one of:
	Weight-for-age <-2 SD from the international reference median value
	Weight-for-height <-2 SD from the international reference median value
	Height-for-age <-2 SD from the international reference median value
	>10% body mass loss
Nutritional deficiency	As evidenced by any one of:
	Absence (or near absence if other criteria definitely present) of entire food groups from diet (fruit and vegetables / carbohydrates and grains / protein / dairy products)
	Nutritional blood investigation abnormalities (e.g., anaemia, micronutrient deficiency)
	≥50% daily caloric intake via prescribed nutritional or food supplementation
	Use of any tube feeding not required by a concurrent medical condition.
As evidenced by any one of:	

Interference with psychosocial functioning	• Extreme and frequent distress about eating (tearfulness, tantrums, refusal to eat) • Inability to eat except only in certain situations (e.g., only alone/only with family members) • Other impairment of social and emotional development or functioning secondary to eating behaviour (e.g., poor school attendance, limited peer relationships, excessively long mealtimes impacting on self/family)
Not explained by ANY of the following:	
Lack of available food	e.g., from poverty, famine, or neglect
Culturally sanctioned practice	e.g., endorsed religious and cultural practice
Other known diagnosis*	• Allergy to specific food group (e.g., dairy) • Gastrointestinal disorder • Constipation • Swallowing difficulties • Other eating disorder e.g., anorexia nervosa, bulimia nervosa • Other medical or psychiatric disorder that fully explains food restriction (not requiring additional clinical attention) e.g., depression, anxiety, OCD, malignancy, diabetes mellitus, inflammatory bowel disease, thyroid disease.

*If the eating disturbance occurs in the context of another condition/disorder, then to meet case definition for ARFID, the severity of eating disturbance should exceed that routinely associated with the particular condition/disorder - and warrant additional clinical attention.

Incidence of Avoidant/Restrictive Food Intake Disorder (ARFID) in children and young people presenting to secondary care in the UK and Ireland

Case notification form - Strictly ConfidentialThe first two sections of the case notification form will be stored separately from the rest of the questionnaire and personal identifying information for the case will be used only for linkage of records.

Reporting Instructions:

Please report any child seen by you for the first time in the past month who meets the case definition.

Case Definition:

Any child or adolescent aged 5 to 17 years with persistent restriction of quantity and/or range of food intake, associated with one or both of the following:

Nutritional deficiency that requires additional clinical investigation or treatment (e.g. anaemia, micronutrient deficiency, weight loss or poor growth, reliance on nutritional supplementation) that is not fully accounted for by poverty or neglect, cultural practice or an existing medical condition or another mental disorder*Interference with day-to-day functioning due to eating behaviour (e.g. unable to eat at school or with peers, needs to take preferred foods when out of home).*If eating disturbance occurs in the context of another condition/disorder, then in order to meet case definition for ARFID, the severity of eating disturbance should exceed that routinely associated with the particular condition/disorder - and warrant additional clinical attention.

Section A: Reporter Details

1.1 Date of completion of questionnaire

1.2 Full name of consultant responsible for case:

1.3 Hospital or Service Name:

1.4.1Telephone Number of consultant responsible for case:

1.4.2Email address of consultant (or delegate) responsible for case:

1.5 Has the patient been referred to/from another centre (any specialty)?

- ☐ Yes
- ☐ No
- ☐ Not known

1.5.1Is the name of the centre or service known?:

- ☐ Yes
- ☐ No

1.5.1Please name the centre or service:

1.5.2Is the name of the doctor known?

- ☐ Yes
- ☐ No

1.5.2 Please name the doctor:

Section B: Case Details

Is this a patient from Northern Ireland? ☐ Yes ☐ No

2.1 Please enter NHS or CHI number for the patient. Note that this information will not be saved.

This Patient ID hash is calculated automatically and will not be saved

2.2 First half of postcode:

2.3 Sex: ☐ Male ☐ Female

2.3.1Date of Birth:

2.3.1Month and year of birth (MM/YYYY):

2.4 Ethnicity*:
*Please choose the correct ethnicity code from below
Coding for Ethnic Group (ONS 2011 for UK wide data collection)

Ethnicity

Code Ethnicity

Code

A) White English / Welsh / Scottish / Northern Irish / British C) Asian / Asian British Indian
Irish Pakistani
Gypsy or Irish Traveller Bangladeshi
Any other White background, please write in "other"

Chinese

B) Mixed/ Multiple Ethnic Groups White and Black Caribbean Any other Asian background, please write in "other"

White and Black African D) Black / African / Caribbean / Black British African
White and Asian Caribbean
Any other Mixed / Multiple ethnic background, please write in "other"

Any other Black / African / Caribbean background, please write in "other"

E) Other Ethnic group Arab
Any other ethnic group, please write in "other"

2.5 Was patient seen in:

☐ NHS

☐ Independent sector

Section C: Presentation

3.1 Date of diagnosis of ARFID:

3.2 Date first seen in secondary health care for this problem:

3.2.1Please specify which speciality the patient has seen for this problem (paediatricians, psychiatrists etc.) :

3.3 Duration of symptoms up to diagnosis:

weeks

months years

3.4 Does the patient have a restriction of quantity and/or range of food intake resulting in ANY of the following:

☐ Yes

☐ No

☐ Unknown

a) Weight loss/failure to achieve expected weight gain

How many recorded weights (Kg), heights (cm) and dates were done?

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

Recorded Weight, Height, Date 1:

weight (Kg) height (cm) date

Recorded Weight, Height, Date 2:

weight (Kg) height (cm) date

Recorded Weight, Height, Date 3:

weight (Kg) height (cm) date

Recorded Weight, Height, Date 4:

weight (Kg) height (cm) date

Recorded Weight, Height, Date 5:

weight (Kg) height (cm) date

Please indicate which of the following apply:

☐ Yes

☐ No

☐ Unknown

b) Absence of entire food groups from diet

Please tick food groups excluded :	☐ fruit and vegetables ☐ carbohydrates and grains ☐ protein ☐ dairy products
Is absence of almost one or more food groups from diet present?	☐ Yes ☐ No ☐ Unknown
c) Nutritional deficiency that requires additional clinical attention	☐ Yes ☐ No ☐ Unknown
Please tick food groups almost excluded:	☐ fruit and vegetables ☐ carbohydrates and grains ☐ protein ☐ dairy products
Specify which test(s) demonstrate this and the results:	
d) Reliant on tube feeding	☐ Yes ☐ No ☐ Unknown
e) Reliant on oral nutritional supplements	☐ Yes ☐ No ☐ Unknown
f) Distress associated with eating	☐ Yes ☐ No ☐ Unknown
g) Inability to eat with others	☐ Yes ☐ No ☐ Unknown
h) Avoidance of social activities involving food	☐ Yes ☐ No ☐ Unknown
3.5 Does the patient present with any of the following?	☐ Yes ☐ No ☐ Unknown
a) Lack of appetite	
b) Lack of interest in food	☐ Yes ☐ No ☐ Unknown
c) Difficulties with practicalities of feeding behaviour (e.g. small bites/slow eating)	☐ Yes ☐ No ☐ Unknown
Please specify:	

d) Limited variety of food on basis of sensory characteristics (e.g. taste/smell/colour/texture)	☐ Yes ☐ No ☐ Unknown
Please specify (select multiple options if appropriate):	☐ Taste ☐ Smell ☐ Colour ☐ Texture ☐ Other
Please specify:	
e) Rigid eating behaviour	☐ Yes ☐ No ☐ Unknown
Please specify (select multiple options if appropriate):	☐ Brand-specific ☐ Food items cannot touch ☐ Other
Please specify:	
f) Fear of aversive consequences of eating	☐ Yes ☐ No ☐ Unknown
Please specify (select multiple options if appropriate):	☐ Fear of choking ☐ Vomiting ☐ Other
Please specify:	
3.6 Exclusion Criteria	☐ Yes ☐ No ☐ Unknown
Is there any evidence of:	
a) Lack of available food	
b) Culturally sanctioned practice of restricted eating	☐ Yes ☐ No ☐ Unknown
c) Food allergy	☐ Yes ☐ No ☐ Unknown
Please specify:	
d) Other diagnosis or symptoms which may fully explain difficulties	☐ Yes ☐ No ☐ Unknown

Please specify (select multiple options if appropriate):

☐ Gastrointestinal disorder

☐ Constipation

☐ Swallowing difficulties

☐ Anorexia nervosa

☐ Bulimia nervosa

☐ Other eating disorder

☐ Other Medical disorder which, if treated, would be expected to result in the resolution of the food restriction (e.g. diabetes mellitus, inflammatory bowel disease, thyroid disease, malignancy)

☐ Other Psychiatric disorder which, if treated, would be expected to result in the resolution of the food restriction (e.g. depression, anxiety, OCD)

Other medical disorder

Other psychiatric disorder

***IF YOU HAVE ANSWERED 'YES' TO ANY OF THE QUESTIONS IN 3.6
THESE ARE EXCLUSION CRITERIA FOR A DIAGNOSIS OF ARFID.
PLEASE RECONSIDER WHETHER THIS PATIENT MEETS THE CASE DEFINITION***

Section D: Clinical features

4.1 Clinical observations:

a) Heart rate in bpm (if known)

b) Blood pressure in mmHg (if known)

c) Orthostatic changes in HR/BP (if known)

d) Hypothermia in °C (if known)

e) Medications currently prescribed (if known, specify name and dose)

4.2 Does the patient present with any of the following?

☐ Arrhythmia / ECG changes

☐ Dizziness

☐ Syncope

☐ Dehydration

☐ Constipation

☐ Muscle wasting

☐ Gastro-oesophageal reflux

☐ None of these symptoms

Arrhythmia/ECG changes - Specify:

Arrhythmia/ECG changes - QTc if known:

Dehydration - Specify signs:

4.3 Pubertal development at diagnosis

☐ Pre-pubertal (no evidence of puberty)?

☐ In puberty?

☐ Fully mature (post menarche, completed growth and puberty)?

☐ Unknown

Is there secondary amenorrhoea?

☐ Yes

☐ No

☐ Unknown

4.4 Gestation

☐ Born at term (>=37 weeks gestation)

☐ preterm (< 37 weeks gestation)

☐ Unknown

4.4.1Is birthweight known?

☐ Yes

☐ No

Specify:

4.5 Concurrent mental disorder, developmental disorder or disability (specify past or current)

Past	Present	Past	Present
Depression		Deliberate self-harm	
Anxiety		Anorexia nervosa	
OCD		Bulimia nervosa	
Alcohol misuse		Other eating disorder	
Substance misuse		Other (If yes, please specify below)	

Intellectual disability

ADHD

Autism spectrum disorder

4.6 Concurrent physical health symptoms/problems (specify past or current)

Past	Present
Gastrointestinal disorder	
Diarrhoea	
Abdominal pain	
Nausea	
Vomiting	
Other (please specify)	

4.7 Family history (specify relation and past/current)

Past

Present

Past

Present

Depression

Deliberate self-harm

Anxiety

24-04-2024 10:47

Anorexia nervosa

OCD

Bulimia nervosa

Alcohol misuse

Other eating disorder

Substance misuse

Other (please specify)

Intellectual disability _____

ADHD _____

Autism spectrum disorder _____

Section E: Management

5.1

Outpatient management of this patient has included (please select multiple options if appropriate):

☐ Medical outpatient monitoring

☐ Dietetic advice

☐ Psychoeducation

☐ Medication

☐ Tube feeding

☐ Nutritional supplements

☐ Individual therapy

☐ Family therapy

☐ Input from another specialty

Specify input from another specialty:

Specify medication:

5.2

a) Is paediatric inpatient admission or day care indicated for the present disorder?

☐ Yes

☐ No

☐ Unknown

b) Is psychiatric day patient or inpatient admission indicated for the present disorder?

☐ Yes

☐ No

☐ Unknown

Specify (and include for what reason):

Specify (and include for what reason):

Follow up

Specify:

6.1

What is the follow-up plan for this patient (please select multiple options if appropriate)?

☐ Follow-up with me

☐ Onwards referral to medical specialist

☐ Onwards referral to psychiatric specialist

☐ Onwards referral to psychologist

☐ Onwards referral to other

☐ Discharge to primary care

Thank you for taking the time to complete the Questionnaire.
Please make a note of this patient as we will do a follow-up questionnaire in one year.

Incidence of Avoidant/Restrictive Food Intake Disorder (ARFID) in children and young people presenting to secondary care in the UK and Ireland

Page 1

12 month FOLLOW-UP QUESTIONNAIRE- Strictly ConfidentialThe first two sections of the 12 month follow-up form will be stored separately from the rest of the questionnaire and personal identifying information for the case will be used only for linkage of records.

Section A: Reporter Details

1.1

Date of completion of questionnaire

1.2

Full name of consultant responsible for case:

1.3

Hospital name:

1.4.1

Telephone number of consultant responsible for case:

1.4.2

Email address of consultant responsible for case:

1.5

Has the patient been referred to/from another centre (any specialty)?

☐ Yes

☐ No

☐ Not known

1.5.1

Is the name of the centre or service known?:

☐ Yes

☐ No

1.5.1

Please name the centre or service:

1.5.2

Is the name of the doctor known?

☐ Yes

☐ No

1.5.2

Please name the doctor:

Section B: Case Details

Is this a patient from Northern Ireland?

☐ Yes

☐ No

2.1 Please enter NHS or CHI number for the patient. Note that this information will not be saved.

This patient ID hash is calculated automatically and will not be saved.

2.2 First half of postcode:

2.3.1Sex:

☐ Male

☐ Female

2.3.2Date of Birth:

2.3.2Month and year of birth (MM/YYYY):

Section C: Current Symptoms

3.1 Please specify which specialities the patient has seen for this problem since first reported (paediatricians, psychiatrists etc.) :

3.2 Does the patient still have a restriction of quantity and/or range of food intake resulting in ANY of the following:

☐ Yes

☐ No

☐ Unknown

a) Weight loss/failure to achieve expected weight gain

How many recorded weights, heights and dates were done?

☐ 1

☐ 2

☐ 3

☐ 4

☐ 5

Recorded Weight, Height, Date 1:

_____ weight _____ height _____ date

Recorded Weight, Height, Date 2:

_____ weight _____ height _____ date

Recorded Weight, Height, Date 3:

_____ weight _____ height _____ date

Recorded Weight, Height, Date 4:

_____ weight _____ height _____ date

Recorded Weight, Height, Date 5:

_____ weight _____ height _____ date

Please indicate which of the following apply:

☐ Yes

☐ No

☐ Unknown

b) Absence of entire food groups from diet

Please tick food groups excluded :

☐ fruit and vegetables

☐ carbohydrates and grains

☐ protein

☐ dairy products

Is absence of almost one or more food groups from diet present?

☐ Yes

☐ No

☐ Unknown

Please tick food groups almost excluded:

☐ fruit and vegetables

☐ carbohydrates and grains

☐ protein

☐ dairy products

c) Nutritional deficiency that requires additional clinical attention	☐ Yes ☐ No ☐ Unknown
Specify which test(s) demonstrate this and the results:	
d) Reliant on tube feeding	☐ Yes ☐ No ☐ Unknown
e) Reliant on oral nutritional supplements	☐ Yes ☐ No ☐ Unknown
f) Distress associated with eating	☐ Yes ☐ No ☐ Unknown
g) Inability to eat with others	☐ Yes ☐ No ☐ Unknown
h) Avoidance of social activities involving food	☐ Yes ☐ No ☐ Unknown
i) Does eating interfere with school attendance?	☐ Yes ☐ No ☐ Unknown
Would you like to mention further information for any of your responses?	☐ Yes ☐ No
Please give further information:	
3.3 Does the patient still present with any of the following?	
a) Lack of appetite	☐ Yes ☐ No ☐ Unknown
b) Lack of interest in food	☐ Yes ☐ No ☐ Unknown
c) Difficulties with practicalities of feeding behaviour (e.g. small bites/slow eating)	☐ Yes ☐ No ☐ Unknown
Please specify:	

d) Limited variety of food on basis of sensory characteristics (e.g. taste/smell/colour/texture)	☐ Yes ☐ No ☐ Unknown
Please specify (select multiple options if appropriate):	☐ Taste ☐ Smell ☐ Colour ☐ Texture ☐ Other
Please specify:	
e) Rigid eating behaviour	☐ Yes ☐ No ☐ Unknown
Please specify (select multiple options if appropriate):	☐ Brand-specific ☐ Food items cannot touch ☐ Other
Please specify:	
f) Fear of aversive consequences of eating	☐ Yes ☐ No ☐ Unknown
Please specify (select multiple options if appropriate):	☐ Fear of choking ☐ Vomiting ☐ Other
Please specify:	
3.4 Overall, has the patient's eating behaviour:	☐ Improved without treatment ☐ Improved with treatment ☐ Changed in presentation ☐ Persisted unchanged ☐ Worsened ☐ Don't know

Section D: Clinical Features

4.1 Comorbidities & psychosocial factors

Has any concurrent mental disorder, developmental disorder or disability emerged since completion of the baseline questionnaire?

☐ Depression

☐ Anxiety

☐ OCD

☐ ADHD

☐ Alcohol misuse

☐ Substance misuse

☐ Autism spectrum disorder

☐ Intellectual disability

☐ Deliberate self-harm

☐ Anorexia nervosa

☐ Bulimia nervosa

☐ Other eating disorder

☐ Other

Other (please specify):

4.2 Have concurrent physical health symptoms/problems emerged since completion of the baseline questionnaire?

☐ Gastrointestinal disorder

☐ Diarrhoea

☐ Abdominal pain

☐ Nausea

☐ Vomiting

☐ Other

Other (please specify):

Section E: Management

5.1

Management of this patient has included (please select multiple options if appropriate):

☐ Medical outpatient monitoring

☐ Dietetic advice

☐ Psychoeducation

☐ Medication

☐ Tube feeding

☐ Nutritional supplements

☐ Individual therapy

☐ Family therapy

☐ Input from another specialty

Specify medication:

Specify input from another specialty:

5.2

a) Paediatric inpatient admission or day care for the present disorder?

☐ Yes

☐ No

☐ Unknown

Specify reason:

Estimated length of stay:

_____ days _____ weeks _____ months

b) Psychiatric day patient or inpatient admission for the present disorder?

☐ Yes

☐ No

☐ Unknown

Specify reason:

Estimated length of stay:

_____ days _____ weeks _____ months

5.3

What is the medical follow-up plan for this patient (please select multiple options if appropriate)?

☐ Follow-up with me

☐ Onwards referral to medical specialist

☐ Onwards referral to psychiatric specialist

☐ Onwards referral to psychologist

☐ Onwards referral to other

☐ Discharge to primary care

Specify:

5.4

Has referral to/involvement of other agencies taken place since completion of the first questionnaire?

☐ Safeguarding referral

☐ Other Social Care support

☐ Special Educational assessment

☐ Special Educational provision (including change of school)

☐ Other

Please specify:

Thank you for taking the time to complete this questionnaire.

Supplementary Material: Incidence rate in the UK adjusted for unreturned BPSU and CAPSS notification cards and questionnaires.

The response rate to the monthly electronic reporting ecards was 78.5% for BPSU and 47.5% for CAPSS. To account for incidence among the unreturned ecards, we made two assumptions, and an appropriate correction applied to observed incidence rate (IR0), which have been used in prior surveillance studies reporting incidence.^{1,2}

- *Assumption 1:* To take into consideration the possibility that unreturned ecards are more likely to be 'nil' returns, it was assumed that half (10.75% for BPSU and 26.25% for CAPSS) of unreturned ecards were 'negative' and half followed the same proportion of 'negative' and 'positive' as the returned ecards. This assumption translates into a correction coefficient of 1.14 derived from $(10.75+78.5)/78.5$ for BPSU and into a correction coefficient of 1.55 derived from $(26.25+47.5)/47.5$ for CAPSS.
- *Assumption 2:* Making no assumptions of bias in the likelihood of unreturned ecards being either positive or negative returns, it was assumed that all unreturned ecards followed the same proportion of 'negative' and 'positive' as returned cards. This assumption translates into a correction coefficient of 1.27 derived from $(21.5+78.5)/78.5$ for BPSU and into a correction coefficient of 2.11 derived from $(52.5+47.5)/47.5$ for CAPSS.

These assumptions provide a range of IRs, from a minimum (observed IR) to a maximum (assumption 2). We applied this adjustment only in the incidence rates in the UK.

We received 81.2% of the questionnaires that were sent to paediatricians (BPSU) reporting positive cases of ARFID and 78.1% of those sent to child and adolescent psychiatrists (CAPSS). Since all these questionnaires relate to a 'positive' notification, we assumed that the IR for the unreturned questionnaires is the same as the IR identified in the returned questionnaires for each year of age. Therefore, we applied a correction coefficient of 1.23 derived from $(18.8+81.2)/81.2$ for BPSU and a correction coefficient of 1.28 derived from $(21.9+78.1)/78.1$ for CAPSS.

We then combined the correction coefficients described above, to generate two adjusted incidence rates (IR1 and IR2):

$$IR1 = (\text{confirmed new cases from BPSU converted to 12 months} \times 1.14 \times 1.23) + (\text{confirmed new cases from CAPSS converted to 12 months} \times 1.55 \times 1.28) / \text{Population at risk} \times 100\,000$$

$$IR2 = (\text{confirmed new cases from BPSU converted to 12 months} \times 1.27 \times 1.23) + (\text{confirmed new cases from CAPSS converted to 12 months} \times 2.11 \times 1.28) / \text{Population at risk} \times 100\,000$$

Adjusted incidence rates using the two assumptions are reported below.

Supplementary Table. Adjusted annual incidence of ARFID in young people aged 5–18 for 2021, reported per 100000 young people in the UK.

Age group	Sex	United Kingdom	
		IR1	IR2
5 to 9 years	Female	2.45 (1.84-3.26)	2.92 (2.25-3.79)
	Male	6.47 (5.45-7.68)	7.68 (6.56-8.99)
	Total	4.51 (3.89-5.22)	5.36 (4.68-6.13)
10 to 13 years	Female	5.26 (4.24-6.51)	6.71 (5.55-8.11)
	Male	3.68 (2.87-4.73)	4.46 (3.55-5.59)
	Total	4.45 (3.78-5.24)	5.56 (4.80-6.43)
14 to 18 years	Female	6.06 (4.93-7.45)	7.84 (6.55-9.40)
	Male	3.67 (2.84-4.75)	4.69 (3.73-5.89)
	Total	4.83 (4.11-5.68)	6.22 (5.40-7.17)
All age groups (5 to 18 years)	Female	4.42 (3.87-5.04)	5.58 (4.96-6.27)
	Male	4.75 (4.19-5.37)	5.76 (5.15-6.45)
	Total	4.59 (4.19-5.02)	5.68 (5.24-6.16)

REFERENCES

1. Petkova H, Simic M, Nicholls D, Ford T, Prina AM, Stuart R, et al. Incidence of anorexia nervosa in young people in the UK and Ireland: a national surveillance study. *BMJ Open*. 2019;9(10):e027339.
2. Eke H, Ford T, Newlove-Delgado T, Price A, Young S, Ani C, et al. Transition between child and adult services for young people with attention-deficit hyperactivity disorder (ADHD): findings from a British national surveillance study. *Br J Psychiatry*. 2020;217(5):616-22.