University of Hertfordshire UH
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ARFID Presentations & Diagnostic Pathways

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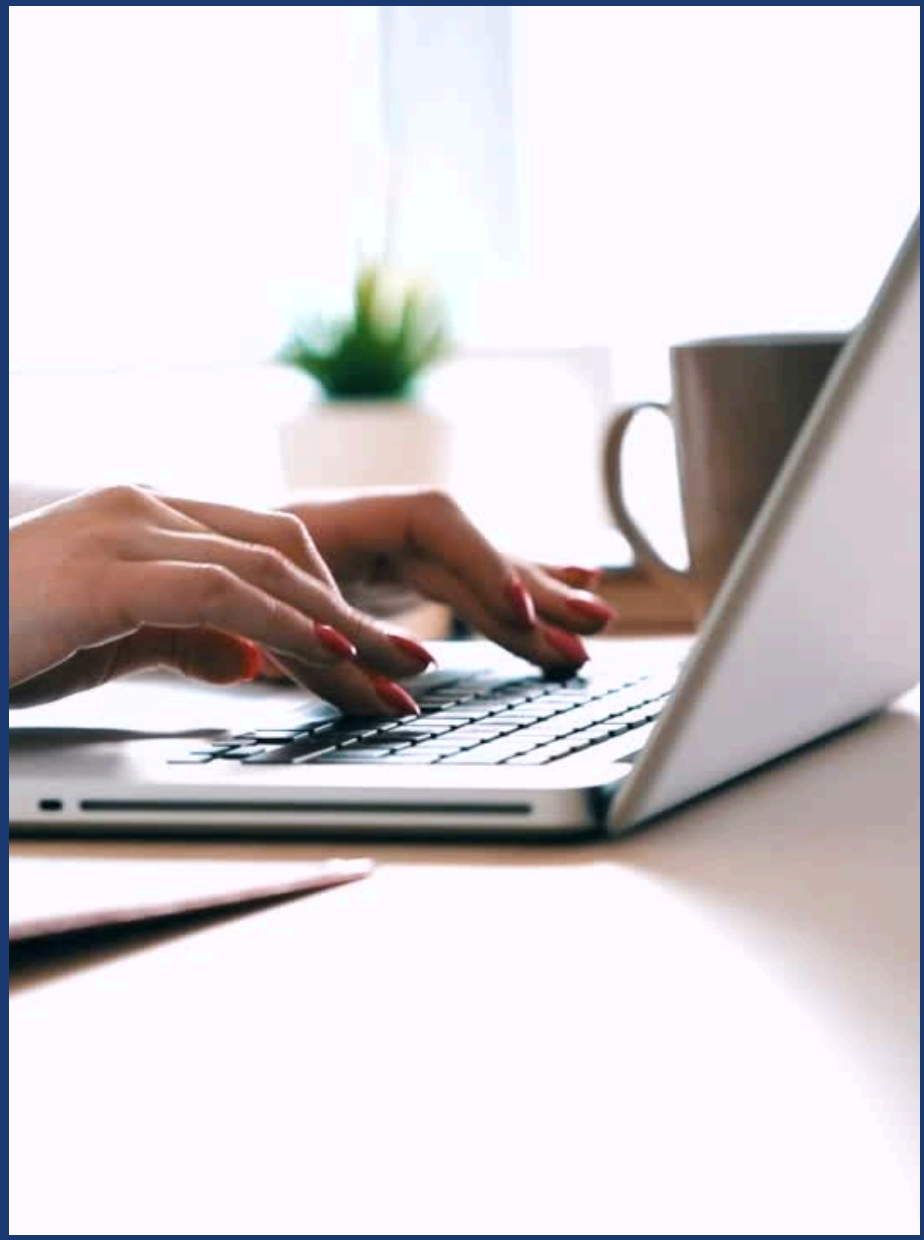
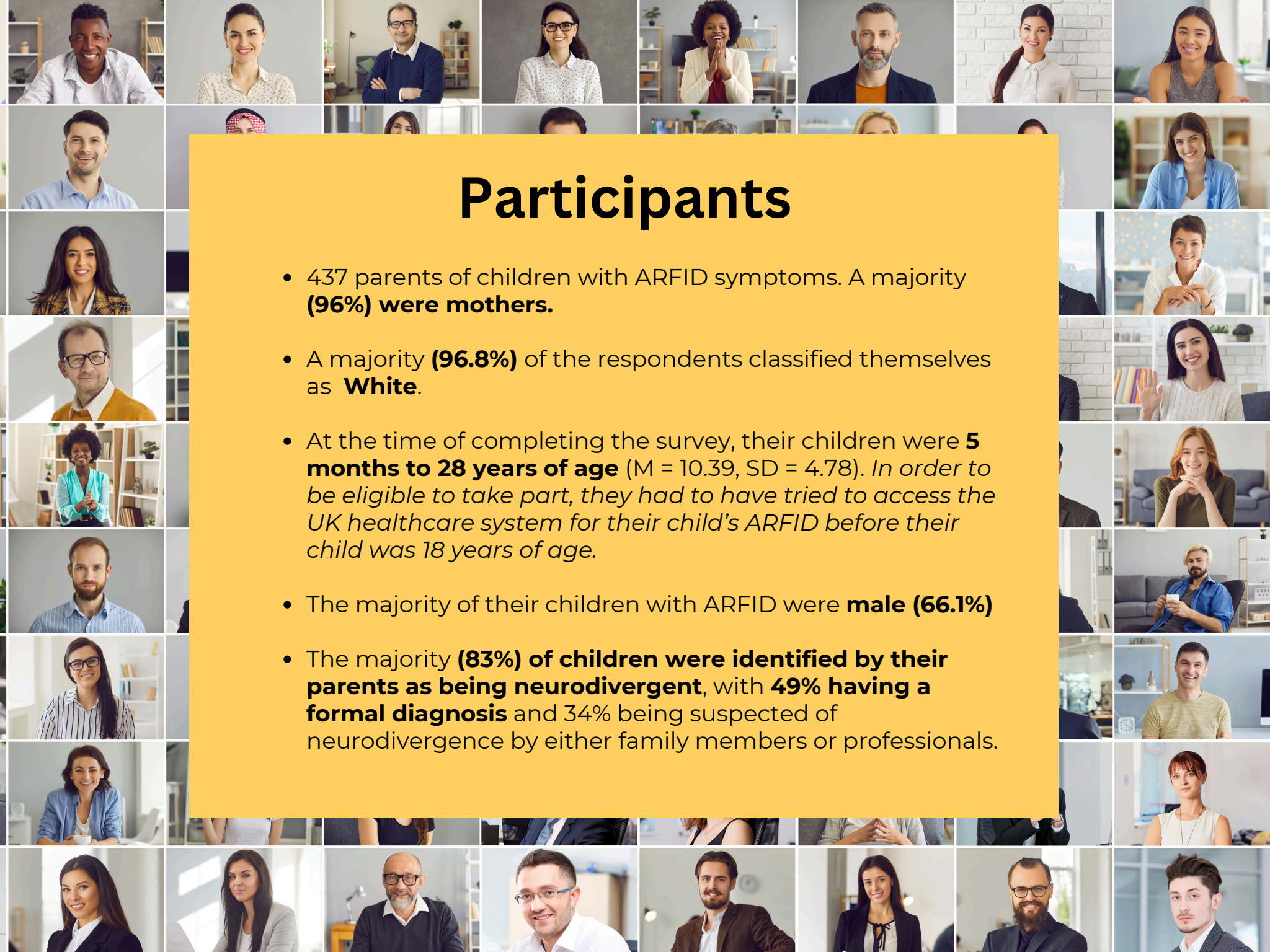
Primary Aim:
Explore differences in ARFID presentations and healthcare experiences based on demographic factors such as age, gender, diagnostic status, and neurodivergence.

Additional Aims: Examine diagnostic delays and satisfaction with healthcare services.





Participants

- 437 parents of children with ARFID symptoms. A majority **(96%) were mothers.**
- A majority **(96.8%)** of the respondents classified themselves as **White**.
- At the time of completing the survey, their children were **5 months to 28 years of age** (M = 10.39, SD = 4.78). *In order to be eligible to take part, they had to have tried to access the UK healthcare system for their child's ARFID before their child was 18 years of age.*
- The majority of their children with ARFID were **male (66.1%)**
- The majority **(83%) of children were identified by their parents as being neurodivergent**, with **49% having a formal diagnosis** and 34% being suspected of neurodivergence by either family members or professionals.

How does child age vary by ....

Neurodivergence?

- Among those diagnosed as neurodivergent, a majority (75.2%) received their diagnosis prior to their ARFID assessment.
- Neurodivergent children were statistically older than neurotypical and suspected neurodivergent children.

Variable	NT (n = 73)		SUS (n = 149)		DN (n = 214)		*df*	*F*	*p*
	M	*SD*	*M*	*SD*	*M*	*SD*			
Age	9.74	4.42	9.20	4.54	11.47	4.84	2,433	11.28	< .001

NT: Neurotypical, **SUS**: Suspected Neurodivergence, **DN**: Diagnosed Neurodivergent

indicates significant at the 0.05 level

ARFID diagnostic status?

- Children diagnosed with ARFID were statistically older than those not assessed or assessed but not diagnosed.
- Children who were assessed and not diagnosed were statistically significantly older than children who had not been assessed for ARFID.

Variable	NO AX (n = 235)		NO DX (n = 51)		DX (n = 151)		*df*	*F*	*p*
	M	*SD*	*M*	*SD*	*M*	*SD*			
Age	9.42	4.53	11.63	4.78	11.50	4.84	2	11.8	<.001

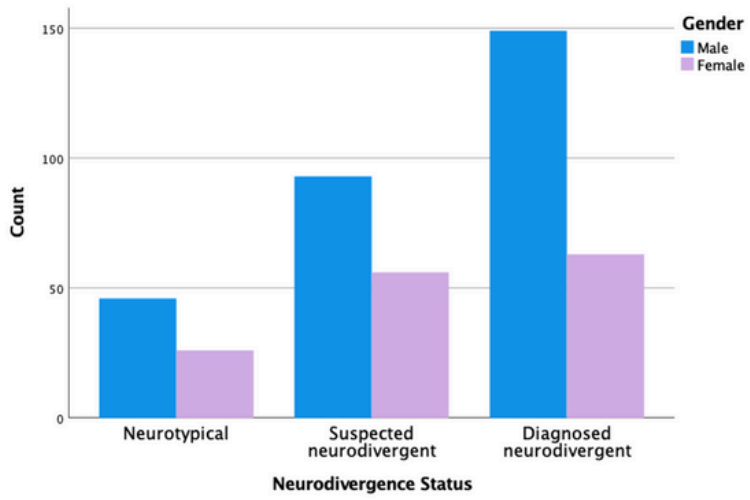
NO AX: Not assessed for ARFID, **NO DX:** Assessed and not diagnosed with ARFID, **DX:** Diagnosed with ARFID

* Indicates significant at the 0.05 level

How does child gender vary by ....

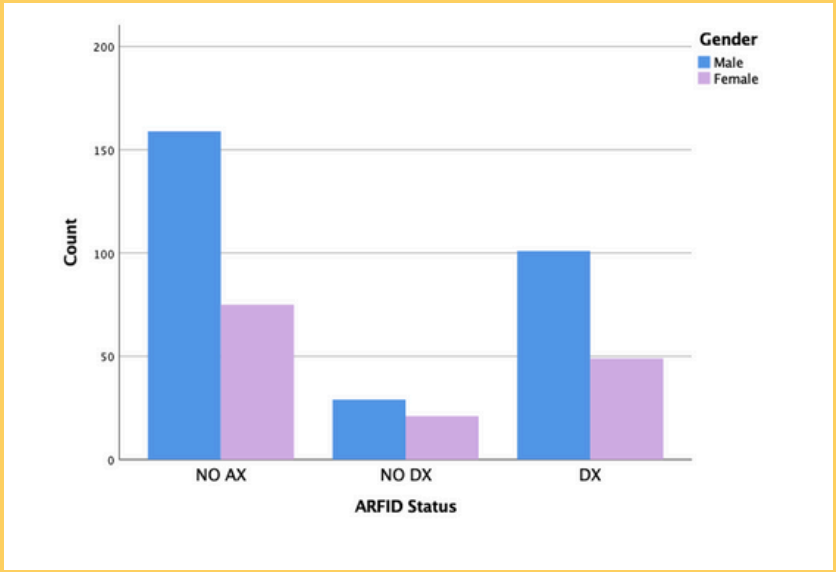
Neurodivergence?

- Gender differences not statistically significant.



ARFID diagnostic status?

- Gender differences not statistically significant.



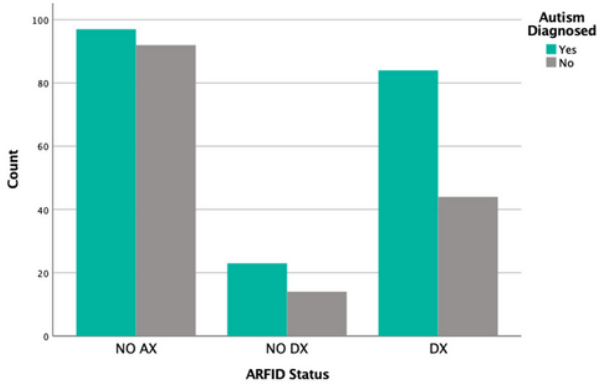
What differences exist in the prevalence of comorbidities between children diagnosed with ARFID and those who are not?

Neurodevelopmental Comorbidities

- The most prevalent diagnosed neurodivergences were Autism (47% total sample, 56% diagnosed ARFID sample) and Sensory Processing Disorder (45% total sample, 60% diagnosed ARFID sample)

- The results indicated a significant association between Autism diagnosis and ARFID status, χ^2 (2, N = 354) = 6.74, p = .034. **Children diagnosed with Autism were more likely to be diagnosed with ARFID than children without an Autism diagnosis.** Specifically, **65.6%** of children with an Autism diagnosis also had diagnosed ARFID, compared to only **34.4%** of children without an Autism diagnosis. Also, **a substantial portion of Autistic children have not been assessed for ARFID (51.3%) despite having ARFID symptoms.** This finding underscores the **importance of screening for ARFID in children diagnosed with Autism**, as early identification and intervention can lead to improved outcomes and tailored treatment strategies for affected individuals.

- The results indicated that there was a significant association between SPD diagnosis and ARFID status, χ^2 (2, N = 348) = 16.67, p < .001. **Children diagnosed with SPD were more likely to be diagnosed with ARFID than those without SPD.** Specifically, **71.1%** of children with an SPD diagnosis also had an ARFID diagnosis, compared to only **28.9%** of children without an SPD diagnosis. These findings underscore the **importance of screening for ARFID in children diagnosed with SPD**, as early identification and intervention can lead to improved outcomes and inform treatment strategies.



What differences exist in the prevalence of comorbidities between children diagnosed with ARFID and those who are not?

Other Comorbidities

- There was a significant association between having a Mental Health diagnosis and ARFID status, χ^2 (2, N = 327) = 11.76, p = .003. **Children diagnosed with ARFID were more likely to be diagnosed with a Mental Health Condition (29.3%) than those assessed and not diagnosed (11.8%) and those not yet assessed for ARFID (14.4%).** Treatment approaches that address both mental health needs and ARFID symptoms could be beneficial for improving patient outcomes. The 5 most prevalent mental health diagnoses among those diagnosed with ARFID were **anxiety** (45.9%), **OSFED** (13.2%), **depression** (9%), **EDNOS** (9.8%) and **OCD** (5%).

- There was a significant association between Anxiety diagnosis and ARFID status, χ^2 (2, N = 426) = 25.63, p < .001. **Among children diagnosed with ARFID, 45.9% had a formal anxiety diagnosis.**

- The 5 most prevalent physical health diagnoses among children diagnosed with ARFID were **constipation** (30%), **allergies** (30%), **Eczema** (21%), **Asthma** (15%) and **GI or digestive issues** (11%).

- Eating Disorder Not Otherwise Specified (EDNOS) and Other Specified Feeding or Eating Disorder (OSFED) were the most prevalent eating disorders. **Children diagnosed with ARFID had higher rates of EDNOS (9.8%, p = <.001) and OSFED (13.2%, p = <.001) diagnoses.** These figures halved among those not diagnosed with ARFID, suggesting that the introduction of ARFID into the diagnostic manuals **reduced residual eating disorder diagnoses**.

What are the clinical presentations and correlates of ARFID symptomology based on …

Neurodivergence?

- Neurodivergent children, particularly those with confirmed diagnoses, showed higher rates of most ARFID symptoms compared to neurotypical or suspected neurodivergent cases.

ARFID diagnostic status?

- Children diagnosed with ARFID show higher prevalence rates of severe symptoms, such as the need for enteral feeding (18%), compared to those not assessed or assessed but not diagnosed.

ARFID Symptomology (most prevalent to least prevalent)	Total sample (n = 437)	ARFID Diagnostic Status			Neurodivergence Status		
		NO AX (n = 235)	NO DX (n = 51)	DX (n = 151)	NO (n = 73)	SUS (n=149)	DX (n=214)
My child avoids or restricts certain foods or food groups based on how they look, taste, smell, or the texture	420 [96%]	223 [95%]	50 [98%]	147 [97%]	66 [90%]	142 [95%]	211 [99%]
My child's difficulties with eating impacts on our family life and wellbeing	414 [95%]	220 [94%]	49 [96%]	145 [96%]	66 [90%]	140 [94%]	207 [97%]
My child's difficulties with eating impacts on their life and wellbeing	406 [93%]	215 [92%]	45 [88%]	146 [97%]	66 [90%]	138 [93%]	202 [94%]
My child avoids or restricts certain fluids based on their appearance, taste, smell, or texture (e.g., not drinking juices because of their strong flavour, texture, or smell)	380 [87%]	198 [84%]	42 [82%]	140 [93%]	55 [75%]	130 [87%]	194 [91%]
My child's limited diet has led to significant weight loss or failure to gain weight	263 [60%]	126 [54%]	27 [53%]	110 [73%]	41 [56%]	84 [56%]	137 [64%]
My child's limited diet has led to significant nutritional deficiency (i.e., deficiencies that result in noticeable symptoms)	233 [53%]	107 [46%]	28 [55%]	97 [64%]	33 [45%]	74 [50%]	126 [59%]
My child's limited diet has led to needing to take prescribed vitamins due to deficiencies (this does not include general multivitamins taken without medical advice)	188 [43%]	70 [30%]	21 [41%]	97 [64%]	26 [36%]	56 [38%]	106 [50%]
My child's limited diet has led to needing to take prescribed nutritional supplement drinks such as Ensure, Pediasure and Fortini	158 [36%]	54 [23%]	21 [41%]	83 [55%]	22 [30%]	49 [33%]	86 [40%]
My child avoids or restricts certain foods or food groups based on worries about choking or being sick	124 [28%]	58 [25%]	16 [31%]	50 [33%]	24 [33%]	37 [25%]	62 [29%]
My child avoids or restricts certain fluids based on worries about choking or experiencing discomfort, impacting their ability to consume a variety of liquids (e.g., will only take small sips of a drink or will avoid thicker drinks like smoothies or milkshakes due to fear of choking)	50 [11%]	19 [8%]	5 [10%]	26 [17%]	9 [12%]	13 [9%]	28 [13%]
My child's limited diet has led to needing to have NG tube or PEG	43 [10%]	15 [6%]	1 [2%]	27 [18%]	2 [3%]	7 [5%]	34 [16%]

NO AX: Not assessed for ARFID, **NO DX:** Assessed and not diagnosed with ARFID, **DX**: Diagnosed with ARFID, **SUS:** Suspected neurodivergence.

Colour Key: 75%+ | 50 – 74% | 25- 49%. | 1% or less

What are the clinical presentations and correlates of ARFID symptomology based on child factors?

- Neurodivergence was significantly correlated with multiple severe ARFID symptoms, namely:
  - Avoidance based on sensory characteristics
  - Family impact
  - Fluid restriction
  - Nutritional deficiency
  - Prescribed vitamins
  - Enteral nutrition requirement.
- Older children showed significant correlations with:
  - Weight loss
  - Nutritional supplement drinks
  - Enteral nutrition requirement.
- Males were significantly more likely to avoid certain fluids based on sensory characteristics.
- Premature children were significantly more likely to avoid fluids based on worries about choking.
- Early feeding and weaning challenges were significantly correlated with avoidance of fluids based on sensory characteristics and the need for nutritional supplement drinks.

ARFID Symptomology (most prevalent to least prevalent)	Age	Male	Premature	Early Feeding & Weaning Challenges	Neurodivergent
A. My child avoids or restricts certain foods or food groups based on how they look, taste, smell, or the texture	-.069	.058	.072	.086	.151**
B. My child's difficulties with eating impacts on our family life and wellbeing	-.002	.007	-.013	.059	.103*
C. My child's difficulties with eating impacts on their life and wellbeing	-.003	.031	.042	.027	.057
D. My child avoids or restricts certain fluids based on their appearance, taste, smell, or texture (e.g., not drinking juices because of their strong flavour, texture, or smell)	-.043	.101*	-.034	.107*	.150*
E. My child's limited diet has led to significant weight loss or failure to gain weight	.157**	.025	-.007	-.037	.071
F. My child's limited diet has led to significant nutritional deficiency (i.e., deficiencies that result in noticeable symptoms)	.044	.031	.072	.031	.109*
G. My child's limited diet has led to needing to take prescribed vitamins due to deficiencies (this does not include general multivitamins taken without medical advice)	.087	.057	.027	.057	.120*
H. My child's limited diet has led to needing to take prescribed nutritional supplement drinks such as Ensure, Pediasure and Fortini	.099*	.052	.064	.097*	.085
I. My child avoids or restricts certain foods or food groups based on worries about choking or being sick	.004	-.049	.082	-.027	-.012
J. My child avoids or restricts certain fluids based on worries about choking or experiencing discomfort, impacting their ability to consume a variety of liquids (e.g., will only take small sips of a drink or will avoid thicker drinks like smoothies or milkshakes due to fear of choking)	.011	.037	.123*	-.001	.027
K. My child's limited diet has led to needing to have NG tube or PEG	.125**	.050	-.020	.069	.187**

Colour Key Code: * Correlation is significant at the 0.05 level (2-tailed) ** Correlation is significant at the 0.01 level (2-tailed)

Is there a significant difference in the age of onset of ARFID symptoms based on neurodivergence?

No significant association between the age of onset of ARFID symptoms and neurodivergence status, χ^2 (6, N = 424) = 6.26, p = .40. These findings suggest that the age at which ARFID symptoms are first noticed does not significantly differ based on neurodivergence status.

Age of Onset	NT	SUS	DN	Total	χ^2	*p*
Before 1 year old	18 (24.7%)	32 (22.1%)	60 (29.1%)	110 (25.9%)		
Between 1 and 2 years old	20 (27.4%)	48 (33.1%)	48 (23.3%)	116 (27.4%)	6.26	.40
Between 2 and 4 years old	18 (24.7%)	41 (28.3%)	55 (26.7%)	114 (26.9%)		
Age 5 and over	17 (23.3%)	24 (16.6%)	43 (20.9%)	84 (19.8%)		
Total	73 (100%)	145 (100%)	206 (100%)	424 (100%)		

NT: Neurotypical, **SUS**: Suspected Neurodivergent, **DN**: Diagnosed Neurodivergent

Is there a significant difference in the age of onset of ARFID symptoms based on ARFID diagnostic status?

- The results indicated a significant association between the age of onset of ARFID symptoms and ARFID diagnostic status, χ^2 (6, N = 425) = 32.23, p < .001. Notably, **those with symptom onset before 1 year old had a significantly higher likelihood of ARFID diagnosis** (39.5%, Z-Score = 3.2).

- In contrast, **onset between 2 and 4 years old was associated with a significantly lower likelihood of diagnosis** (17%, Z-Score = -2.3), **and a higher likelihood of not being assessed for ARFID** (34.4%, Z-Score = 2.2). This may be because this age range corresponds with developmentally appropriate and transient picky eating.

- The age 5 and over group had a higher proportion of individuals assessed but not diagnosed with ARFID. Thus, **the overall pattern suggests that earlier onset of symptoms is linked to a higher probability of being diagnosed with ARFID.**

Age of Onset		NO AX	NO DX	DX	Total	χ^2	*p*
Before 1 year old	Count (%)	43 (18.9%)	9 (17.6%)	58 (39.5%)	110 (25.9%)		
	Z-Score	-2.1	-1.2	3.2			
Between 1 and 2 years old	Count (%)	64 (28.2%)	14 (27.5%)	39 (26.5%)	117 (27.5%)		
	Z-Score	.2	.0	-.2			
Between 2 and 4 years old	Count (%)	78 (34.4%)	11 (21.6%)	25 (17%)	114 (26.8%)	32.23	<.001
	Z-Score	2.2	-.7	-2.3			
Age 5 and over	Count (%)	42 (18.5%)	17 (33.3%)	25 (17%)	84 (19.8%)		
	Z-Score	-.4	2.2	-.8			
Total	Count (%)	227 (100%)	51 (100%)	147 (100%)	425 (100%)		

NO AX: Not assessed for ARFID, **NO DX**: Assessed and not diagnosed with ARFID, **DX**: Diagnosed with ARFID

* Indicates significant at the 0.05 level

Are there differences in the type of professional first contacted by parents about ARFID behaviours based on the child's neurodivergence status?

GPs and Health Visitors were the initial professionals contacted by parents across all neurodivergence statuses to discuss their concerns regarding their child's eating behaviours or ARFID symptoms. Specifically, 39.2% of the sample first reached out to GPs, while 34.9% initially contacted Health Visitors. This underscores the **pivotal role these primary care professionals occupy in the early stages of families' ARFID healthcare journey**.

Are there differences in the mean ages at first assessment, diagnosis, or commencement of treatment based on neurodivergence status?

- The results indicated **no significant differences** in the mean ages at first assessment, diagnosis, or commencement of treatment based on neurodivergence status.

- This suggests that the timing of these key stages in the ARFID care pathway does not vary significantly by neurodivergence status.

Age (months)	NT		SUS		DN		*F*	*p*
	Mean	SD	Mean	SD	Mean	SD		
Age at First Assessment	89.39	55.07	98.86	54.68	107.17	51.68	1.50	.26
Age at Diagnosis	103.95	50.45	102.41	55.28	108.80	51.84	0.23	.80
Age at Commencement of Treatment	116.85	51.06	95.25	44.44	110.02	42.37	1.15	.32

NT: Neurotypical, **SUS**: Suspected Neurodivergent, **DN**: Diagnosed Neurodivergent

Are there differences in delays based on the type of professional parents first raised concerns with?

The results indicated **a significant difference in the overall diagnostic delay based on the type of professional first contacted** (F (3, 14) = 3.27, p = .02).

The post-hoc comparisons for overall diagnostic delay found significant differences between primary care and specialist care professionals, with **specialist care professionals associated with shorter overall diagnostic delays** (Mean Difference = 30.10 months, p = .016).

Variable	Levene's Test (p)	Primary			Mental Health			Specialist			Other			df	F	p
		N	*M*	*SD*	*N*	*M*	*SD*	*N*	*M*	*SD*	*N*	*M*	*SD*			
Diagnostic Delay After First Assessment	5.78	111	5.40	13.70	3	5.67	8.96	31	13.84	34.30	4	.00	.00	3, 145	1.67	.18
Overall Diagnosis Delay	.80	108	90.83	50.18	3	86	55.03	30	60.73	40.81	4	64.50	37.97	3, 14	3.27	.02*
Treatment Delay	.007*	73	85.86	40.63	1	146	-	12	65.92	40.18	2	90	43.84	3, 84	1.64	1.9

* Indicates significant at the 0.05 level

Overall Diagnostic Delay: The time between the age of the first parental concern (lower age bound) and age at diagnosis.
Diagnostic Delay After First Assessment: The time between age at first assessment and age at diagnosis.
Treatment Delay: The time between age at diagnosis and age at the start of first treatment.
Primary Care: GPs and Health Visitors
Mental Health: Clinical Psychologists and Psychiatrists,
Specialist Care: Allergists/Immunologists, Dietitians, Gastroenterologists, Paediatricians, Speech and Language Therapists, Occupational Therapists)
Other (e.g., teachers)

Professional Comparison	Mean Difference	Std. Error	Tukey p	Tukey 95% CI Lower Bound	Tukey 95% CI Upper Bound
Primary Care vs. Mental Health	4.83	38.34	1.00	-68.58	78.24
Primary Care vs. Specialist Care	30.10*	9.96	.016	4.22	55.98
Primary Care vs. Other	26.33	24.56	0.71	-37.53	90.20
Mental Health vs. Specialist Care	25.27	29.21	0.82	-50.68	101.21
Mental Health vs. Other	21.50	36.84	0.94	-74.29	117.29
Specialist Care vs. Other	-3.77	25.68	1.00	70.53	62.99

* Indicates significant at the 0.05 level

How might parental satisfaction with healthcare experiences vary based on neurodivergence, if at all?

- No significant differences in parental satisfaction levels based on the child's neurodivergence status.

- **Parental satisfaction scores were relatively low** across all groups for **NHS** processes, including **assessment**, **diagnosis**, and **treatment**.

- Overall, satisfaction levels were generally below the midpoint of the scale, indicating **somewhat to extreme dissatisfaction with NHS ARFID processes** and **somewhat dissatisfied to neither satisfied nor dissatisfied for the availability of ARFID treatment options through the NHS, Private Healthcare and Third Sector Organisations**.

Thoughts, Reflections & Questions

Stay in Touch

Icons are hyperlinked for ease!

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