Parental Experiences of Accessing Healthcare in England for Children with Avoidant/Restrictive Food Intake Disorder

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In memory of my beloved mother,

Sonnia Bamigbade
(née Soumaya Loudiyi)

09/01/1970- 11/12/2022

إِنَّا لِلَّهِ وَإِنَّا إِلَيْهِ رَاجِعُونَ

To my dearest mother, who whispered prayers for me day and night, who texted:

I'm your mama and it is my job to love you, protect you, fight for you, advise you, guide you and be there for you no matter what happens. I will always be here when you need me until I die.

Even then, I will still watch over you and your brother.

I'm so proud of you and lucky to have you, my shining star.

I am the living manifestation of your prayers, forever grateful for your boundless love and guidance. In loving memory of you, I dedicate my research to the countless mothers who have graciously shared their stories with me throughout my career. Your narratives continue to inspire and guide my work as I strive to capture the essence of your experiences, struggles, and triumphs in relation to your children. Your stories serve as a testament to the resilience and strength that defines maternal love, and I hope I can do justice to your stories.

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Abstract

This thesis explores the complex healthcare journey experienced by parents of children diagnosed with Avoidant/Restrictive Food Intake Disorder (ARFID) in England. Through a mixed-methods approach, combining a systematic literature review, a survey of 437 parents, and interviews with six mothers of Autistic children diagnosed with ARFID, the study sought to illuminate the challenges parents face as they navigate the healthcare system and the strategies they employ in the face of these challenges.

The literature review identified significant gaps in healthcare professionals' (HCPs) understanding of ARFID, including lack of confidence, difficulties with differential diagnoses, challenges with referrals, and lack of established care pathways. Survey findings revealed a significant association between a child's neurodivergence and the severity of ARFID symptoms, with neurodivergent children exhibiting higher prevalence rates for most ARFID symptoms. The survey also highlighted systemic barriers within primary care pathways, showing that parents who first contacted specialist professionals experienced shorter diagnostic delays compared to those who approached primary care providers. Overall parental satisfaction with NHS ARFID processes and treatment options was generally low.

Qualitative data highlighted the profound emotional toll on mothers, who described their healthcare journey as an exhausting obstacle race and being trapped on a referral merry-go-round. They faced significant challenges, including judgement and dismissal from HCPs,

diagnostic overshadowing, a lack of clear referral pathways, and frequent rejections of referrals, prolonging their pathway to support while their children deteriorated. The constant need to advocate for their child's needs, coupled with the emotional strain of managing ARFID's complex symptomatology, and exhaustion from battling the system, led to widespread feelings of hopelessness, loneliness, fear, desperation, guilt, and anxiety among mothers. These narratives underscore the urgent need for HCPs to provide empathetic and supportive responses, recognising the emotional burden on parents and the importance of early intervention.

Overall, the study underscores the need for HCPs to adopt a holistic and nuanced approach to ARFID, integrating specialised knowledge and fostering a more collaborative relationship with parents. Improving training, establishing clear referral pathways, and enhancing multidisciplinary collaboration are essential to improving diagnostic processes and treatment outcomes for children with ARFID, thereby alleviating the significant burden on their parents and improving the experiences of HCPs who face similar systemic challenges. These findings provide a foundation for future research and clinical recommendations to address critical gaps in the healthcare system.

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Abbreviations, Acronyms, and Initialisms

ADHD	Attention Deficit Hyperactivity Disorder
APA	American Psychiatric Association
ARFID	Avoidant/Restrictive Food Intake Disorder
ASC	Autism Spectrum Condition (also known as Autism Spectrum Disorder)
BED	Binge Eating Disorder
BMI	Body Mass Index
BN	Bulimia Nervosa
CAMHS	Child and Adolescent Mental Health Services
DSM	Diagnostic and Statistical Manual of Mental Disorders
EDNOS	Eating Disorder Not Otherwise Specified
EbE	Expert by Experience
GP	General Practitioner
HCPs	Healthcare Professionals
ICD	International Classification of Diseases
IPA	Interpretative Phenomenological Analysis
JBI	Joanna Briggs Institute
MARSIPAN	Management of Really Sick Patients with Anorexia Nervosa
MDT	Multi-Disciplinary Team
MEED	Medical Emergencies in Eating Disorders
NDDs	Neurodevelopmental Disorders

NICE	National Institute for Health and Care Excellence
NHS	National Health System
NHSE	National Health System England
OCD	Obsessive-Compulsive Disorder
OSFED	Other Specified Feeding or Eating Disorder
PDA	Pervasive Drive for Autonomy (also known clinically as Pathological Demand Avoidance)
PRISMA	Preferred Reporting Items for Systematic Reviews and Meta-Analysis
RR	Relative Risk (also known as Risk Ratio)
SD	Standard Deviation
SPD	Sensory Processing Disorder
UK	United Kingdom
WHO	World Health Organization

Language Use Disclaimer

This dissertation employs both identity-first and person-first language, alternating depending on the community being discussed. Identity-first language is used to align with the preferences of the Autistic community, with capitalisation of Autism and Autistic being purposeful and maintained. Conversely, person-first language is used when referring to Avoidant Restrictive Food Intake Disorder (ARFID), as this condition is typically viewed as a separate aspect of an individual's experience rather than an integral part of their identity. However, our understanding may evolve with time, and advocates with lived experience may influence future preferences. More information on language use can be found in Appendix A.

Finally, for brevity purposes, the term 'parent' will be used inclusively to refer to any adult with parental responsibility or guardianship over a child.

Thesis Overview

Chapter One introduces the problem statement, research aims and questions, and provides an overview of ARFID as a diagnostic construct. Chapter Two consists of a systematic review of the literature, focusing on the experiences of HCPs in relation to ARFID. Chapter Three details the overarching methodology and methods of this research. Chapter Four presents the quantitative findings from an online survey of 437 parents, exploring if there are differences in the presentations and healthcare journeys of children with ARFID based on demographic factors such as age, gender, ARFID diagnostic status, and neurodivergence status. Chapter Five delves into the rich qualitative accounts of six mothers' journeys through the healthcare system on behalf of their eight Autistic children with ARFID. The research concludes with Chapter Six, where all findings are integrated to discuss the overall contribution to knowledge, along with reflections on the limitations, strengths, implications, and recommendations.

Chapter One: Introduction

1.1 Problem Statement

ARFID, a relatively new diagnostic category, is classified as avoidant/restrictive eating without shape and weight disturbance that spans the age and weight spectrums (Kambanis & Thomas, 2023). Presently, there are no national guidelines for the assessment and treatment of ARFID due to limited research in this area, leading to varying care provision. Given the absence of established guidelines, there is a pressing need to explore the support and management available to people with ARFID. This includes understanding if referrals to other services are made and the extent of clinical follow-up they receive. This is particularly important given that early intervention is widely considered an important factor in improving outcomes for people with eating disorders, including ARFID (Kurotori et al., 2019).

Increasing understanding about the presentation of ARFID in children is crucial due to the significant impact chronic restricted diets can have on physical health (Nitsch et al., 2021), psychosocial wellbeing (Krom et al., 2021; Wells, 2024) Thus, this research comprehensively studies the journey that parents of children with ARFID undertake as they seek an ARFID diagnosis and access to treatment for their children. By focusing on parents the research identifies gaps, opportunities, and potential shortcomings in the current healthcare system. Additionally, the study proposes recommendations that could improve the healthcare journey.

1.2 Project Aims and Research Questions

Table 1 outlines the overarching aims of the thesis and chapter research questions.

Table 1 Project aims and research questions.

Overarching Aims:
1 Explore the journey parents of children with ARFID undergo in seeking an ARFID diagnosis and accessing treatment.
2 Contribute towards improved healthcare access and quality for children with ARFID and their families by identifying gaps, opportunities, and potential shortcomings in the current healthcare system, and propose well-informed and pragmatic recommendations to enhance healthcare experiences.
3 Capture the challenges parents face as they navigate the healthcare system and the strategies they employ in the face of these challenges.
Systematic Review Research Question:
1. What barriers and facilitators do HCPs experience in relation to ARFID identification, diagnosis, and treatment?
Quantitative Research Questions:
1. How, if at all, does child age and gender vary by neurodivergence and ARFID diagnostic status?
2. What differences, if any, exist in the prevalence of comorbidities between children diagnosed with ARFID and those who are not?
3. What might be the clinical presentations and correlates of ARFID symptomology based on diagnostic status and neurodivergence?
4. Is there any significant difference in the age of onset of ARFID symptoms based on neurodivergence and ARFID diagnostic status?
5. Are there differences in the type of professional first contacted by parents about ARFID behaviours based on the child's neurodivergence status, and do the delays in receiving a diagnosis vary depending on the type of professional first contacted?
6. How might parental satisfaction with healthcare experiences vary based on neurodivergence, if at all?

Qualitative Research Questions:
1. How do mothers make sense of their experiences during the process of obtaining an ARFID diagnosis for their child in the UK?
2. What is the perceived impact on mothers and their families of obtaining an ARFID diagnosis in the UK, and how do they make sense of these impacts?
3. How do mothers describe and make sense of their interactions with HCPs and the quality of care received during their ARFID healthcare journey in the UK?
4. How do mothers perceive and interpret the emotional and psychological impact of navigating the healthcare system for ARFID diagnosis and ongoing care?

1.3 Situating the Research in Context

1.3.1 Introduction to ARFID

ARFID is a relatively newly recognised eating disorder with a heterogenous clinical presentation, introduced in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5, APA, 2013) and 11th revision of the International Classification of Diseases (ICD-11) (World Health Organization, 2019). ARFID is characterised by a persistent failure to meet appropriate nutritional and/or energy needs, which can lead to significant weight loss, nutritional deficiency, dependence on enteral feeding or nutritional supplements, and marked interference with psychosocial functioning (APA, 2013). Unlike other eating disorders, eating behaviours in ARFID are not influenced by concerns about body weight or shape. Instead, the diagnostic manuals identify three neurobiological drivers for food avoidance:

(a) Sensory sensitivities: Certain textures, tastes, smells, or appearances of food can be overwhelming and lead to food avoidance.

(a) Fear of adverse consequences: Previous negative experiences with food, such as choking, vomiting, or severe allergic reactions, can cause an intense fear of eating.

(b) Lack of interest in eating: Some individuals lack interest in food and eating, resulting in insufficient intake.

A recent latent class analysis identified four distinct classes of ARFID psychopathology in a sample of British and Irish children and adolescents (Sanchez-Cerezo et al., 2024). These classes

correspond to each of the drivers, with an additional combined subtype. In order of classification prevalence, they are:

(a) **Combined subtype** (38.2%)

(b) **Sensory subtype** (29.5%)

(c) **Lack of interest subtype** (25.1%)

(d) **Fear subtype** (7.2%)

These subtypes clearly demonstrate that drivers are not mutually exclusive, with a combined presentation being the most prevalent ARFID subtype. Some research suggests that as many as 50% of individuals experience more than one driver (Duncombe Lowe et al., 2019). Moreover, these findings align with a three-dimensional model proposed by Thomas et al. (2017) suggesting that subtype severity varies, but that these are not separate diagnostic groups, thereby explaining the heterogeneous presentation of ARFID.

1.3.1.1 Prevalence and Incidence

The prevalence of ARFID varies widely, with a recent review reporting prevalence estimates ranging from 0.3% to 64% (Sanchez-Cerezo et al., 2023). In non-clinical samples specifically, the higher end reduces to 15.5%. The authors attribute the significant discrepancy to differences in study settings, methodologies, and sample characteristics. Moreover, Harshman et al. (2021) highlighted the ambiguity in DSM-5 criteria A for ARFID, demonstrating how heavily it relies on clinical judgment. Their study found that using the most lenient definitions, compared to the

strictest, resulted in a doubling of the prevalence. This variability underscores the challenges in establishing consistent diagnostic criteria, which contribute to variance in reported prevalence rates. Additionally, the only incidence study on ARFID, conducted in Canada, indicates an incidence rate of 2.02 per 100,000 among paediatric populations (5-18 years) (Katzman et al., 2021).

1.3.1.2 Age Differences

ARFID can manifest at any age but is commonly diagnosed in children and adolescents, with the highest incidence between 10 and 14 years (Katzman et al., 2021). Research is beginning to explore age differences and has found that ARFID drivers can vary with age. For example, sensory sensitivities and lack of interest are associated with a younger age of onset (Katzman et al., 2021; Zickgraf, Murray, et al., 2019).

A recent study by Sanchez-Cerezo et al. (2024) found that the lack of interest subtype sample was significantly older than the combined and sensory subtypes. Those showing a lack of interest, having a younger age of onset and a longer chronicity of symptoms, thus being older at the point where they engage with Paediatricians. The data for Sanchez-Cerezo et al. (2024) was collected through a paediatric surveillance study, emphasising the role of paediatricians in diagnosing and managing ARFID. This variation highlights the importance of understanding the developmental trajectory of ARFID.

1.3.1.3 Gender Differences

Some research suggests that gender differences exist in ARFID, with higher rates reported in males (Katzman et al., 2019) and males experiencing greater chronicity of symptoms (Duncombe Lowe et al., 2019). In relation to ARFID drivers, the findings are mixed. Katzman et al. (2021) found that sensory sensitivities were a greater driver in males and Zickgraf, Lane-Loney, et al. (2019) found that fear of adverse consequences was greater in females. However, other studies found no significant gender differences for ARFID drivers (Norris et al., 2018; Watts et al., 2023). These mixed findings indicate that more research into gender differences in ARFID is warranted.

1.3.1.4 Weight Differences

ARFID is also heterogeneous in relation to weight status. Those with fear or lack of interest as a driver tend to lean towards being underweight and report greater weight loss (Norris et al., 2018; Sanchez-Cerezo et al., 2024). In contrast, individuals who have sensory sensitivities as a driver vary more greatly across the weight spectrum (Zickgraf, Murray, et al., 2019). This diversity in weight status underscores the importance of not assuming a uniform presentation of ARFID based on weight alone and highlights the need for careful assessment of each individual's specific drivers and nutritional needs.

1.3.1.5 Psychiatric Comorbidities

Among the ARFID population, co-occurring psychiatric conditions are highly prevalent. Kambanis et al. (2020) found that 45% of their sample of children and adolescents with full and subthreshold ARFID met the criteria for a current comorbid psychiatric diagnosis. This increased to 53% when considering lifetime comorbid diagnoses. Interestingly, they also found that ARFID drivers were associated with different diagnoses. Those with sensory sensitivity as a driver exhibited greater odds of comorbid neurodevelopmental, disruptive, and conduct disorders; anxiety, obsessive-compulsive, and trauma-related disorders; depressive and bipolar-related disorders. Those with fear of aversive consequences as a driver exhibited greater odds of anxiety, obsessive-compulsive, and trauma-related disorders. Kambanis et al. (2020)

In studies specifically focused on treatment-seeking samples, the rate of psychiatric comorbidity increases, ranging from 57% in a paediatric hospital (Cooney et al., 2018) to 95% in a day hospital (Bryson et al., 2017). The picture is further complicated by research suggesting that patients with ARFID can often meet the criteria for more than one psychiatric disorder, with estimates ranging from 10% to 25% (Cooney et al., 2018; Lieberman et al., 2019). Of the psychiatric comorbidities, anxiety disorders are the most common, with prevalence estimates ranging from 9.1% to 72% (Sanchez-Cerezo et al., 2023). Mood disorders follow, with estimates ranging from 17% to 33% (Duncombe Lowe et al., 2019; Nicely et al., 2014). Importantly, Fuller et al. (2022) found that patients with psychiatric comorbidities had more prolonged episodes of nasogastric tube feeding under restraint. This highlights the importance of considering psychiatric comorbidity when treatment planning for ARFID.

1.3.1.6 Neurodiversity

ARFID is notably overrepresented among neurodivergent populations. For example, Lieberman et al. (2019) found that the prevalence of neurodivergence among individuals with ARFID was 10%, whereas Kambanis et al. (2020) reported a prevalence of 16% for current and 19% for lifetime neurodivergence. Moreover, Dinkler et al. (2022) found that neurodivergent children aged 4-7 years were at a three times increased risk of developing ARFID compared to children without a diagnosis. While ARFID can be diagnosed at this age, typically it is diagnosed after the developmentally appropriate food neophobia stage (after 6 years) (Norris et al., 2016). However, due to the increased risk among neurodivergent children, early intervention is likely warranted over the usual 'watch and wait' approach. Taylor and Taylor (2021) urge professionals to make referrals for feeding assessments as early as 6 months of age and to prioritise access to evidence-based treatments by the age of 1. While these recommendations are general and applicable to all children, they are particularly pertinent for neurodivergent children due to their heightened risk and where developmental delay trajectories diverged after 6 months of age.

ARFID is also frequently found in populations with Attention Deficit/Hyperactivity Disorder (ADHD), with co-occurrence rates ranging from 4% to 26% (Duncombe Lowe et al., 2019; Nicely et al., 2014). Additionally, around a third of individuals with intellectual and developmental disabilities have ARFID (Nicely et al., 2014; Sharp et al., 2020).

The most common neurodivergence among those with ARFID, is Autism. A recent systematic review reported that the prevalence of Autism among children with ARFID ranges from 9.2% to 54.75% (Sanchez-Cerezo et al., 2023). Koomar et al. (2021) estimated the risk for ARFID in Autistic individuals is approximately 21%, with a 17% risk for their parents, suggesting that ARFID may be hereditary. This wide range reflects differences in study methodologies and sample characteristics. Moreover, clinical observations indicate a higher prevalence of Autism among treatment-seeking ARFID populations, with estimates suggesting that more than half of these individuals may be Autistic.

Autistic children with ARFID tend to exhibit more sensory sensitivities (RR = 1.26) and a greater lack of interest in eating (RR = 1.18) compared to their non-Autistic peers (Watts et al., 2023). Moreover, a key finding from Watts et al. (2023) was that being Autistic did not drive a completely different presentation but rather accentuated particular drivers and highlights the need for tailored interventions that address the unique challenges faced by these individuals. Moreover, ARFID in Autistic people can often be viewed as part of their Autism profile rather than as a valid comorbidity, as Autistic children are five times more likely than neurotypical peers to experience feeding challenges (Sharp et al., 2013). Thus, this could lead to underdiagnosis in Autistic populations (Smile et al., 2021).

1.3.1.7 Physical Health Complications

Due to the nature of ARFID, repetitive and restricted diets increase the risk of macro- and micronutrient deficiencies, leading to an array of health complications. Risk to life is high enough to warrant inclusion in Medical Emergencies in Eating Disorder (MEED) guidance (Pennick et al., 2023). The nutritional consequences of ARFID remain scarcely described beyond weight loss (Feillet et al., 2019). However, studies have begun to elucidate these effects. A macro- and micronutrient analysis study by Schmidt et al. (2021) compared 20 treatment-seeking children and adolescents with ARFID to healthy age- and sex-matched controls. They found that the ARFID group only met 20–30% of the recommended daily intake for most vitamins and minerals, with significantly lower intakes of vitamins B1, B2, C, K, zinc, iron, and potassium.

A systematic review by Yule et al. (2021) examined 63 case reports and series involving 76 patients with ARFID and Autism. The review found that nearly two-thirds of cases involved scurvy, a vitamin C deficiency. The second-largest percentage involved eye disorders caused by vitamin A deficiency. Other significant nutrient deficiencies reported included vitamins B1, B-12, and D.

ARFID is associated with a myriad of physical health complications, which can vary in severity and impact. Malnutrition, electrolyte abnormalities, and low bone density are common in patients with ARFID, often resulting from their restrictive eating patterns (Nitsch et al., 2021). In a study by Katzman et al. (2021), older children (10-18 years of age) were more likely to

present to Paediatricians with a lower mean Body Mass Index (BMI) Z score and bradycardia.[1] Additionally, children aged 10-14 demonstrated a greater propensity towards faltering growth during the adolescent growth spurt, reinforcing the importance of early identification and treatment. In older girls, amenorrhea is frequently reported, highlighting the disorder's impact on reproductive health (Nakai et al., 2017).

Dependence on enteral nutrition or nutritional supplements is not uncommon among those with ARFID, and hospitalisation for nutritional rehabilitation or medical stabilisation is sometimes necessary (Sharp et al., 2017). Gastrointestinal symptoms, such as abdominal pain, are also frequently reported (Nitsch et al., 2021) and are more common in children with ARFID when compared to the general population (Boerner et al., 2022).

1.3.2 Diagnostic Landscape and ARFID

ARFID was first introduced as a diagnostic category in the DMS-5 (APA, 2013) and subsequently added to the ICD-11 (World Health Organization, 2019). This addition filled a significant clinical gap by providing a diagnosis for avoidant/restrictive eating without shape and weight disturbance that spans various age and weight spectrums (Kambanis & Thomas, 2023).

In England, the diagnostic landscape in mental health is shaped by the simultaneous use of the ICD-10 and the DSM-5. While the ICD-10 serves as the primary classification system for health conditions in the United Kingdom (UK) and internationally, providing a comprehensive

[1] Bradycardia is the medical term for an abnormally slow heart rate.

framework across various medical disciplines, the DSM-5 plays a crucial role in mental health. Mental health professionals widely rely on the DSM-5 for its specific and detailed criteria in diagnosing mental and behavioural disorders. This dual utilisation acknowledges the importance of both systems, allowing for a comprehensive understanding of health conditions with the ICD's broad scope and the DSM-5's focused expertise in mental health.

While WHO officially released the ICD-11 in 2018, with global implementation scheduled for 2022, it has not yet replaced the ICD-10 as the mandated national information standard for disease classification in England. Anticipated timelines suggest that the mandated implementation of ICD-11 across the National Health Service (NHS) in England is expected to occur after April 2026 and before April 2028 (NHS England, n.d.). Although, some early adopters have already embraced ICD-11 – most probably influenced by its greater emphasis on clinical utility (Sampogna et al., 2020; Stein et al., 2013). Moreover, the inclusion of ARFID in the ICD-11 reduced reliance on residual diagnoses like ‘other specified’ or ‘unspecified’ eating disorders. The impending transition to ICD-11 is anticipated to bring about positive changes in care provision for ARFID. Its standardisation and detailed classification system is expected to facilitate more accurate diagnosis, enhance reporting capabilities, and contribute to informed decision-making in healthcare policy and resource allocation.

1.3.2.1 The Feeding and Eating Disorder Debate

ARFID is classified as one of the 'Feeding and Eating Disorders' in both the DSM-5 and ICD-11. Despite this classification, there is ongoing debate regarding whether ARFID is more accurately described as a feeding disorder or an eating disorder. Many of ARFID's symptoms, such as persistent failure to thrive, align more with a feeding disorder, reflecting its historical roots as a feeding disorder in early childhood (Sharp & Stubbs, 2019). The adoption of ARFID by the eating disorder community has led to expectations that existing mental health services can provide effective care, despite the limited evidence and absence of robust clinical guidelines. Duffy et al. (2024) argue that viewing ARFID primarily through an eating disorder lens can create biases in the literature, limiting the generalisability of findings and highlights the pitfall of not considering nor appreciating the range of effective skills and interventions available within the feeding disorder perspective.

Research by Kennedy et al. (2018) highlights ARFID's shared characteristics with both feeding and eating disorders. Moreover, patients with ARFID are treated by feeding disorder, gastroenterology, and eating disorder services (Ornstein et al., 2017; Richmond et al., 2023). Kennedy et al. (2018) advocate for improved interdisciplinary communication to enhance the treatment and understanding of ARFID. In line with this, the neurobiological model for ARFID draws upon evidence from both feeding and eating disorders to develop effective treatment avenues (Thomas et al., 2017).

Chapter Two: Systematic Literature Review

3.1 Overview

This chapter presents the systematic review. While other reviews on ARFID exist, none specifically focus on the experiences of HCPs as they navigate care provision for this population. Therefore, this systematic review aims to identify and synthesise how HCPs experience ARFID, highlighting what barriers and facilitators HCPs experience in relation to ARFID identification, diagnosis, and treatment.

Identifying barriers and facilitators is crucial, as they profoundly shape how families experience the healthcare system. Interactions between HCPs and families are co-created, making it essential to comprehend the nature of the professional experience. This understanding influences the clinical landscape with which parents interact and provides important context for what parents' experience when navigating the system.

3.2 Method

In accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) guidelines (Page et al., 2021), a literature search was conducted. The review protocol was registered[2] 24/10/2023 (Appendix B).

[2] https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42023447759

3.2.1 Search Strategy

Utilising four databases (Pubmed, PsychArticles, CINAHL Plus, and SCOPUS), searches were performed. In accordance with guidance from Siddaway et al. (2019), the search string was devised from key concepts and consisted of various terminologies that describe the same construct. Search terms related to (a) the condition of interest, (b) the targeted professional group, and (c) the desired outcome (Table 2). Relevant records were identified through Boolean searches performed on 02/03/2024, with no date restrictions.

The framing of the search strategy was supported by consultations with the supervisory team and departmental information manager.

Table 2 Search Terms

Condition	Professional	Outcome
1. Avoidant/Restrictive Food Intake Disorder	1. Clinician*	1. Barrier*
	2. Healthcare provider*	2. Facilitator*
2. ARFID	3. Healthcare professional*	3. Challenge*
3. Selective eating disorder	4. Therapist*	4. Obstacle*
	5. Psychiatrist*	5. Enabler*
	6. Psychologist*	6. Perspective*
	7. Paediatrician*	7. Experience*
	8. Physician*	

3.2.2 Inclusion and Exclusion Criteria

Studies were included that explored HCPs knowledge and experience working with ARFID. As an aide for the screening process a decision flow-chart was created that demonstrates how article titles and abstracts were screened. Table 3 details the inclusion and exclusion criteria. These were grouped according to study characteristics and condition of interest. Figure one shows outcome of interest (i.e., HCPs' knowledge and experience with ARFID). To provide an international understanding, no geographical restrictions were imposed. However, imposing a language restriction (English only) would have impacted the breadth of international perspectives captured.

Table 3 Inclusion and exclusion criteria

	Inclusion Criteria	Exclusion Criteria
Study Characteristics	Language: English Design: Empirical studies Full-text available	Language: Non-English Design: Reviews, Letters, Commentaries, Case Reports, Case Series Abstract only (e.g., conference, workshop, poster)
Condition of Interest	ARFID	Studies about other feeding and eating disorders or eating behaviours with no reference to ARFID or extractable ARFID data
Participant	HCPs of any discipline and in any setting	Studies with other participant groups, for example people with ARFID
Outcome of Interest	HCPs knowledge of ARFID HCPs experience related to ARFID care/management, i.e., identifying, assessing, diagnosing, or treating ARFID	Studies not reporting on HCPs knowledge or experiences with ARFID

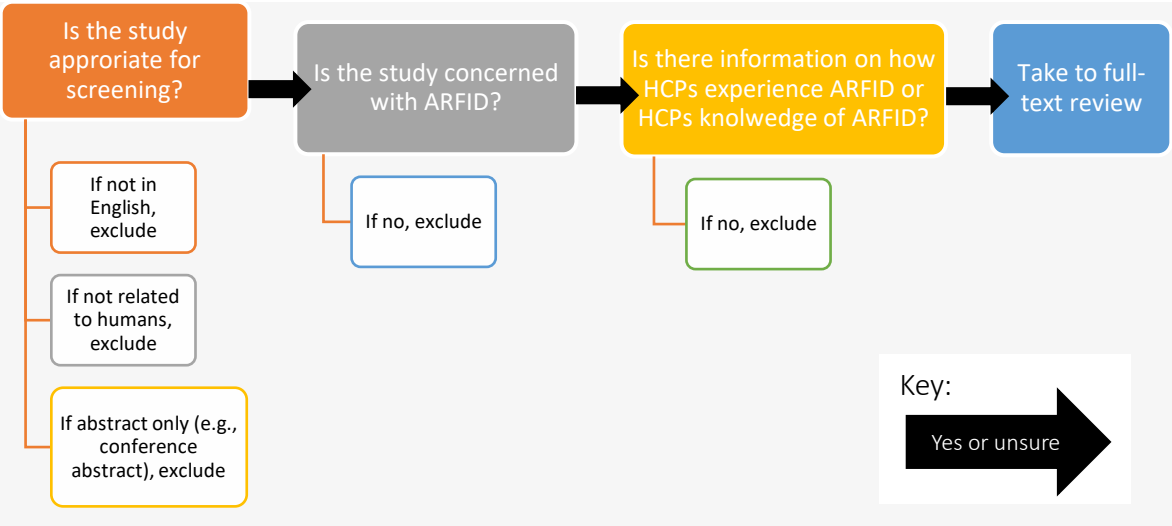

Figure 1 Title/abstract screening decision flow chart

3.2.3 Title/Abstract Screening

The initial search yielded 778 records. Utilising Covidence[3], duplicates were identified and removed, resulting in 710 unique citations for screening. Two reviewers participated in the data screening process. The author conducted the initial screening of all titles and abstracts against the inclusion and exclusion criteria for all records. An independent reviewer (primary supervisor) screened 10% of the articles using the same criteria to ensure consistency and accuracy. In total 120 records were taken into full-text review.

3.2.4 Full-Text Screening

The same process for the title/abstract screening was undertaken for the full-text review. The author read 120 papers and the independent reviewer read 10%. As an aide for screening full texts a decision flow-chart was created. More specific aspects of the inclusion and exclusion

[3] Covidence is an online systematic review software system.

criteria (Table 4) were grouped into sections regarding study characteristics, condition of interest, and outcome of interest (Figure 2). A total of 113 studies were excluded, leaving 7 to be included in the review.

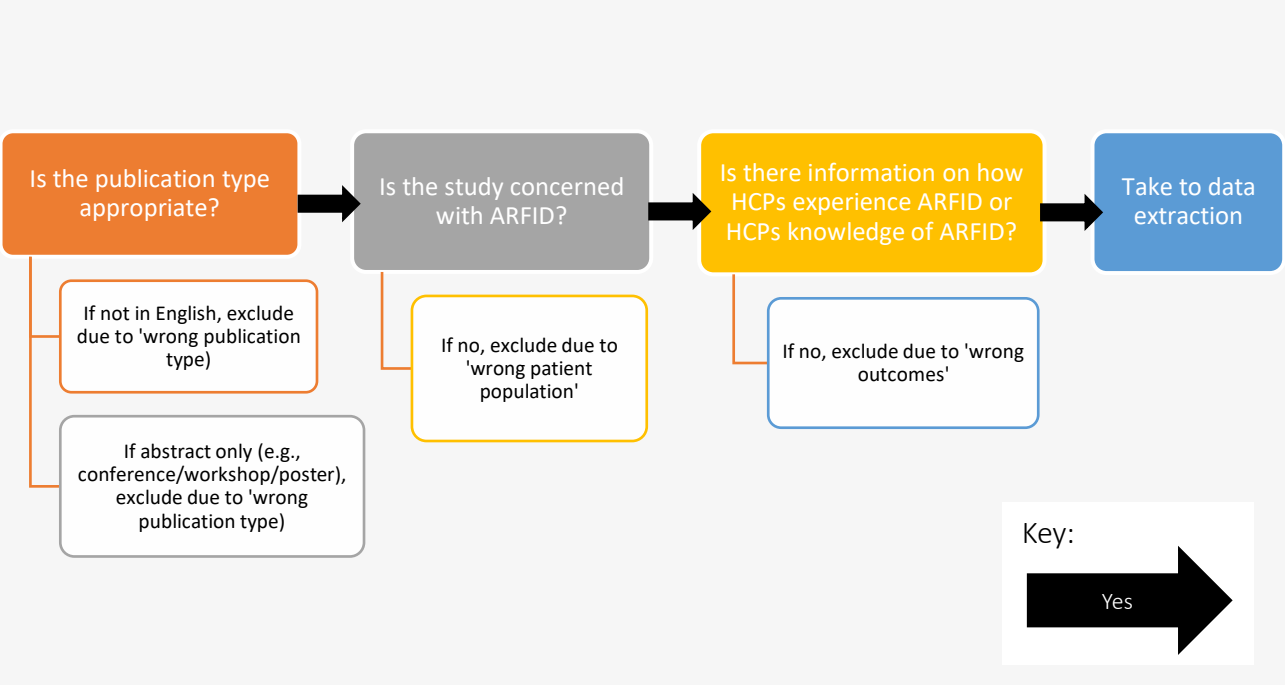

Figure 2 Full-text screening decision flow chart

3.2.5 Backward and Forward Snowballing

The selected studies from the database search formed what Wohlin (2014) calls a starter set. References from the starter set were subjected to backward snowballing, a process aimed at identifying potentially relevant articles that might have been missed through the electronic database search. Additionally, studies that cited any of the starter set were also identified (forward snowballing, Wohlin, 2014). Research Rabbit[4] was used to identify additional studies for screening. Snowballing resulted in an additional 211 unique records being identified for

[4] Research Rabbit (https://researchrabbit.ai/) is an online tool that uses algorithms to support finding relevant literature.

screening. Records were imported into Covidence and subjected to the same screening process as records identified through Boolean searches. All 211 records had their title and abstracts screened, and 60 were eligible for full-text screening (Figure 3) with 3 studies meeting the inclusion criteria. During the full-text review process, the primary researcher identified an additional study that initially met the inclusion criteria, resulting in a total of 11 studies considered for analysis. However, data could only be extracted from 9 studies based on the publications and the data presented. Two of the studies included aggregated data that required a request for access to the raw data to extract relevant information. One author provided access to this data, supporting the study's inclusion, but the other author did not respond. Therefore, the review presents the findings of 10 studies. For a description of the included articles, please see Table 4.

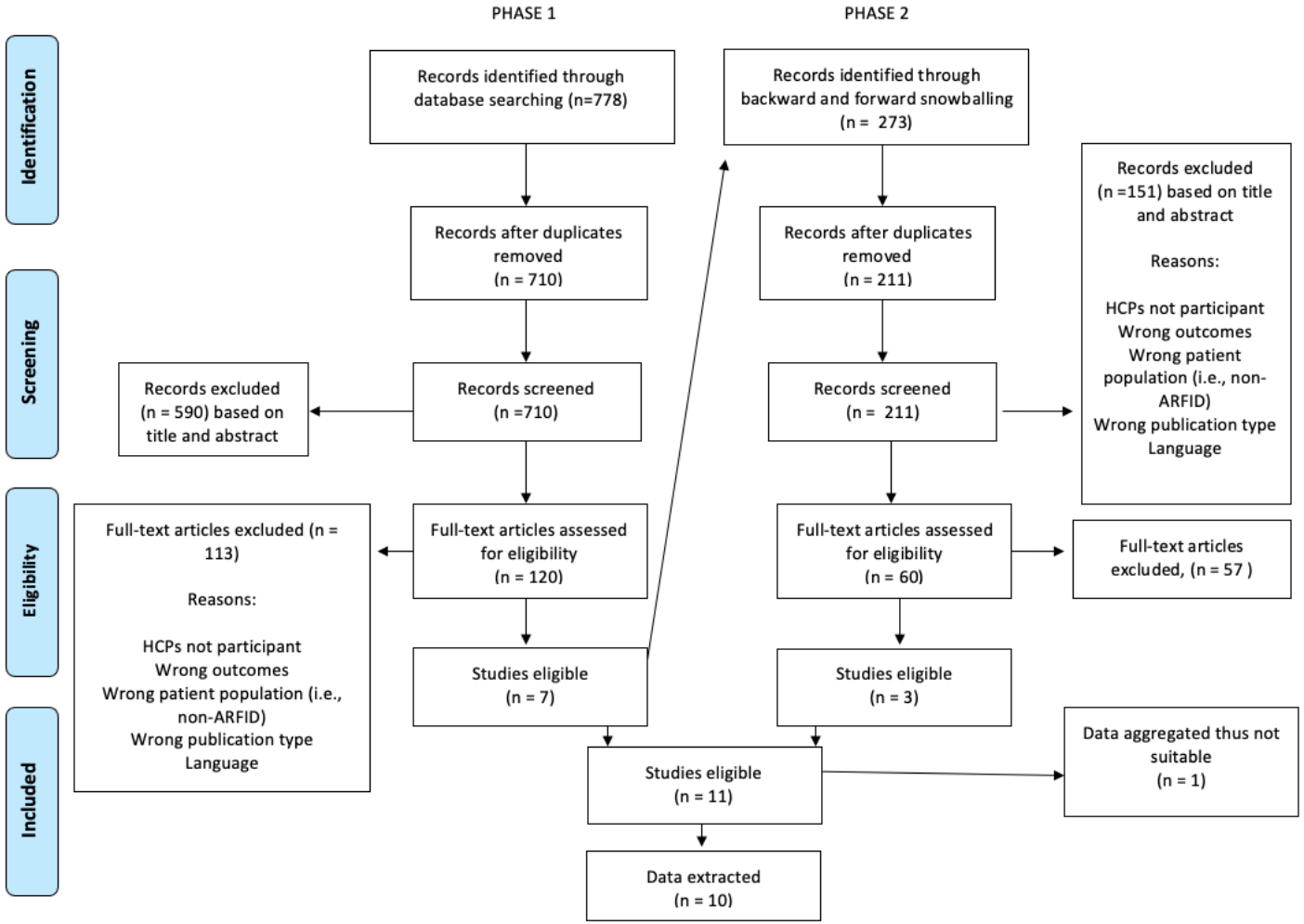

Figure 3 PRISMA diagram

Table 4 Characteristics of studies included in the review.

Year	First Author	Country	Design	Study Aims	Data Collection	HCP Type (n, %)
2014	Katzman	Canada	Cross-Sectional	Not named (case report including unpublished data)	Survey	Paediatricians and Paediatric Subspecialists (n = 657)
2016	Seike*	Japan	Cross-Sectional	To calculate the encounter rate by ED type (based on DSM-5), and examine the relations between the rates and location, school type, number of students, years of experience as a Yogo teacher, nursing experience, and eating disorder knowledge.	Survey	Yogo Teacher[1] (n = 1,886)
2018	Guss*	USA	Mixed-Methods	To determine the current protocols and practices used for inpatient medical stabilisation of patients with ARFID in the United States.	Survey	Physicians (n = 37)
2019	Claudino	International	Experimental vignette-based case-control	To assess clinical utility of ICD-11 guidelines. ARFID-specific research questions: Does the proposed addition of ARFID in the ICD-11 result in individuals with ARFID being more accurately distinguished from anorexia, and does the proposed addition of ARFID to ICD-11 reduce the number of individuals diagnosed with residual eating disorder categories (atypical, other specified, and unspecified)? Can clinicians distinguish between ARFID, and no eating pathology based on the proposed ICD-11 guidelines?	Online Survey	Mental Health and Primary Care Professionals (n = 2,288) from the following disciplines: Medicine (n = 1,367, 59.7%) Psychology (n = 693, 30.3%) Counselling (n = 85, 3.7%) Nursing (n = 49, 2.1%) Social Work (n = 24, 1.0%) Sex Therapy (n = 6, 0.3%) Speech Therapy (n = 2, 0.1%) Other (n = 62, 2.7%)

Year	First Author	Country	Design	Study Aims	Data Collection	HCP Type (n, %)
				Some individuals present with atypical reasons for restricting eating, such as feeling uncomfortable when full. In such cases, can clinicians accurately distinguish between AN and ARFID based on the proposed ICD-11 guidelines?		
2021	Magel	Canada	Qualitative (presented in letter to the editor)	Individuals with ARFID often seek help from various HCPs, many of whom do not specialise in mental health treatment and may be unfamiliar with ARFID. This study sought to fill this knowledge gap and evidence the need for training among community clinicians.	Semi-Structured Interviews	Clinicians (n = 35) Mental Health Professionals (n = 20, 56.5%) Occupational Therapists (n = 8, 21.7%) Dietitians (n = 6, 17.4%) Physicians (n = 1, 4.4%)
2021	Coelho	Canada	Cross-Sectional with Vignettes	Two aims: To elucidate health professionals' familiarity and experience in working with ARFID in a broad sample of multi-disciplinary paediatric health professionals. To assess the ability of health professionals with experience in working with ARFID to differentiate between different clinical presentations of restrictive eating.	Online Survey	Health professionals (n = 93) Dietitians (n = 25, 26.9%) Paediatrician/adolescent health physicians (n = 18, 19.3%) Nurse/psychiatric nurses (n = 10, 10.8%) Medical/paediatric residents (n = 9, 9.7%) Primary care provider/family physicians (n =8, 8.6%) Psychologists (n = 8, 8.6%) Social workers (n = 5, 5.4%)

Year	First Author	Country	Design	Study Aims	Data Collection	HCP Type (n, %)
						Therapist/clinical supports (i.e., registered clinical counsellor, child, and youth worker, n = 5, 5.4%) Other (i.e., psychiatrist, internist; occupational therapist, speech-language pathologist, n = 5, 5.4%)
2021	Harrison*	UK	Mixed-Methods	Two aims: To investigate the level of HCP confidence in identifying and referring paediatric patients with ARFID, focusing on HCPs working in both primary and secondary (specialist) care in the UK. To report and describes HCPs experiences of any current barriers to effective healthcare for children with ARFID.	Online Survey	Primary and Secondary Care Professionals (n = 45) Health Visitors (n = 14, 31.1%) Paediatricians (n = 8, 17.8%) Speech and Language Therapists (n = 8, 17.8%) Psychologists (n = 7, 15.6%) Dieticians (n = 4, 8.9%) General Practitioners (n = 3, 6.7%) School Nurse (n = 1, 2.2%)
2022	Jackson**	New Zealand	Mixed-Methods with Vignette	To explore health professionals' understanding of children with picky eating and the consensus among professions for the labelling of a particular condition portrayed in a vignette.	Online Survey	Health Professionals (n = 73 in 2013, 68 in 2018) Medical practitioners 2013 (n = 13, 17.8%) 2018 (n =12, 17.7%) Dietitians

Year	First Author	Country	Design	Study Aims	Data Collection	HCP Type (n, %)
						2013 (n = 15, 20.6%) 2018 (n = 18, 26.5%) Speech-language therapists 2013 (n = 45, 61.6%) 2018 (n = 29, 42.7%) Other 2013 (n = 0) 2018 (n = 9, 13.2%)
2022	Raffoul	USA	Quasi-Experimental	Pilot-test the efficacy of online training to improve paediatric HCPs comfort in screening and referrals, knowledge about eating disorders, and behaviours related to screening for eating disorders and referral to services.	Online Survey	Pediatrics Primary Care (n = 84) Physicians (n = 21, 25.3%) Nurses (n = 51, 60.2%) Other or did not respond (n = 12, 14.5%)
2023	Dinkler	Sweden	Cross-Sectional Mixed-Methods	Assess self-reported knowledge and confidence regarding ARFID diagnosis and treatment in Swedish HCPs from various disciplines.	Online Survey	Clinicians (n = 489) Speech and Language Therapist (n = 138, 28.2%) Dietician (n = 60, 12.3%) Nurse (n = 58, 11.9%) Psychologist (n = 56, 11.4%) Counsellor (n = 37, 7.6%) Physician (n = 12, 2.5%)

Year	First Author	Country	Design	Study Aims	Data Collection	HCP Type (n, %)
						Occupational Therapist (n = 10, 2.0%) Special Education Teacher (n = 7, 1.4%) Other (n = 49, 10.0%)

* Studies located through snowballing technique

** Study located during full-text review screening as referenced in a study and appeared to meet criteria for this review

1. Yogo teachers are unique teachers in Japan that act as school nurses as part of their role. They are health educators responsible for weighing students and reviewing medical records to screen for medical concerns.

3.2.6 Approach to synthesis

To capture the diversity of included studies, a thematic synthesis approach was adopted. Data underwent analysis to uncover themes and sub-themes related to HCPs knowledge of ARFID and their experiences with the disorder, with a particular emphasis on identifying barriers and facilitators for different tasks required of professionals. Thematic analysis was conducted through a combination of deductive and inductive line-by-line open coding of pertinent information, allowing for focused exploration while remaining open to the emergence of unexpected patterns and insights.

NVivo 12 software was employed to streamline the thematic analysis process and effectively organise the coded data. Mindview 7 software was used to synthesise findings by categorising based on thematic similarities. This enabled a comprehensive comparison of perspectives across studies. The presentation of synthesised findings is narrative in nature, elucidating commonalities, differences, and observed patterns across the included studies.

3.2.7 Quality Assessment

All studies that met the inclusion criteria were critically appraised using Joanna Briggs Institute (JBI) Critical Appraisal Checklists (Barker et al., 2024; Barker et al., 2023; Lockwood et al., 2015; Moola S, 2020) (Appendix C).

3.3 Results

3.3.1 Knowing how to identify ARFID

3.3.1.1 HCPs understanding of ARFID

The task of discerning clinical significance and determining the appropriate course of action squarely rests with the HCPs. Therefore, awareness of a variety of presentations is a crucial first step in effectively identifying and addressing conditions such as ARFID. Unfortunately, awareness of ARFID is limited, thus emerging as the first significant hurdle.

Katzman et al. (2014) found that 63% of Paediatricians and Paediatric subspecialists were unfamiliar with ARFID. A notable distinction from Magel et al. (2021), revealed that half (51.4%) of HCPs, predominantly Mental Health Professionals, had not heard of ARFID previously, despite two-thirds (65.7%) encountering patients with ARFID presentations along their professional journey. In contrast, Coelho et al. (2021) found that 78.5% of HCPs, predominantly Dieticians, reported familiarity with the diagnosis. Although, this was mediated by whether the HCPs provided care in their clinical practice for paediatric feeding or eating disorders. Notably, 84.8% of those with experience providing care reported familiarity compared to 42.9% of those without. While this finding is expected, the differences in clinical judgment depending on experience suggests that there are some HCPs working with ARFID-like presentations who are unfamiliar with the diagnosis. This discrepancy underscores deeper systemic issues with diagnostic classification and multi-disciplinary awareness, highlighting the distinction between lack of awareness of ARFID as a diagnostic label and lack of awareness of ARFID presentations as a phenomenon. Both of which, bring about their own challenges.

Harrison (2021) captured similar uncertainty among UK HCPs, particularly Health Visitors, who expressed reservations about recognising and confidently diagnosing ARFID: *"It [ARFID] is not well recognised by paediatricians in my experience and not a diagnosis we would feel confident making at the moment"* (p.7). Moreover, Harrison (2021) asked primary and secondary HCPs whether they felt confident they could identify a child with ARFID. Most (67%) primary HCPs did not agree that they could identify a child with ARFID, with the most common response being 'unsure' (44%). Secondary HCPs were more confident in their ability to identify ARFID, with 74% agreeing and only 22% being unsure.

Beyond Canada and the UK, Seike et al. (2016) detailed a lack of ARFID awareness among Yogo teachers in Japan, where the majority (58.8%) reported unfamiliarity with ARFID. Interestingly, they assessed odd ratios to identify factors associated with increased occurrence of encountering ARFID and found that greater knowledge of ARFID (OR = 4.23) was associated with increased odds of encountering ARFID. This demonstrates the importance of knowledge supporting an ability to identify ARFID. Dinkler et al. (2023) further emphasised the universality of this challenge, reporting that only 4.1% of their sample of Swedish HCPs, predominately Speech and Language Therapists, had never heard of ARFID. A further 18.5% had merely heard of ARFID but knew nothing about the condition. These findings highlight a significant gap in ARFID awareness and understanding among various HCPs worldwide, underscoring the urgent need for comprehensive education and training initiatives. Without these efforts, the ability to accurately identify and address ARFID will remain limited, potentially leading to misdiagnosis and inadequate care for affected individuals. Addressing this gap is crucial for improving the recognition and treatment of ARFID across diverse healthcare settings.

Viewing the findings with a chronological understanding reveals an evolving landscape of awareness surrounding ARFID among HCPs. However, it is essential to acknowledge the complexity inherent in comparing these findings across studies. Variations in study methodologies, design, sampling biases, and the characteristics of HCPs contribute to the heterogeneity of reported awareness rates. Therefore, making simplistic claims regarding changes in awareness rates based solely on reported percentages may not capture the full scope or be entirely accurate. Instead, a nuanced understanding of the contextual factors shaping awareness is warranted. Future research efforts should aim to standardise assessment methods and consider contextual factors to facilitate meaningful comparisons across studies. Longitudinal studies would be preferable for investigating changes in awareness over time and would benefit from assessing differences among HCPs to identify audiences for more targeted awareness-raising campaigns.

3.3.1.2 Lack of ARFID-training, education, and resources

As documented, awareness among HCPs regarding ARFID remains a significant challenge. In a third of studies, a lack of ARFID education emerged as an issue. Notably, Dinkler et al. (2023) detailed insights, revealing that a majority of Swedish HCPs (64%) reported never having received formal ARFID training. Additionally, 25.8% received less than 2 hours of training, while 7.9% had less than 10 hours. Only 2.3% of HCPs received at least 10 hours of training, highlighting a substantial gap in knowledge acquisition and depth of learning. Consequently, only 4.3% of the sample considered themselves as ARFID experts.

The professional makeup within Dinkler et al. (2023) was diverse, spanning eight different identified professional disciplines. This diversity raises pertinent questions about the equitable distribution of ARFID-specific training across different healthcare professions. Further analysis revealed that education levels and subsequent knowledge varied among different types of HCPs. Physicians/Psychologists and Eating Disorder Clinicians exhibited higher levels of knowledge compared to Neurodevelopmental and Child and Adolescent Habilitation Clinicians. This discrepancy may be attributed to role-specific continuous professional development and increased exposure within specific clinical settings necessitating further training.

Moreover, it is crucial to place the level of ARFID-specific education within the context of a particular professional discipline as it provides insight into whether there is cause for concern regarding the seemingly limited hours of training provided. It is important to acknowledge that the extent of ARFID training needed may vary among professionals, with some requiring more than others. This underscores the need for caution when interpreting these findings, as blanket conclusions may not accurately reflect the nuanced training requirements across different disciplines.

In addition to the insights provided by Dinkler et al. (2023), other studies highlighted similar challenges. Jackson et al. (2022) found low levels of knowledge among medics in New Zealand, with all HCPs referencing a lack of resources as a challenge. Thematically, Harrison (2021) found that British HCPs felt they had inadequate ARFID training. Unfortunately, no further detail was provided on the extent of this issue. Additionally, Magel et al. (2021) found that only 8.6% of Canadian HCPs treating patients with ARFID reported having received any ARFID-related

training. This suggests that a significant majority are providing care beyond the scope of their clinical training, highlighting a systemic flaw.

3.3.1.3 Increased awareness through alternative means

Dinkler et al. (2023) assessed basic ARFID knowledge among Swedish HCPs and found that despite low levels of formalised training, most clinicians possessed some basic ARFID knowledge and could correctly identify key aspects, such as the most common onset being in childhood, cases can occur across the weight spectrum, and that different ARFID presentations can co-occur. Additionally, HCPs were also able to correctly estimate the prevalence rate and identify common comorbidities associated with ARFID.

While formalised education was lacking, HCPs still acquired knowledge through various means. Jackson et al. (2022) identified sources such as reading academic literature, reviewing guidelines and policies, attending conferences, and engaging in professional development activities such as webinars, podcasts, journal clubs and general discussions with multidisciplinary colleagues. HCPs also reported accessing a wide range of continuing professional development nationally (in New Zealand) and internationally. However, despite these efforts, Jackson et al. (2022) also reported low levels of knowledge, suggesting familiarity with the basics but limited depth of understanding. This highlights the need for more comprehensive and targeted educational initiatives to bridge the gap between basic awareness and proficiency in ARFID identification and management.

Additionally, while informal educational resources such as webinars, podcasts, and journal clubs provide valuable opportunities for learning, they may not always offer structured and comprehensive coverage of ARFID-related topics. Thus, there remains a crucial need for formalised training programs and resources tailored specifically to ARFID to ensure that HCPs are equipped with the necessary knowledge and skills to effectively identify and manage this heterogenous disorder.

3.3.1.4 Differentiating ARFID from picky/fussy eating, Autism, and anorexia

Distinguishing ARFID from normative and transient picky/fussy eating, Autism, and anorexia, posed a notable challenge for HCPs. Furthermore, understanding the nuances between these conditions requires keen awareness of their distinct characteristics and presentation, as well as recognising when eating behaviours transition from normative to clinical.

Harrison (2021) noted the general lack of ARFID awareness among British HCPs, particularly in distinguishing it from 'fussy eating', however, there was very little information provided around this. Dinkler et al. (2023) shed light on the difficulties faced by Swedish HCPs, revealing that a significant majority (70-90%) indicated difficulty distinguishing ARFID from Autism and selective eating. Specifically, less than a third (28.3%) felt able to discern ARFID from Autism, and even fewer (9.7%) felt adept at differentiating ARFID from selective eating. Notably, professionals specialising in eating disorders exhibited greater confidence in distinguishing ARFID from anorexia and selective eating, while those working with neurodevelopmental disorders (NDDs) or in child and adolescent habilitation units felt more assured in their ability to differentiate ARFID from Autism. This disparity could be attributed to varying levels of exposure to specific

presentations. Essentially, familiarity with nuances of NDDs or eating disorders enhanced HCPs ability to differentiate these disorders from ARFID. Similarly, Dinkler et al. (2023) found that Physicians and Psychologists, who are likely trained to recognise both clinical and subclinical presentations of eating disorders, were more likely to differentiate ARFID from selective eating and anorexia when compared to other professionals. Further exploration into professional differences was limited in the study, warranting additional investigation into how varying levels of exposure and training influence diagnostic accuracy.

Moreover, Magel et al. (2021) also discussed challenges differentiating ARFID from Autism**,** suggesting that ARFID symptoms might be 'overshadowed' by Autistic symptoms due to a shared presentation of ridged, obsessive, or repetitive behaviours and sensory sensitivities. However, this assumption implies that ARFID and Autism are mutually exclusive disorders, when they often coexist (Farag et al., 2022; Koomar et al., 2021). Therefore, it is crucial to evaluate whether eating behaviours exceed what is typical within an Autistic presentation and, if so, whether the impact necessitates an additional diagnosis (World Health Organization, 2019). This requirement underscores the importance of understanding the norms of Autism to discern whether an ARFID diagnosis is warranted alongside an Autism diagnosis, providing further support for why professionals working with NDDs report a greater ability to differentiate (Dinkler et al., 2023).

In contrast to evaluating self-reported confidence in distinguishing ARFID from other disorders, Coelho et al. (2021) employed clinical vignettes to assess the application of diagnostic criteria among HCPs who have provided clinical care for paediatric cases of ARFID. Among these

vignettes, Case 4 (Coelho et al., 2021, p. 591) was deliberately designed to deviate from typical ARFID characteristics, aiming to test HCPs' ability to differentiate between ARFID and anorexia. The study revealed increased ambiguity in responses to Case 4. However, the authors cautioned against overinterpretation due to factors associated with the vignette's design, namely the patient's gender (male), and ambiguities regarding pertinent information such as exercise motivations and the types of excluded foods. Specificity around these factors would have been indicators of anorexia. Nonetheless, given consistent challenges highlighted by other studies, further support is needed to support awareness of different clinical and subclinical presentations of restrictive eating behaviour.

3.3.1.5 Identifying different ARFID presentations

Recognising ARFID extends beyond a superficial understanding of the condition. Coelho et al. (2021) illustrated this well through their use of vignettes to assess HCPs' ability to correctly identify different restrictive eating presentations. While HCPs were skilled at differentiating restrictive eating without an ARFID diagnosis, those with psychosocial impairment alone and those with restrictive eating and excessive exercise (anorexia) were less accurately classified. Further analysis revealed there was ambiguity surrounding the belief ARFID must be associated with weight loss or failure to gain weight, with ARFID being correctly identified in 76.7% of HCPs who did not believe in this criterion compared with 48.4% of those who did agree. This discrepancy suggests a potential cognitive dissonance among those who endorsed the criterion, yet still identified ARFID.

Recognising this ambiguity, revisions were made in the DSM-5 Text Revision (APA, 2022); explicitly expanding the criteria to include individuals with psychosocial impairment alone (Kambanis & Thomas, 2023). However, given the time it took to increase awareness of ARFID following its introduction into the DSM-5 a decade ago, it may take time for professionals to become familiar with expansive diagnostic criterion.

3.3.1.6 Variable terminology and uni-dimensional conceptualisations

Jackson et al. (2022) anticipated that following the introduction of ARFID into the DSM-5, there would be a consensus among HCPs regarding terminology-use and their understanding of restrictive eating. While increased awareness was observed, variability persisted in how HCPs labelled the presented case in the vignette. Notably, most HCPs in both 2013 and 2018 labelled the condition as 'failure to thrive secondary to undereating,' although this decreased in 2018, with more HCPs opting for the ARFID label.

Alongside the emergence of ARFID as a diagnostic term, factors such as professional background, experience, and training were identified as influencing how professionals conceptualised and labelled the condition. For instance, Medics, Speech and Language Therapists, and Dieticians expressed the use of different terminology based on their respective expertise and understanding.

Furthermore, HCPs agreed on reduced food quantity and variety as defining features of 'picky eating', but they diverged on causal factors, resultant behaviours, and the impacts. Understandably, Speech and Language Therapists focused on sensory influences and family mealtimes, whilst Dieticians emphasised the chronicity of food refusal and gave examples of specific mealtime behaviours such as food spitting and crying.

Moreover, while some HCPs adopted a uni-disciplinary approach to the case, others demonstrated a more holistic understanding, considering medical, nutritional, feeding skills, behavioural, psychosocial, and environmental factors. This variability underscores the need for enhanced interdisciplinary collaboration and a comprehensive approach to effectively address the complexities of ARFID and related eating disorders.

3.3.2 Experiences assessing and diagnosing ARFID

3.3.2.1 Lack of confidence assessing and diagnosing ARFID

Harrison (2021) captured a significant lack of self-reported confidence among British HCPs in diagnosing ARFID, with 89% of primary care and 67% of secondary care HCPs expressing no confidence in their ability to diagnose. Notably, confidence levels were higher in secondary care, which is to be expected considering the more specialised nature of such services.

Similarly, a majority (86.6%) of Swedish HCPs, as reported by Dinkler et al. (2023), expressed a lack of confidence in their ability to diagnose ARFID. When examining professional differences, it was found that HCPs working in Child and Adolescent Habilitation Units exhibited the highest

proportion of professionals (95.4%) reporting a lack of confidence in ability to diagnose ARFID. Confidence was relatively better among HCPs predominantly working with eating disorders (82% lacked confidence) and Physicians and Psychologists (68.2% lacked confidence). Nevertheless, confidence was widely lacking. Dinkler et al. (2023) also explored whether HCPs were familiar with the diagnostic tools available to assess ARFID, finding that very few were; only 8.6% (12.3% among Physicians/Psychologists) reported knowing which tools they could use to assess and diagnose ARFID. Concerns were rightly raised about the insufficient familiarity with these tools, particularly among Physicians and Psychologists, who play a pivotal role in assessing and diagnosing ARFID, which was further reiterated by Magel et al. (2021).

Raffoul et al. (2022, unpublished data) conducted a pilot study to assess the effectiveness of an online training video aimed at enhancing the comfort, knowledge, and screening behaviours of US Paediatric HCPs regarding eating disorders, including ARFID. Prior to the webinar, 40.85% of HCPs reported feeling 'not at all comfortable' with screening for ARFID, while 36.62% felt 'a little comfortable', 16.90% felt 'mostly comfortable', and only 5.63% felt 'very comfortable'. Following the webinar, there was a notable improvement in these figures, with a decrease in responses indicating discomfort and an increase in those expressing comfort. The responses post-training were: ‘not comfortable’ = 1.43%, ‘a little comfortable’ = 28.57%, ‘mostly comfortable’ = 52.86%, and very comfortable’ = 17.14%. In the follow-up assessment, the percentage of HCPs reporting 'not at all comfortable' fell to 0%, while 'very comfortable' responses rose to 18.84%, indicating the enduring impact of the training. Additionally, significant enhancements were observed in HCPs' knowledge across more than half of the assessment items, particularly in correctly identifying tools for screening ARFID (38.36% at

baseline, 54.22% post-video). These findings suggest that even a brief educational intervention can lead to heightened awareness of screening tools, as well as improvements in knowledge and confidence among HCPs.

3.3.2.2 Lack of familiarity with diagnostic criteria

Coelho et al. (2021) conducted assessments regarding Canadian HCPs' ability to accurately identify various presentations of restrictive eating and their comprehension of the DSM-5 criteria for ARFID. A significant proportion (78.3%) recognised ARFID as involving a persistent failure to meet nutritional or energy needs, while 50% believed it must be associated with substantial weight loss or failure to achieve expected weight gain, or faltering growth. Only a third (37%) could correctly identify all the DSM-5 diagnostic criteria, with those experienced in ARFID showing higher proficiency identifying all criteria (47.5%) compared to the inexperienced (16.1%). Given ARFID's heterogeneity, this knowledge gap bears clinical significance, potentially contributing to underdiagnosis and misdiagnosis, particularly for presentations involving sole psychosocial impairment, as discussed earlier.

Akin to Coelho et al. (2021), Jackson et al. (2022) also used a vignette to gauge how HCPs would classify a case and whether there were any changes from 2013 to 2018. They presented the case of a 3-year-old, providing pertinent information supporting a potential ARFID diagnosis. HCPs, predominantly Speech and Language Therapists, were asked whether they believed there was a consensus in the medical field for labelling for his condition, revealing a significant shift in opinion between 2013 and 2018, though not as expected. In 2013, a majority (75.3%) of HCPs agreed there was no consensus on a label for the vignette. Surprisingly, this increased

to 89.7% in 2018 despite the introduction of ARFID into the DSM-5. Further exploration uncovered a notable decrease in 'I don't know' responses (15.1% in 2013, 2.9% in 2018), and an increase in those indicating 'no consensus' (75.3% in 2013, 89.7% in 2018). Jackson et al. (2022) suggest that this shift may be due to variability in understanding terminology for food refusal and picky eating. Despite the rise in those believing there was no consensus, professionals expressed a desire for more information (e.g., *"what other investigations have been done?"*, and *"what percentiles, what food does he eat, what behaviour he exhibits at mealtimes?"*), indicating increased awareness of picky eating and its impact. Moreover, Jackson et al. (2022) reported HCPs across both years recognised reduced food quantity and variety as defining features of picky eating in children, and that picky eating was no longer considered benign. In 2013, one HCPs said, *"I have never heard of these 'disorders' they sound like…claptrap"* (p.43) capturing the previously common dismissal of picky eating, however, in 2018, HCPs appeared to be recognising the clinical significance due to the introduction of ARFID as a diagnosis and accompanying professional development opportunities.

According to Katzman et al. (2014), unpublished findings from the Canadian Paediatric Surveillance Program revealed that Paediatricians and Paediatric subspecialists retrospectively reported encountering 339 cases of ARFID within the past year. Surprisingly, a third (30%) who suspected ARFID misapplied the exclusion criteria, resulting in misdiagnosis. While specifics are limited due to the nature of the publication, these findings highlight errors in diagnosis attributed to misunderstanding or misapplication of exclusion criteria and are consistent with the findings of Coelho et al. (2021).

Due to its relative novelty, many HCPs are unfamiliar with ARFID as a diagnostic label and the specific diagnostic criteria that defines the disorder. For instance, Magel et al. (2021) found that half of their Canadian HCPs were unfamiliar with the diagnostic label. They suggest lack of familiarity could stem from community clinicians outside of the mental health profession being unaware of changes to DSM diagnoses. Furthermore, the introduction of ARFID into the ICD-11 likely increases awareness of the diagnostic label outside of mental health as it is not a mental health specific manual.

Similarly, Dinkler et al. (2023) found that only 11.9% of their sample knew the diagnostic code for ARFID. Although better for HCPs who worked with eating disorders (17.3%) and among Physicians and Psychologists (21.5%), the overall figures may raise concerns. However, when considering the context, this lack of awareness becomes more understandable. Dinkler et al. (2023) note that the Swedish healthcare system has yet to implement ICD-11, the version which includes ARFID as a diagnosis, and provides a specific code (6B83). Therefore, it is logical that most Swedish HCPs are unaware of the appropriate code to use. Moreover, it is important to exercise caution when inferring the consequences of not knowing the diagnostic code. In practice, HCPs can readily refer to diagnostic manuals to retrieve this information, mitigating potential challenges associated with code unfamiliarity.

3.3.2.3 Clinical utility of ICD-11

Claudino et al. (2019) conducted a study using vignettes to assess HCPs proficiency in utilising the new ICD-11 guidelines and assessing overall clinical utility. This international investigation revealed that the ICD-11 guidelines were favourably rated over ICD-10 for each feeding and

eating disorder diagnosis in terms of ease of use, clarity, and alignment with the presented vignettes. Particularly for ARFID, being a novel diagnostic label in ICD-11, its application was understandably more accurate compared to ICD-10, aiding the precise diagnosis of ARFID vignettes. Under the ICD-11 guidelines, HCPs demonstrated a higher ability to distinguish between ARFID cases (88.5% correct) and those without a diagnosis (78.4% correct). Positively, even without a specific diagnostic label in ICD-10, HCPs could still differentiate individuals exhibiting ARFID symptoms from those without a diagnosis (76.8% and 79.6% respectively), although the specific diagnoses applied varied, including atypical anorexia nervosa, feeding disorder of infancy or childhood, other eating disorders, or eating disorder unspecified. The authors concluded that the inclusion of ARFID in the ICD-11 simplified the diagnostic process, and HCPs utilising these guidelines were better equipped to distinguish ARFID cases from anorexia.

3.3.3 Experiences treating ARFID

Treating ARFID poses a multifaceted challenge for HCPs as evidenced by several studies shedding light on confidence levels, knowledge gaps, and treatment protocols. Coelho et al. (2021) delved into the confidence levels of Canadian HCPs regarding clinical care for young people with ARFID. Naturally, those with experience in treating ARFID demonstrated higher confidence levels compared to those without such experience, although it is worth stressing that overall confidence remained relatively low. On a 5-point Likert scale ranging from '1 = not at all' to '5 = very much' for confidence providing clinical care the mean confidence ratings were 2.77 for HCPs with ARFID care experience and 2.33 for those without. Remarkably, only a small fraction of the sample reported confidence ratings above the mid-point of the scale, with 13.3%

selecting 4 and 3.3% selecting 5. Coelho et al. (2021) speculated that the lack of evidence-based treatments might contribute to this low confidence.

In a parallel exploration, Dinkler et al. (2023) explored the extent of knowledge among Swedish HCPs regarding the treatment of ARFID. The results were stark, with a significant majority expressing uncertainty about how to approach ARFID cases. Specifically, 89.3% of Swedish HCPs reported uncertainty about treating ARFID. This lack of clarity extended across various professional groups, highlighting a systemic gap in understanding, and managing ARFID. With only 15.5% of HCPs specialising in eating disorders and 14.3% of Physicians and Psychologists reporting knowing how to treat ARFID.

Magel et al. (2021) provides additional insights into the challenges of treating ARFID by revealing a trend among Canadian community HCPs to provide treatment for ARFID without any training (57.1%). This shortfall in expertise was compounded by a lack of guidance on where to refer patients for specialised care, forcing many HCPs to navigate ARFID treatment independently, with varying degrees of success. Notably, a wide arrange of treatment methods were employed, including the SOS approach to feeding, food exposure, hypnotherapy, nutritional counselling, integrative psychotherapy, behavioural learning theory, and emotion-focused therapy.

Highlighting the ethical dilemma faced by HCPs, Magel et al. (2021) draws attention to the tension between the ethical obligation to provide care and the imperative to balance the lack of training and remaining within the bounds of clinical competence. Furthermore, many HCPs

expressed a lack of awareness regarding how to acquire the necessary skills to effectively treat ARFID, a predicament compounded its novelty and the limited availability of resources.

In a parallel exploration, Harrison (2021) echoes similar concerns surrounding the challenges faced by HCPs in reconciling their duty to provide care with their level of knowledge and training. Thematic analysis unveiled instances where the lack of expertise led to parents receiving conflicting and unhelpful advice. Participants underscored the issue by highlighting instances where families were given conflicting advice or unrealistic expectations regarding the speed and likelihood of improvement in eating behaviours.

Additionally, the absence of a clear care pathway exacerbates the dilemma, compelling some HCPs to provide care despite feeling ill-equipped to do so. One participant shared their struggle in finding suitable help for a teenage patient, lamenting the lack of support from Child and Adolescent Mental Health Services (CAMHS) due to the absence of a care pathway (Harrison, 2021). This underscores the urgent need for enhanced support systems and training programs to enable HCPs to effectively address the complex challenges posed by ARFID.

Guss et al. (2018) completed a survey of US Physician practices concerning the inpatient medical stabilisation of patients with ARFID, revealing notable gaps in standardised protocols. Surprisingly, only half had standardised protocols in place. Among those with protocols, more than half used the same protocol for ARFID as they did for anorexia, despite substantial differences between these conditions. A mere 22.7% of the sample reported having a non-anorexia refeeding protocol specifically designed for ARFID patients highlighting a notable gap.

The variability in treatment approaches is somewhat to be expected given the heterogeneous nature of ARFID, reflecting the reality of providing clinical care for such a multi-faceted condition where treatment often necessitates a formulation-led individualised approach. What is worrisome is the adoption of protocols designed for anorexia without appropriate modifications for ARFID, and the consequences. Namely, exacerbating psychological risks associated with increasing food range and volume simultaneously.

Free-text responses highlight the need for ARFID to be treated differently to anorexia and the use of a multidisciplinary approach with additional services such as behaviour modification or exposure therapy as being an important aspect of ARFID care. In sum, the collective findings underscore the arduous challenges that HCPs face in treating ARFID. From confidence crises to knowledge gaps and protocol deficiencies, addressing these challenges requires a concerted effort to enhance education, training, and resource allocation within healthcare systems internationally.

3.3.3.1 Pathways and referrals

Harrison (2021) examined the confidence levels of HCPs in knowing where to refer to children with ARFID for assessment and treatment. Their findings reveal a significant lack of confidence among both primary and secondary HCPs, with 67% expressing uncertainty about where to refer children for an ARFID assessment. Challenges also persisted when it came to knowing where to refer for treatment and support. Less than half of both primary (28%) and secondary (41%) HCPs felt they knew where to make onward referrals for treatment and support for children with ARFID. This lack of clarity poses considerable challenges for families seeking

appropriate identification and timely referrals to specialist services. Harrison (2021) suggests that this may indicate a discrepancy in the application of general care principles outlined in NICE Guidelines, Eating Disorders: Recognition and Treatment (2017), particularly for children presenting with ARFID, resulting in delays in diagnosis and a lack of treatment or support.

Similarly, Magel et al. (2021) and Jackson et al. (2022) also found that HCPs faced difficulties in determining where to refer patients with ARFID. In Magel et al. (2021), this often led to HCPs attempting treatment themselves despite lacking ARFID training. Jackson et al. (2022) further noted the absence of clear referral criteria and professional support once children are deemed medically stable, exacerbating the challenge of appropriate referrals.

Compounding the confusion faced by HCPs is the rejection of ARFID referrals by some services (Harrison, 2021). HCPs expressed concerns that services established exclusion criteria aimed at rejecting ARFID referrals. For instance, a HCP cited the exclusion of children with Autism, saying *"our growth and nutrition clinic exclusion criteria includes children with Autism and most of the children I see with these symptoms have Autism"* (p.6). This rejection of referrals contributes to a loss of faith in the effectiveness of relevant services among professionals, leaving children with ARFID falling through the gaps between different services.

Moreover, commissioning challenges further exacerbate the fragmentation of ARFID care. HCPs critiqued the lack of structured support for ARFID within healthcare systems, with services often not commissioned to provide diagnosis or treatment and that *"these children fall between the gaps because they do not fit neatly into a service"* due to their complex

presentations (Harrison, 2021, p. 6). This was evidenced by one HCP who said: *"we don't offer ARFID diagnosis or treatment within the Paediatric Gastroenterology team as we are not commissioned to do so"* and "*we struggle to get support for these young people from other services as local CAMHS […] ED services also tell me they are not commissioned to provide a service either. So, I feel commissioning gaps may be a significant barrier. It may be that these services are commissioned but don't communicate this and if so then communication and joined up services would be the barrier"* (Harrison, 2021, p. 6). This disjointed approach to commissioning results in a lack of clear pathways or specific services tailored to the needs of ARFID patients, leaving them feeling marginalised and without access to long-term specialist care (Harrison, 2021).

Raffoul et al. (2022, unpublished data) conducted a study evaluating the impact of a brief training video on HCPs confidence in screening and referring patients with eating disorders, including ARFID. Prior to the webinar, the data exhibited a distribution split between varying levels of comfort among HCPs when referring patients with ARFID. Specifically, 27.87% of HCPs reported feeling 'not at all comfortable', 31.15% felt 'a little comfortable', 26.23% felt 'mostly comfortable', and 14.75% felt 'very comfortable'. However, following the webinar, there was a significant shift in this distribution. The percentage of HCPs indicating 'not at all comfortable' decreased to 0%, while the percentage of those feeling 'very comfortable' increased substantially to 47.69%. Thus, demonstrating the benefit of brief educational interventions to increase confidence referring. Furthermore, Raffoul et al. (2022) demonstrated the benefit of brief educational interventions in increasing HCPs' confidence in referring patients with ARFID, it is important to acknowledge that confidence levels may also be influenced by prior referral

experiences as noted by other studies. Future research could explore how past experiences with making ARFID referrals and the outcomes of those referrals affect HCPs' confidence in their referral practices and the system.

3.3.3.2 Lack of multi-disciplinary team (MDT) working

Both New Zealander and British HCPs recognised the importance of a multidisciplinary approach when treating children with ARFID yet faced challenges in implementing it effectively within their healthcare systems. Jackson et al. (2022) observed this need among New Zealander HCPs, who acknowledge the necessity of involving various professionals but often found it challenging to do so consistently. Despite recognising the value of MDTs, many HCPs tended to refer to single professions due to the lack of suitable services, particularly in smaller communities where access to multidisciplinary teams is limited.

Similarly, Harrison (2021) reported similar sentiments among British HCPs, who commented on the lack of multidisciplinary collaboration. One participant highlighted the issue by stating that *"diagnoses are often made in an inconsistent and uni-disciplinary manner"* (p.7). This deficiency in MDT working is particularly concerning when considering the broader lack of awareness, knowledge, and confidence among HCPs, especially those outside specialist services. Furthermore, given the existence of several exclusion criteria for an ARFID diagnosis, it becomes imperative that those involved in assessment possess the necessary skills and training to conduct comprehensive medical, psychological, and nutritional evaluations.

The challenges of limited access to MDTs were compounded by the reluctance of services to accept referrals for ARFID patients, as noted by Harrison (2021). Many relevant services, including Psychology, Dietetics, Speech and Language, and Specialist Nursing teams, acknowledged the need for a multidisciplinary approach but often declined referrals as this approach was lacking. This situation leaves patients with ARFID in a precarious position, as they may not receive any services unless a specific clinician makes an exception. Highlighting the significance of MDT working and underscoring the plight of ARFID patients caught in the gap. One HCP aptly expressed their frustration: *"Often the relevant services (psychology, dietetics, speech and language, specialist nursing teams) do not accept referrals for these children because they all acknowledge that a multidisciplinary team is required to best meet the needs of this children and young people. Sadly, this tends to mean that, unless a specific clinician bends the rules, they don't get any service"* Harrison (2021, p. 7).

Guss et al. (2018) observed that many US Physicians caring for inpatient ARFID cases were part of MDTs. This finding underscores the recognition of the complex nature of ARFID and the necessity of MDTs in its management. Moreover, the study highlighted that the most common complementary therapies provided during medical admissions included group therapy and nutritional education, indicating the importance of comprehensive treatment strategies. HCPs acknowledged the absence of a one-size-fits-all treatment for ARFID patients, emphasising the value of an MDT in offering a diverse range of interventions to address the multifaceted challenges presented by the condition.

3.4 Summary

Table 5 presents key insights, illuminating HCPs experiences concerning ARFID. Aligned with the review's aim of elucidating barriers and facilitators, this table synthesises pivotal insights in a pragmatic manner. Implications and recommendations are also addressed.

Table 5 Summary of Insights from the systematic literature review

Main Insights	Barriers, Facilitators, Implications and Recommendations
Limited Awareness and Confidence Among HCPs	**Barriers:** Many HCPs lack awareness and confidence when it comes to ARFID. Lack of confidence was linked to limited formal training and experience in identifying and diagnosing ARFID.
	Facilitators: Increased awareness of ARFID among HCPs was associated with (1) experience in providing care for paediatric feeding or eating disorders, (2) participation in professional development activities such as workshops, webinars, and podcasts, (3) engagement with informal educational resources like academic literature and guidelines, and (4) professional specialisation.
	Implications & Recommendations: Gaps in knowledge can lead to misdiagnosis or delayed diagnosis, affecting the timely and appropriate care that families receive. Continuous professional development and exposure to ARFID through various educational means, including informal means, are essential to improve awareness and confidence among HCPs.
Variable Terminology and Conceptualisation	**Barriers:** HCPs use varying terminology and have different conceptualisations of ARFID, influenced by their professional background and training. This leads to confusion and miscommunication within the healthcare system, resulting in inconsistent approaches to identifying and managing the disorder. Additionally, there was an increased lack of consensus in classifying a case of ARFID between 2013 and 2018, contrary to expectations that consensus would improve over time with standardised diagnostic nomenclature.
	Facilitators: None identified.

	Implication & Recommendation: The variability in terminology and conceptualisation of ARFID among HCPs can lead to miscommunication and inconsistent care, negatively impacting patient outcomes. Recognising the need for standardised terminology is crucial for improving communication and consistency in care. Interdisciplinary collaboration among HCPs can foster a more cohesive and unified approach to understanding and managing ARFID. Implementing ongoing professional development and training can help align HCPs' understanding and approach to ARFID, enhancing diagnostic accuracy and care consistency.
Barriers to Accurate Diagnosis	**Barriers:** HCPs often struggle with identifying and diagnosing ARFID due to difficulties distinguishing it from other eating behaviours/disorders and Autism due to overlapping symptomology. This is compounded by differing diagnostic manuals and a lack of validated assessment tools, thus strengthening the reliance on clinical judgment despite lack of confidence. Recognising psychosocial-only presentations was particularly challenging, furthering reliance on clinical judgment, and some HCPs being unaware of the Text Revision (APA, 2022). **Facilitators:** The ICD-11 guidelines were found to be more user-friendly and accurate compared to ICD-10, aiding in the precise diagnosis of ARFID. HCPs with more experience and those who participated in brief educational interventions, such as webinars, demonstrated improved knowledge and confidence in diagnosing ARFID. Additionally, professionals specialising in neurodiversity were better at distinguishing ARFID from Autism, while eating disorder professionals were more adept at differentiating ARFID from anorexia. **Implications & Recommendations:** Diagnostic ambiguity can lead to misdiagnosis or delayed diagnosis, impacting the timely and appropriate care that families receive. It is crucial to implement comprehensive training and ensure HCPs stay up to date with relevant diagnostic changes. To support clinical judgment, the development of appropriate screening tools and validated measures is essential. Furthermore, multidisciplinary assessments are advised, alongside supporting knowledge transfers, enhancing differential diagnosis abilities among differing professional groups.

Referrals and Care Pathways	**Barriers:** HCPs face a lack of clear referral pathways for ARFID, leading to confusion about where to refer patients for assessment and treatment. This issue is compounded by stringent specialist service exclusion criteria and commissioning gaps, resulted in rejected referrals, particularly for children with Autism. Consequently, patients were left without structured support, and in some cases, HCPs attempted treatment despite lacking confidence and training, driven by a duty of care for their patients. **Facilitators:** Multidisciplinary working was recognised as facilitating better referral pathways for ARFID. **Implications & Recommendations:** The lack of clear referral pathways and stringent service exclusion criteria can lead to patients being left without structured support, and inappropriate or rejected referrals can result in unnecessary delays. Moreover, while well-meaning, HCPs attempting treatment despite lacking confidence and training in ARFID can compromise the quality of care. ARFID is a complex disorder, and generic advice can be harmful with some HCPs giving inappropriate and conflicting advice. To address this, it is essential to establish clear and consistent referral pathways, increase commissioning and provisioning of services equipped to deliver specialist MDT care, and develop clear service criteria without exclusionary practices (e.g., excluding people with Autism). Promoting multidisciplinary working and ensuring that HCPs are well-informed about appropriate referral options can help improve care coordination and support for patients with ARFID.

Chapter Three: Methodology and Ethics

3.1 Overview

This chapter explores the theoretical and methodological framework that underpins this dissertation, providing an overview of decisions guiding the research. This dissertation adopted a mixed-method design, pragmatically using a blend of analytical techniques tailored to the aims and research questions.

3.2 Mixed-Methods Sequential Exploratory Design

This study utilised a sequential exploratory design, with the primary quantitative study informing the secondary qualitative study. The quantitative study involved an online survey of parents of children with ARFID, capturing demographic information, clinical characteristics, and healthcare experiences. This initial phase aimed to identify broader patterns and trends within the population, exploring if there were differences in the presentations and healthcare journeys of children with ARFID based on demographic factors. The qualitative study followed, consisting of in-depth semi-structured interviews with a subset of survey participants, specifically six mothers of eight Autistic children with ARFID.

3.3 Personal and Philosophical Context

3.3.1 Positionality

It is commonly said that research is me-search, highlighting the intrinsic motivation that drives a researcher to deeply engage with a particular topic among the endless possibilities available. Me-search suggests that researchers choose a phenomenon because of a personal connection. The risk of me-search is that it can threaten scientific impartiality and neutrality, potentially bringing the trustworthiness of the research and researcher into question (Altenmüller et al., 2021). As such, it is important one positions themselves.

In many ways, I am an outsider researcher. I am not yet a parent, nor do I, or anyone in my network, have intimate experience with ARFID. Yet, my research has often centred around key themes: a spectrum of eating difficulties from colloquially 'picky' to clinically disordered, neurodiversity, and the politics of mothering and feeding. Food has always been a source of both pleasure and strife in my life, which likely fuels my interest in these research themes and understanding barriers to convivial mealtime experiences. Moreover, I have clinical experience working on an inpatient CAMHS eating disorder ward before training and am concluding my training journey within a community CAMHS eating disorder service with an ARFID pathway. This current clinical context moves me closer to an insider position, yet one from the other side of the help-seeking dynamic. Undoubtedly my clinical practice has informed my research, and my research has informed my practice.

As a reader, you likely come from a different position than I and those who took part in this project. My hope is that this work fosters empathy and a deeper understanding of the complex dynamics at play in the realms of parenting, food, neurodiversity, and the intersection where they meet.

3.3.2 Philosophical Stance

To ensure pragmatic allocation of words[5] to aspects directly contributing towards aims and holding potential for real-world impact, a decision was made favouring brevity and avoiding repetition (see Bamigbade, 2021, for detail on my philosophical stance). In short, the philosophical orientation that guides my actions as a researcher is one that acknowledges the value of both objectivism and subjectivism. While objectivism possesses the power of numbers, subjectivism captivates with stories (Pluye & Hong, 2014). As a Pragmatist, I view both as meaningful tools to wield rather than positions to embody, with my primary concern directed towards capturing the depth, complexity, and multifaceted richness of the human experience (Yardley & Bishop, 2015).

[5] This was written but substantially reduced during the final edit.

3.3.3 Reflexivity

Throughout the research process, a commitment to reflexivity has been integral to ensuring transparency, rigour, and accountability. This reflexivity was enacted through several key practices:

- Supervisory Discussions: Regular supervisory meetings provided an opportunity to transparently discuss factors influencing research decisions and processes. These conversations enriched both the methodology and interpretation of findings.
- Reflective Diary: Keeping a diary served a dual-purpose, capturing the bidirectional relationship between my clinical practice and research.
- Engagement with Diverse Consultants: Actively engaging with diverse consultants, including Expert by Experience (EbE) and HCPs, enriched the research process. Their perspectives and experiences provided valuable insights and challenged assumptions, contributing to a more comprehensive understanding of the phenomenon under study.
- Participation in Professional Communities: Regular attendance at the ARFID Special Interest Group and completion of specialist training[6] has been instrumental in furthering ongoing discussions about the state of ARFID care in the UK and staying abreast of the latest advances. These professional engagements have significantly broadened my knowledge base and have cultivated interest and investment in the research findings. Hopefully, amplifying the real-world impact.

[6] NHS England-funded ARFID Masterclass (2 days) and Intensive Foundation Practitioner Training in Eating Disorders in Children and Young People (5 days).

3.4 Quantitative Methodology

3.4.1 Survey Design

An online survey was created using Qualtrics, comprising of both closed and open-ended questions to capture various aspects of parents' experiences navigating the healthcare system on behalf of their child in relation to their ARFID symptoms (Appendix D). The initial draft of the survey was developed based on the insights gained from the literature and the expertise of the research team. This was then reviewed by consultants and underwent iterative changes. This collaborative approach ensured that the survey was comprehensive, well-structured, and effectively captured the nuances of participants' experiences and the realities of journeying through the healthcare system. Moreover, EbE consultants were also able to provide helpful feedback on the accessibility, content, and overall design, optimising the survey's quality and relevance and maximising completion rates and participation levels.

3.4.2 Participants

3.4.2.1 Participant Criteria

To be eligible for this study, participants had to be parents or caregivers with primary or equal responsibility for a child displaying symptoms of ARFID and who had sought support through the UK health system. These criteria were chosen to ensure a diverse range of experiences related to ARFID healthcare. Detailed explanations of each criterion were provided to avoid bias, clearly communicating the inclusive approach and welcoming participation regardless of ARFID healthcare outcomes. For more detailed information (Appendix D).

3.4.2.2 Recruitment

Participants were recruited through a closed Facebook group. Recruitment materials (Appendix E) were posted by an administrator and further disseminated by consultants among their informal networks. Additionally, advertisements for the study were circulated on Instagram and X to ensure access for non-Facebook users. The survey launched 10/01/2024 and was active for two weeks. Out of the 1,084 people who accessed the survey link, 68% consented and passed the eligibility screening questions (Table 6). Among these, 59% completed the survey without missing data, forming the final sample for this study.

Table 6 Participant Enrolment and Eligibility Details

Participant Engagement Stage		Response Rate, N (%)
Accessed the link		1,084
Consent		Yes = 823 (100%) No = 1 (0%)
Eligibility Criteria 1	Are you the parent or caregiver of a child with Avoidant Restrictive Food Intake Disorder (ARFID) symptoms? Please note that you can still select 'Yes' even if your child has not been diagnosed.	Yes = 818 (100%) No = 1 (0%)
Eligibility Criteria 2	Are you primarily or equally responsible for the medical care and well-being of the child with ARFID symptoms?	Yes = 841 (100%) No = 3 (0%)
Eligibility Criteria 3	Have you attempted to access support, advice, assessment, diagnosis, and/or treatment for your child's ARFID symptoms through the English healthcare system while they were under the age of 18 years?	Yes = 783 (97%) No = 28 (3%)
Finished Survey		Yes = 481 (61%) No[1] = 302 (39%)
Missing Data		Yes = 44 (9%) No = 437 (91%)

1. Respondents who did not reach the end of the survey had their responses closed due to session expiration. Participants had one week from when they last accessed the survey to return to their surveys before closure.

3.4.2.3 Sample

Four hundred and thirty-seven parents of children with ARFID symptoms (421 mothers, 6 fathers, 4 other carer, 3 grandmothers, 2 legal guardians and 1 stepmother) aged between 22 and 71 (*M*=42.06; *SD*=7.80) completed our survey. A vast majority (96.8%) of the respondents classified themselves as ethnically White. The remaining classified themselves as either mixed/multiple ethnic heritage (2.1%), Black (0.2%) or preferred not to say (0.5%). Employment status and highest level of formal schooling were the sole socio-economic indicators captured. The most common employment status was part-time employment (33%), followed by unpaid full-time family caregiving (26%). Regarding educational attainment, 46% of the sample held an undergraduate degree, master's degree, or doctorate, indicating a higher level of education compared to the national average.

3.4.3 Data Collection

Participants completed an online survey via Qualtrics (Appendix D), providing detailed information on the following topics:

- Demographic information
- Child diagnostic and developmental history
- Child ARFID symptomology (against DSM-5 criterion and further differentiation)
- Key touchpoints in ARFID healthcare journey (assessment, diagnosis, and treatment)

The section on ARFID symptomology is based on the DSM-5-TR criterion for ARFID (APA, 2022). Criterion A was further broken down to capture specific symptomatology in greater detail. Unlike the DSM-5, this checklist also includes the restriction of fluids, which is not typically addressed. Each item on the list provided specific examples of how children may avoid or restrict certain foods or fluids based on their sensory characteristics or fears related to choking and illness. This detailed approach allowed for a more nuanced understanding of the various ways ARFID can manifest. As with the survey, the development of this ARFID symptomology checklist was informed by consultations with EbE and HCPs with specialised expertise, ensuring the diverse ways in which ARFID can manifest and its impact was captured.

Survey completion times varied widely, ranging from 434 seconds (7 minutes and 14 seconds) to 857,891 seconds (over 9 days and 22 hours), with a mean of 8,229.3 seconds (2 hours, 17 minutes, and 9 seconds) and a standard deviation of 56,407.2 seconds (15 hours, 40 minutes, and 7 seconds). This variability likely reflects interruptions in survey completion, where participants paused and resumed later.

3.4.4 Data Analysis

Survey data[7] were analysed using IBM SPSS Statistics, version 28. Initially, data distribution was examined to determine the appropriate statistical tests for analysis. Descriptive statistics were generated to summarise demographic information, including child age, gender, ARFID diagnostic status, and neurodivergence status.

[7] For the purpose of this thesis, only close-end data was analysed. Open-ended data will be analysed in the future and published.

For comparative analyses, chi-square tests of independence were used to examine the relationships between categorical variables such as the type of professional first contacted and delays in obtaining a diagnosis based on neurodevelopmental status. One-way ANOVAs with post-hoc comparisons using Tukey's HSD were employed to compare means for continuous variables such as age. When necessary, Levene's test was conducted to assess the equality of variances.

3.5 Qualitative Methodology

The second phase involved follow-up interviews with select participants, employing IPA to unravel the deeper layers of their experiences. IPA, rooted in phenomenology and hermeneutics, facilitated a thorough exploration of participants' sense-making processes (Larkin et al., 2021). Through this qualitative phase, the study sought to capture the essence of the participants' journeys, acknowledging the subjectivity inherent in their narratives.

3.5.1 IPA

IPA was chosen as the methodological approach because it is particularly suited to exploring lived experiences and understanding how participants make sense of said experiences (Larkin et al., 2021). This approach aligns with the overarching aims of this project and specific aims of the qualitive component (Table 1).

Within IPA, findings are interpretative rather than objective and claims are made based on how the researchers make sense of participants' sense-making through engaging deeply with the information they share (Pietkiewicz & Smith, 2014). While the findings provide a rich interpretation of the data, they represent one possible interpretation among many (Larkin et al., 2021). To enhance the credibility and plausibility of the findings, the supervisory team corroborated interpretations to ensure trustworthiness. The hermeneutic circle was a crucial aspect of this process, involving continuous questioning of the data, uncovering meanings, and further questioning.

By exploring extensive verbatim quotes, the study considered various ways of viewing the data, ultimately selecting interpretations that accurately portrayed the essence of participants' experiences. This interpretative process allows for a deep and nuanced understanding of the participants' experiences, which is essential for addressing the complex issues explored in this study.

3.5.2 Participants

3.5.2.1 Participant Criteria

Insights from the quantitative component revealed significant differences in the prevalence and presentation of ARFID among neurodivergent children, with Autism being the most prevalent neurodivergence (47% diagnosed). These findings highlighted unique challenges and patterns in the healthcare journeys of neurodivergent children with ARFID.

Given that IPA is best suited to a purposive and homogeneous sample to ensure relevance and personal significance to respondents (Larkin et al., 2021), this follow-up study specifically focused on capturing mothers' experiences of accessing healthcare for their Autistic child's ARFID. By concentrating on this specific subgroup, the study sought to provide deeper insights into the barriers, facilitators, and overall experiences of this subgroup, building upon some of the trends found in the quantitative arm of this thesis.

3.5.2.2 Recruitment

Participants for this study were recruited from the pool of survey respondents. At the end of the survey, respondents were invited to express interest in participating in a follow-up interview. Of the 481 respondents who finished the survey, 57% indicated an interest in being interviewed. These potential interviewees were screened for eligibility based on the specific criteria pertinent to this study.

From the pool of 65 eligible participants, a random selection process was used to invite 30 participants via email. These potential participants were emailed the participant information sheet and a consent form (Appendix F). Of these mothers, 50% responded with their signed consent forms and subsequently took part in a semi-structured interview in March 2024.

3.5.2.3 Participant Demographics

Due to time constraints, six transcripts were randomly chosen to form the primary dataset for this study[8]. Of the six mothers, two have two Autistic sons diagnosed with ARFID, therefore this project represents eight healthcare journeys (Table 7 and 8). All names have been changed to preserve anonymity and to help readers easily connect mothers with their children, children were assigned pseudonyms starting with the same letter (e.g., Erica and Elijah).

Table 7 Maternal information

Pseudonym[1]	Total Children	Other neurodivergence in immediate family?	Other Selective Eating in immediate family?	Maternal paid employment status
Erica	One	No	No	Employed, full-time
Fern	Two	Yes	Yes [ARFID]	Employed, part-time
Ivy	Three	Yes	No	Unpaid family carer, full-time
Jasmine	Two	Yes	Yes [ARFID]	Self-employed, part-time
Marigold	Two	Yes	Yes [Selective Eating]	Employed, part-time
Violet	Three	Yes	Yes [Selective Eating]	Unpaid family carer, full-time

1. All names have been changed to preserve anonymity and as an ode to their strength, resilience, and beauty, mothers were given botanical names. Just as plants thrive and endure through the various conditions, they find themselves in, so too did these mothers, often with remarkable grace and fortitude.

[8] The remaining transcripts will be analysed and included in future publications.

Table 8 Child demographic and healthcare information

Pseudonyms		Child Demographic			Child Diagnoses				Healthcare				
Mother	Child	Gender	Weight Status	Age (Years)	Age at ASC Diagnosis (Years)	Age at ARFID Diagnosis (Years)	Other NDD diagnosis	Other Diagnoses	Healthcare Provision	ARFID Interventions	MH Interventions	ARFID Medical emergencies & hospital admissions	Medication
Erica	**Elijah**	Male	Under	14	7	13	2	2x MH 1x PH	NHS	None	Yes (NHS)	None	1x antidepressant
Fern	**Felix**	Male	Under	12	7	8	3	1 x MH	NHS & Private	Therapy (Private & NHS) & Long-term enteral nutrition (NHS)	None	2 x Hospitalised (NHS)	None
	Fabian	Male	-	5	-	5	1 awaiting	0	NHS & Private	None	None	None	None
Ivy	**Isaiah**	Male	Under	10	4	9	1	1 x MH	NHS & Private	None	Yes (NHS)	None	1x central nervous system stimulant
Jasmine	**Jeremy**	Male	Under	11	10	9	0	2 x MH 2x PH	NHS	None	None	Unresponsive due to Dehydration (ambulance call-out)	1x hormonal supplement

	Jackson	Male	Over	11	10	11	1 awaiting	-	NHS	Therapy (NHS)	None	None	None
Marigold	**Maya**	Female	Under	8	4	3	0	1x PH	NHS & Private	Therapy (NHS) & Long-term enteral nutrition (NHS)	None	1x Refeeding on Eating Disorder Inpatient Ward (NHS)	1x oral nutritional supplement drink; 1x laxative; 1x hormonal supplement
Violet	**Vanessa**	Female	Under	12	5	7	0	1 x MH 2x PH	NHS	None	None	2 x Hospitalised (NHS) 1x Refeeding inpatient (NHS)	1x antidepressant

Other Neurodevelopmental Diagnoses (NDD): Sensory Processing Disorder (SPD) n = 5, ADHD n = 3; and Global Developmental Delay n = 1.
Mental Health (MH) Diagnoses: Anxiety n = 6; Pathological Demand Avoidance n = 2; Misophonia n = 1; Emetophobia n = 1; and Depression n = 1.
Physical Health (PH) Diagnoses: Allergies n = 7 [Cow's Milk Protein n = 4; Pollen n = 2; Nut n = 1], Asthma n = 4; Hypermobility n = 1, Heart murmur n = 1
Medications: Melatonin n = 3; Sertraline n = 2; Methylphenidate n = 2; Macrogol Laxatives n = 2 [Movicol & Laxido]; Iron supplements n = 1; Altrajuce n = 1; and Seravit n = 1

- indicates missing data (The primary child of interest in families with multiple Autistic children with ARFID was the first Autistic child to navigate the healthcare system on behalf of their ARFID. As such, some information about the second children, Fabian, and Jackson, is missing.

Note: Marigold and Fern were the only mothers to have children on long-term enteral nutrition. At the date of the interview, Felix had his G-button[9] for 6 months and Maya had her G-button then G-tube[3] for almost 4 years.

[9] A G-tube is a traditional gastrostomy device with tube projecting out above skin whereas a G-button is a skin-level low profile device, with minimal projections.

3.5.2.3.1 Family and Healthcare Context

All mothers self-identified as White (British n = 4) and were between 30 and 60 years of age. Most families (n = 4) were dual parent households, with all partners being in full-time employment. Of mothers, half were in part-time employment, two were full-time unpaid family carers and one was employed full-time. Families were all based in England, dispersed across London (n = 2), Southeast of England (n = 2), Northwest of England (n = 1) and the Midlands (n = 1). All but one mother had multiple children and had multiple neurodivergent members in the immediate family, including individuals not seeking diagnosis. Notably two of the mothers also had other Autistic children who presented with selective eating, not ARFID. These often gave mothers an intimate and lived knowledge of the difference between selective eating often seen as part of the Autistic profile, and ARFID. Of the mothers themselves, two were neurodivergent; one diagnosed and another not seeking diagnosis due to fear of this being weaponised[10] by professionals.

Of the eight children whose healthcare journeys were the focus of the six maternal interviews, a majority were male (n = 6), underweight (n = 7), and had their Autism diagnosis before their ARFID diagnosis (n=5).

The interviews produced rich and moving accounts regarding each mother's journey through the healthcare system. In all cases, the onset of ARFID symptoms were during infancy, with varying experiences in oral eating, including two children who require long-term enteral

[10] Mother accused by ARFID sceptical professionals of Fabricated or Induced Illness, thus fearing the consequences of receiving an Autism diagnosis herself.

feeding. Alongside their Autism, mothers described other diagnoses and experiences impacting their children's eating behaviours and treatment journeys. These included, anxiety, allergies, and Pervasive Drive for Autonomy (PDA)[11]. These families accessed a range of community and tertiary-level services from various disciplines, including three children being hospitalised at least once due to their ARIFD and medical emergencies. Of these eight journeys, all were either partially or fully NHS care-based and half were in some ways subsidised by private care (in all cases for assessments and diagnosis, and in one case also for treatment following diagnosis). Of the private healthcare journeys, all were partially, if not fully, self-funded, and one was partially funded by NHS England.

3.5.3 Data collection

Prior to interviews, participants were sent a copy of the interview schedule and reminded of their rights as participants. After, a debrief was shared which signposted towards resources (Appendix G). All interviews were held via Teams in March 2024 and lasted 60 to 101 minutes. Interviews were recorded for transcription purposes and transcribed verbatim by the researcher. Empirical and anecdotal evidence guided the creation of the interview schedule (Table 9), which was iteratively refined based on feedback from supervisors and consultants.

[11] Clinically, PDA stands for Pathological Demand Avoidance, referring to an Autistic behavioural profile characterised by an extreme avoidance of everyday demands and expectations. Some within the neurodivergent community advocate for redefining PDA as Pervasive Drive for Autonomy. This reframe seeks to emphasise the individual's need for control and autonomy over their environment, as opposed to pathologising and problematising.

3.5.3.1 Interview Schedule

Table 9 Interview Schedule

Topic	Questions and Prompts
Exploring Your Journey	Can you walk me through you and your child's ARFID journey, starting from when you first noticed something different about your child's eating habits to the present day? Please describe encounters with professionals (e.g., first contact, assessment, diagnosis, and treatment), emotions felt, and challenges faced.
Interactions with HCPs	Can you describe your interactions with HCPs during this journey? Are there specific moments or discussions that stood out to you?
Impact on You and Your Family	How have these experiences navigating the healthcare system for support affected you, your child, and your family as a whole?
Changing Perspectives	Reflecting on your journey, have your perspectives or beliefs about your child's ARFID symptoms, healthcare system, or your role as a caregiver shifted in any way?
Recommendations for Improvement	Do you have any suggestions or recommendations for improving NHS services for families dealing with ARFID?
Advice for Others	What advice would you offer to parents currently navigating the system on behalf of their child, attempting to gain a diagnosis and access to treatment for ARFID?
Navigating Support in the Educational Setting	Can you walk me through how you and your child have navigated challenges related to ARFID within the school environment? What support or challenges have you encountered at school? Additionally, I'm interested to know if support from HCPs has made a noticeable difference in the support available for you and your child at school.

3.5.4 IPA Data Analysis

IPA guidelines by Larkin et al. (2021) were used to analyse transcripts through a structured yet iterative process. This involved: (1) reading and re-reading to immerse oneself in the data, (2) making exploratory notes to examine semantics and language use, and (3) consolidating impressions by constructing experiential statements. The next steps involved (4) clustering these experiential statements and (5) mapping how they interact to support the development of Personal Experiential Themes (PETs). This process was repeated for each case.

After identifying PETs, patterns of convergence and divergence across PETs were explored to create Group Experiential Themes (GETs). Throughout this process, the hermeneutic circle was employed, involving continuous questioning of the data, uncovering meanings, and revisiting the data to refine interpretations (Larkin et al., 2021).

To facilitate the exploration of shared and unique experiences, mind maps were created for each case, representing experiential statements organised by PETs, and a larger mind map was created for the GETs.

3.6 Ethical Considerations

Numerous ethical considerations were carefully addressed throughout this project's lifecycle. This overview focuses on unique considerations specific to this research, while details surrounding conventional standards for good research practices, such as data protection, can be found in the participant information sheets (Appendix D and F). Importantly, all procedures

adhered to ethical standards set by the institutional committee and were conducted in accordance with the 1964 Helsinki Declaration and its later amendments or comparable ethical standards. Ethics approval was granted by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with delegated authority (LMS/PGR/UH/05496).

3.6.1 Writing Qualitative Findings and Use of Quotes

Adhering to the principle of equal representation posed challenges during the writing and editing process. Integration of participant quotes was carefully navigated, aiming to authentically represent their voices with fairness and equitable[12] value to all perspectives. Following guidance from Lingard (2019), quotes were selected for their illustrative relevance and succinctly presented while maintaining participants' intended meanings. Additionally, there was a commitment to preserving participants' original meanings through quote selection and preserving dignity through minor edits, allowing for clarity and readability. This approach respected participants' expressions while addressing grammatical nuances inherent in transcription. Quotes were chosen to reflect overarching data patterns and diverse experiences, balancing fidelity to majority sentiments with attention to nuanced perspectives.

[12] In this context, "equitable" is used instead of equal to emphasise fairness that considers the unique perspectives and circumstances of each participant, ensuring balanced representation without necessarily quoting participants in identical measures. This choice reflects a commitment to acknowledging and valuing diverse experiences within the research context.

3.6.2 Maintaining Anonymity with Rich Idiographic Accounts

There is a responsibility to ensure that rich accounts remain anonymised and do not compromise participants' identities (Kaiser, 2009). This can be a delicate balance to tread, particularly when researching small communities. Maintaining this balance was of the utmost importance, thus identifiable information was amalgamated, and sensitive data omitted.

3.6.3 Emotional Considerations in Sensitive Research

Due to the subject matter and being a Trainee Clinical Psychologist, it was crucial to emphasise that interviews were solely for research purposes. Additionally, the information sheet (Appendix F) outlined the potential emotional impact that discussing these experiences may have, evoking difficult emotions and memories. Mothers were reminded of this at the start of interviews, alongside the importance of self-care, pacing, and their right to terminate without explanation.

While the interview process was not intended as therapy, participants remarked on the therapeutic value of sharing their stories. In hindsight, more consideration should have been given to the personal impact of hearing these stories and carrying such emotionally charged narratives, alongside the sense of responsibility and the need to honour their contributions. This emotional impact was heightened by personal grief and the sensitivity of analysing research focused on mothers. Ad hoc support proved crucial during this period, including calls outside of research supervision, increased frequency of research supervision, and a network of compassionate peers.

Chapter Four: Survey Analysis of ARFID Presentations and Healthcare Experiences

The results of this study are organised to address the research questions systematically, with each section concluding with a summary of key findings. Various statistical analyses were employed to examine the data, tailored to the nature of the variables and research questions.

To analyse the relationships between categorical variables, chi-square tests of independence were utilised. These tests helped determine whether significant associations existed between different categories. For continuous variables, one-way ANOVAs were conducted to compare means across different groups. When significant differences were found, post-hoc comparisons using Tukey's HSD were performed to identify specific group differences. To ensure the robustness of the ANOVA results, Levene's test was applied when necessary to assess the equality of variances.

While each section of the results addresses specific research questions and concludes with a summary of key findings, a comprehensive table (Table 38) summarising the main findings, their implications, and recommendations can be found at the end of the chapter. For readers who prefer visual representations, bar charts corresponding to Tables 14, 15, and 19-26 are included in Appendix H, providing an accessible overview of the data.

4.1 How, if at all, does child age and gender vary by neurodivergence and ARFID diagnostic status?

4.1.1 Descriptive statistics for age and neurodivergence

Children with ARFID symptoms ranged in age from 5 months to 28 years (*M* = 10.39, *SD* = 4.78). The majority were male (66.1%), with the remaining identified as female (33.2%), non-binary (0.5%), or trans-female (0.2%). For gender analysis, non-binary and trans-female children were excluded.

A 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. Among those diagnosed, a majority (75.2%) received their diagnosis prior to their ARFID assessment.

4.1.2 Age differences according to neurodivergence

A one-way ANOVA indicated a significant difference in child age in years according to neurodivergence status (Table 10). There was homogeneity of variances, as assessed by Levene's test for equality of variances (*p* = .75).

Table 10 Comparison of Mean Age of Participants According to Neurodivergence Status

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

Post-hoc comparison using Tukey's HSD test revealed the neurodivergent children were statistically significantly older than neurotypical children and children suspected of neurodivergence. There was no statistically significant difference in age between neurotypical children and children suspected of neurodivergence (Table 11).

Table 11 Post-Hoc Comparisons of Mean Age Using Tukey's HSD (Neurodivergence Status)

Comparison	Mean Difference	Std. Error	(Tukey)		
			p	95% CI	
				Lower Bound	Upper Bound
Neurotypical vs. Suspected Neurodivergent	0.54	0.67	.70	-1.03	2.10
Neurotypical vs. Diagnosed Neurodivergent	-1.74*	0.63	.02	-3.22	-0.25
Suspected Neurodivergent vs. Diagnosed Neurodivergent	-2.27*	0.50	<.001	-3.44	-1.10

* Indicates significant at the 0.05 level

4.1.3 Age differences according to ARFID diagnostic status

A one-way ANOVA indicated a significant difference in child age across the three ARFID diagnosis status groups: Not assessed for ARFID (NO AX), Assessed, and not diagnosed with ARFID (NO DX) and Diagnosed with ARFID (DX) (Table 12). There was homogeneity of variances, as assessed by Levene's test for equality of variances (p = .87).

Table 12 Comparison of Mean Age of Participants based on ARFID assessment and diagnosis status.

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

Post-hoc comparisons using Tukey's HSD revealed significant differences in mean age between the groups (Table 13).

- Children diagnosed with ARFID were statistically significantly older than children who had not been assessed for ARFID.
- Children who were assessed and not diagnosed were statistically significantly older than children who had not been assessed for ARFID.
- There was no statistically significant difference in age between children diagnosed with ARFID and children assessed but not diagnosed with ARFID.

Table 13 Post-Hoc Comparisons of Mean Age Using Tukey's HSD (ARFID diagnosis status)

Comparison	Mean Difference	Std. Error	Tukey p	Tukey 95% CI Lower Bound	Tukey 95% CI Upper Bound
Diagnosed with ARFID vs. Not assessed for ARFID	2.09*	0.49	<.001	0.94	3.23
Diagnosed with ARFID vs. Assessed and NOT diagnosed with ARFID	-0.13	0.76	0.98	-1.91	1.65
Not assessed for ARFID vs. Assessed and NOT diagnosed with ARFID	-2.21*	0.72	.006	-3.91	-.052

* Indicates significant at the 0.05 level

4.1.4 Gender differences according to neurodivergence

A crosstabulation was performed to examine the relationship between gender and neurodivergence status (Table 14).

Table 14 Crosstabulation of Gender and Neurodivergence Status

Gender	NT	SUS	DN	Total	χ^2	*p*
Female	26 (36.1%)	56 (37.6%)	63 (29.7%)	145 (33.5%)		
Male	46 (63.9%)	93 (62.4%)	149 (70.3%)	288 (66.5%)	2.70	.26
Total	72 (100%)	149 (100%)	212 (100%)	433 (100%)		

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

A chi-square test of independence was conducted to examine the association between gender and neurodivergence status. The test results indicated that there was no significant association, χ^2 (2, *N* = 433) = 2.70, *p* = .26. Thus, the data suggest that neurodivergence status is independent of gender in this sample.

4.1.5 Gender differences according to diagnostic status

A crosstabulation was performed to examine the relationship between gender and ARFID diagnostic status (Table 15).

Table 15 Crosstabulation of Gender and ARFID Status

Gender	NO AX	NO DX	DX	Total	χ^2	*p*
Female	75 (32.1%)	21 (42.0%)	49 (32.7%)	145 (33.4%)		
Male	159 (67.9%)	29 (58%)	101 (67.3%)	289 (66.6%)	1.89	.39
Total	234 (100%)	50 (100%)	150 (3%)	434 (100%)		

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

A chi-square test of independence was conducted to examine the association between gender and ARFID status. The chi-square test results indicated that there was no significant association, χ^2 (2, *N* = 434) = 1.89, *p* = .39.

4.1.6 Summary

Children diagnosed as neurodivergent were significantly older than those suspected of neurodivergence or neurotypical. Gender was not significantly associated with either neurodivergence or ARFID status.

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

Table 16 illustrates that Autism (47%), and Sensory Processing Disorder (SPD) (45%) were the most prevalent diagnosed neurodivergences in the sample. Regarding psychiatric comorbidities, 30% of the sample had a diagnosed anxiety disorder, see Table 17. Moreover, Table 17 demonstrates that Eating Disorder Not Otherwise Specified (EDNOS) and Other Specified Feeding or Eating Disorder (OSFED) were the most prevalent eating disorders, affecting 4-5% of the sample. Interestingly, these figures doubled among those diagnosed with ARFID, suggesting that these children met the diagnostic criteria for more specified eating disorder once ARFID was available as a diagnostic option. Table 18 presents physical health conditions. The most common reported were constipation (28%) and allergies (22%).

Table 16 Neurodivergence diagnoses prevalence among sample according to ARFID diagnosis status

Neurodivergence (most prevalent to least prevalent)	Total sample (n = 437), [%]	NO AX (n = 235), [%]	NO DX (n = 51), [%]	DX (n = 151), [%]
Autism	204 [47%]	97 [41%]	23 [45%]	84 [56%]
SPD	198 [45%]	89 [38%]	18 [35%]	91 [60%]
ADHD	44 [10%]	19 [8%]	4 [8%]	21 [14%]
Dyspraxia	45 [10%]	17 [7%]	4 [8%]	24 [16%]
Intellectual Disability/ Global Delay	50 [11%]	22 [9%]	4 [8%]	24 [16%]
Dyslexia	25 [6%]	11 [5%]	2 [4%]	12 [8%]
Dysgraphia	16 [4%]	8 [3%]	2 [4%]	6 [4%]
Tourette Syndrome/Movement Disorder	19 [4%]	8 [3%]	1 [2%]	10 [7%]
Dyscalculia	7 [2%]	2 [1%]	1 [2%]	4 [3%]

Neurodivergence (most prevalent to least prevalent)	Total sample (n = 437), [%]	NO AX (n = 235), [%]	NO DX (n = 51), [%]	DX (n = 151), [%]
Prader-Willi Syndrome	2 [<1%]	1 [<1%]	0	1 [1%]
Williams Syndrome	0	0	0	0
Down Syndrome	0	0	0	0

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

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

Table 17 Mental Health, Feeding and Eating Disorder diagnoses prevalence among sample according to ARFID diagnosis status.

Mental Health and Eating Disorders (most prevalent to least prevalent)	Total sample (n = 437)	NO AX (n = 235)	NO DX (n = 51)	DX (n = 151)
Anxiety	130 [30%]	49 [21%]	14 [27%]	67 [44%]
Mental Health Condition[1]	63 [14%]	25 [11%]	4 [8%]	34 [23%]
OCD	10 [2%]	3 [1%]	0	7 [5%]
Depression	26 [6%]	9 [4%]	3 [6%]	14 [9%]
EDNOS	19 [4%]	3 [1%]	2 [4%]	14 [9%]
OSFED	23 [5%]	2 [1%]	2 [4%]	19 [13%]
Pica	12 [3%]	6 [3%]	0	6 [4%]
Anorexia	2 [<1%]	0	0	2 [1%}
Binge Eating Disorder	0	0	0	0

Bulimia	0	0	0	0
Rumination Syndrome	1 [<1%]	0	0	1 [1%]

1. Examples provided for Mental Health Conditions were bipolar and OCD. Free text responses predominantly reported different anxiety disorders alongside OCD, PDA, and depression.

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

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

Table 18 Physical Health diagnoses prevalence among sample according to ARFID diagnosis status

Physical Health Conditions (most prevalent to least prevalent)	Total sample (n = 437)	NO AX (n = 235)	NO DX (n = 51)	DX (n = 151)
Constipation	124 [28%]	57 [24%]	21 [41%]	46 [30%]
Allergies	96 [22%]	40 [17%]	10 [20%]	46 [30%]
Eczema	81 [19%]	40 [17%]	9 [18%]	32 [21%]
GI or digestive issues	37 [8%]	18 [8%]	2 [4%]	17 [11%]
Asthma	55 [13%]	28 [12%]	5 [10%]	22 [15%]
Condition that affects chewing and swallowing	14 [3%]	6 [3%]	1 [2%]	7 [5%]
Diabetes	1 [<1%]	0	0	1 [1%]
Eosinophilic esophagitis	4 [1%]	1 [<1%]	0	3 [2%]

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

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

4.2.1 Autism Diagnosis by ARFID diagnostic status

A chi-square test of independence was performed to examine the relationship between Autism diagnosis and ARFID status (Table 19).

Table 19 Crosstabulation of Autism Diagnosis and ARFID Status

Autism Diagnosed		NO AX	NO DX	DX	Total	χ^2	*p*
Yes	Count (%)	97 (51.3%)	23 (62.2%)	84 (65.6%)	204 (57.6%)	6.74	.034
	Z-Score	-1.1	.4	1.2			
No	Count (%)	92 (48.7%)	14 (37.8%)	44 (34.4%)	150 (42.4%)		
	Z-Score	1.3	-.4	-1.4			
Total	Count (%)	189 (100%)	37 (100%)	128 (100%)	354 (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

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. The effect size, measured by Cramer's V, was 0.14, indicating a small effect size. 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.

4.2.2 SPD Diagnosis by ARFID diagnostic status

A chi-square test of independence was performed to examine the relationship between SPD diagnosis and ARFID status (Table 20).

Table 20 Crosstabulation of SPD Diagnosis and ARFID Status

Sensory Processing Disorder		NO AX	NO DX	DX	Total	χ^2	*p*
Yes	Count (%)	89 (48.4%)	18 (50%)	91 (71.1%)	198 (56.9%)	16.67	< .001
	Z-Score	-1.5	-.5	2.1			
No	Count (%)	95 (51.6%)	18 (50%)	37 (28.9%)	150 (43.1%)		
	Z-Score	1.8	.6	-2.4			
Total	Count (%)	184 (100%)	36 (100%)	128 (100%)	348 (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

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. The effect size, measured by Cramer's V, was 0.22, indicating a small to medium effect size. 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.

4.2.3 Mental Health Diagnosis by ARFID diagnostic status

A chi-square test of independence was performed to examine the relationship between Mental Health diagnosis and ARFID status (Table 21).

Table 21 Crosstabulation of Mental Health Diagnosis and ARFID Status

Mental Health Diagnosis		NO AX	NO DX	DX	Total	χ^2	*p*
Yes	Count (%)	25 (14.4%)	4 (11.8%)	34 (29.3%)	63 (19.3%)	11.76	.003
	Z-Score	-1.6	-1.0	2.5			
No	Count (%)	152 (85.9%)	30 (88.2%)	82 (70.7%)	264 (80.7%)		
	Z-Score	.8	.5	-1.2			
Total	Count (%)	177 (100%)	34 (100%)	116 (100%)	327 (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

The results indicated that there was a significant association between Mental Health diagnosis and ARFID status, χ^2 (2, N = 327) = 11.76, p = .003. Children diagnosed with mental health conditions were more likely to be diagnosed with ARFID than those without mental health conditions. Specifically, 29.3% of children with a mental health diagnosis also had ARFID, compared to only 70.7% of children without a mental health diagnosis. The effect size, measured by Cramer's V, was 0.19, indicating a small to medium effect size.

While the prevalence of ARFID among children with mental health diagnoses is statistically significant, it is not as high as observed in conditions like Autism or SPD. Therefore, widespread screening for ARFID in children with mental health conditions is not warranted nor pragmatic. However, integrated treatment approaches that address both mental health and ARFID symptoms could still be beneficial for improving patient outcomes. These findings suggest a need for tailored treatment strategies that consider the complex interplay between ARFID and mental health issues.

4.2.4 Anxiety Diagnosis by ARFID diagnostic status

A chi-square test of independence was performed to examine the relationship between Anxiety diagnosis and ARFID status (Table 22).

Table 22 Crosstabulation of Anxiety Diagnosis and ARFID Status

Anxiety Diagnosis		NO AX	NO DX	DX	Total	χ^2	*p*
Yes	Count (%)	49 (21.3%)	14 (28%)	67 (45.9%)	130 (30.5%)	25.63	<.001
	Z-Score	-2.5	-.3	3.4			
No	Count (%)	181 (78.7%)	36 (72%)	79 (54.1%)	296 (69.5%)		
	Z-Score	1.7	.2	-2.2			
Total	Count (%)	230 (100%)	50 (100%)	146 (100%)	426 (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

The results indicated that 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. Interestingly, the prevalence of anxiety diagnosis among those diagnosed with ARFID and those without ARFID is relatively similar, both around half. This similarity may be partially explained by the composition of the 'No Diagnosis' category, which includes a notable number of children with suspected anxiety (combined due to low cell count). Specifically, within the ARFID-diagnosed group, 14.4% were reported by their parent to have no anxiety symptoms, 37% were suspected to have anxiety, and 2.7% were awaiting an anxiety assessment.

The effect size, measured by Cramer's V, was 0.25, indicating a moderate effect size. However, it's important to interpret these findings with caution, as a 'no anxiety diagnosis' does not necessarily mean the absence of anxiety symptoms. The data primarily reflects diagnostic status rather than the actual presence of comorbidity symptoms.

4.2.5 EDNOS Diagnosis by ARFID diagnostic status

A chi-square test of independence was performed to examine the relationship between EDNOS diagnosis and ARFID status (Table 23).

Table 23 Crosstabulation of EDNOS Diagnosis and ARFID Status

EDNOS Diagnosis		NO AX	NO DX	DX	Total	χ^2	*p*
Yes	Count (%)	3 (1.3%)	2 (4.1%)	14 (9.8%)	19 (4.5%)	14.64	< .001
	Z-Score	-2.3	-.1	3.0			
No	Count (%)	225 (98.7%)	47 (95.9%)	129 (90.2%)	401 (95.5%)		
	Z-Score	.5	.0	-.6			
Total	Count (%)	228 (100%)	49 (100%)	143 (100%)	420 (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

The results indicated that there was a significant association between EDNOS diagnosis and ARFID status, χ^2 (2, N = 420) = 14.64, p < .001. Among children diagnosed with ARFID, 9.8% had an EDNOS diagnosis, compared to 4.1% of those assessed but not diagnosed with ARFID and only 1.3% of those not assessed for ARFID. The effect size, measured by Cramer's V, was 0.19, indicating a small effect size.

The data reveals that children diagnosed with ARFID have a notably higher prevalence of EDNOS compared to those with other ARFID statuses. This pattern suggests that while EDNOS is relatively uncommon overall, its prevalence is significantly higher in children diagnosed with ARFID. The high z-score (3.0) for the ARFID-diagnosed group indicates a strong deviation from expected values, reflecting the stronger association between ARFID and EDNOS in this group. This finding aligns with historical diagnostic practices, as ARFID was previously categorised under EDNOS before being recognised as a distinct disorder in the DSM-5 and ICD-11. The overlap between ARFID and EDNOS diagnoses reflects the transition from older diagnostic criteria to the current understanding of eating and feeding disorders.

4.2.6 OSFED Diagnosis by ARFID diagnostic status

A chi-square test of independence was performed to examine the relationship between OSFED diagnosis and ARFID status (Table 24).

Table 24 Crosstabulation of OSFED Diagnosis and ARFID Status

OSFED Diagnosis		NO AX	NO DX	DX	Total	χ^2	*p*
Yes	Count (%)	2 (0.9%)	2 (4.1%)	19 (13.2%)	23 (5.4%)	26.36	< .001
	Z-Score	-3.0	-.4	4.0			
No	Count (%)	228 (99.1%)	47 (95.9%)	125 (86.8%)	371 (87.7%)		
	Z-Score	.7	.1	-1.0			
Total	Count (%)	230 (100%)	49 (100%)	144 (100%)	423 (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

The results indicated a significant association between OSFED diagnosis and ARFID status, χ^2 (2, N = 423) = 26.36, p < .001. Among children diagnosed with ARFID, 13.2% had an OSFED diagnosis, compared to 4.1% of those assessed but not diagnosed with ARFID and only 0.9% of those not assessed for ARFID. The effect size, measured by Cramer's V, was 0.250, indicating a moderate effect size.

Similarly to EDNOS, OSFED is a residual diagnosis, and as such, the introduction of ARFID as a distinct category in the DSM-5 and ICD-11 has led to a clearer classification of feeding and eating disorders. This reclassification means that conditions previously diagnosed under broader categories like OSFED are now more precisely identified as ARFID. Therefore, the higher prevalence of OSFED among ARFID-diagnosed children reflects this historical diagnostic

overlap and the evolving understanding of these disorders. The z-score of 4.0 for the ARFID-diagnosed group underscores this significant association.

4.2.7 Allergy Diagnosis by ARFID diagnostic status

A chi-square test of independence was performed to examine the relationship between Allergies and ARFID status (Table 25).

Table 25 Crosstabulation of Allergies and ARFID Status

Allergies		NO AX	NO DX	DX	Total	χ^2	*p*
Yes	Count (%)	40 (17.4%)	10 (20%)	46 (31.3%)	96 (22.5%)	10.14	.006
	Z-Score	-1.6	-.4	2.3			
No	Count (%)	190 (82.6%)	40 (80%)	101 (68.7%)	331 (77.5%)		
	Z-Score	.9	.2	-1.2			
Total	Count (%)	230 (100%)	50 (100%)	147 (100%)	427 (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

The results indicated a significant association between allergies and ARFID status, χ^2 (2, N = 427) = 10.14, p = .006. Among children diagnosed with ARFID, 31.3% had a diagnosed allergy, compared to 20% of those assessed but not diagnosed with ARFID and 17.4% of those not assessed for ARFID. The effect size, measured by Cramer's V, was 0.154, indicating a small effect size.

Children diagnosed with ARFID show a higher prevalence of allergies compared to those with other ARFID statuses. Therefore, allergy management should be considered in ARFID assessment and treatment planning. Integrated treatment approaches that address both allergy management and ARFID symptoms could improve patient outcomes.

4.2.8 Constipation Diagnosis by ARFID diagnostic status

A chi-square test of independence was performed to examine the relationship between constipation diagnosis and ARFID status (Table 26).

Table 26 Crosstabulation of Constipation Diagnosis and ARFID Status

Constipation Diagnosis		NO AX	NO DX	DX	Total	χ^2	*p*
Yes	Count (%)	57 (24.7%)	21 (42%)	46 (31.9%)	124 (29.2%)	6.78	.03
	Z-Score	-1.3	1.7	.6			
No	Count (%)	174 (75.3%)	29 (58%)	98 (68.1%)	301 (70.8%)		
	Z-Score	.8	-1.1	-.4			
Total	Count (%)	231 (100%)	50 (100%)	144 (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

The results indicated a significant association between constipation diagnosis and ARFID status, χ^2 (2, N = 425) = 6.78, p = .03. Among children diagnosed with ARFID, 31.9% had a constipation diagnosis, compared to 42% of those assessed but not diagnosed with ARFID and 24.7% of those not assessed for ARFID. The effect size, measured by Cramer's V, was 0.13, indicating a small effect size.

The higher prevalence of constipation in children who were assessed but not diagnosed with ARFID suggests that their eating behaviour might have been better explained by gastrointestinal symptoms such as chronic constipation. Given the DSM-5 criteria for ARFID, which requires ruling out other conditions that might account for feeding difficulties, this highlights the importance of differential diagnosis. There is likely a bidirectional relationship between eating behaviours and gastrointestinal challenges. If diagnostic criteria are applied too conservatively, this could lead to underdiagnosing ARFID and overattributing eating behaviour to challenges like constipation. Conversely, if criteria are too liberally applied, overdiagnosis could occur. Therefore, a careful and balanced approach is needed to ensure accurate diagnosis and appropriate treatment planning. This explanation provides a possible understanding of the observed pattern, highlighting the need for comprehensive assessment strategies and formulations that consider gastrointestinal factors alongside eating behaviour.

4.2.9 Summary

The analyses revealed significant associations between several comorbidities and ARFID diagnostic status. Children diagnosed with Autism, Sensory Processing Disorder, anxiety and other mental health diagnoses were more likely to be diagnosed with ARFID compared to those without these diagnoses. Additionally, the data showed significant relationships between ARFID and EDNOS and OSFED, reflecting historical diagnostic overlaps and a move towards a specified diagnosis. Allergies and constipation also showed significant associations with ARFID, though these may reflect complex interactions between symptoms and eating behaviours.

4.3 What might be the clinical presentations and correlates of ARFID symptomology based on diagnostic status and neurodivergence?

This section compares the clinical presentation of ARFID symptoms based on neurodivergence and ARFID diagnostic status. Additionally, it explored correlations between ARFID symptoms and various child factors.

4.3.1 Clinical presentation based on ARFID diagnostic status and neurodivergence.

As illustrated in Table 27, the clinical presentation of ARFID symptoms varies significantly based on both ARFID diagnostic status and neurodivergence status.

Table 27 ARFID Symptomology by ARFID Diagnosis Status and Neurodivergence Status

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%]

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'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%]

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 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

4.3.2 Correlations Among ARFID Symptoms

Given the high prevalence of multiple ARFID symptoms across different diagnostic and neurodivergence statuses, an inter-item correlation analysis was undertaken to explore the relationships between these symptoms in more detail (Table 28). The correlations highlight the interconnected nature of ARFID symptoms, suggesting that children experiencing one symptom are likely to experience related symptoms, particularly those related to sensory characteristics, nutritional deficiencies, and impacts on wellbeing.

Table 28 ARFID symptomology ARFID Symptomology prevalence inter-item correlation matrix

ARFID Symptomology (most prevalent to least prevalent)	A	B	C	D	E	F	G	H	I	J	K
A. My child avoids or restricts certain foods or food groups based on how they look, taste, smell, or the texture	-										
B. My child's difficulties with eating impacts on our family life and wellbeing	.112*	-									
C. My child's difficulties with eating impacts on their life and wellbeing	.221**	.374**	-								
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)	.591**	.061	.131**	-							
E. My child's limited diet has led to significant weight loss or failure to gain weight	.006	.018	.067	.060	-						

ARFID Symptomology (most prevalent to least prevalent)	A	B	C	D	E	F	G	H	I	J	K
F. My child's limited diet has led to significant nutritional deficiency (i.e., deficiencies that result in noticeable symptoms)	.073	.088	.099*	.073	.204**	-					
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)	.031	.019	.024	.186**	.150**	.378**	-				
H. My child's limited diet has led to needing to take prescribed nutritional supplement drinks such as Ensure, Pediasure and Fortini	-.046	.049	.022	.023	.340**	.294**	.327**	-			
I. My child avoids or restricts certain foods or food groups based on worries about choking or being sick	-.005	.080	.075	-.028	.108*	.070	.068	.065	-		

ARFID Symptomology (most prevalent to least prevalent)	A	B	C	D	E	F	G	H	I	J	K
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)	-.039	.053	.071	.054	.057	.135**	.080	.059	.444**	-	
K. My child's limited diet has led to needing to have NG tube or PEG	-.092	.009	-.028	-.009	.175**	.155**	.178**	.311**	.048	.074	

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

4.3.3 Correlation Between ARFID Symptoms and Child Factors

To further understand the complexity of ARFID symptomology, Table 29 explores the correlations between ARFID symptoms and various child factors of interest. The inter-item correlation analysis revealed significant relationships providing deeper insights into the complexity of ARFID symptomatology.

Table 29 ARFID Symptomology correlation with child factors

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*

ARFID Symptomology (most prevalent to least prevalent)	Age	Male	Premature	Early Feeding & Weaning Challenges	Neurodivergent
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

ARFID Symptomology (most prevalent to least prevalent)	Age	Male	Premature	Early Feeding & Weaning Challenges	Neurodivergent
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)

4.3.4 Summary

The analyses revealed significant associations between ARFID symptoms and various diagnostic and neurodivergence statuses. Children diagnosed with ARFID and those with neurodivergence exhibited higher prevalence rates of severe symptoms, such as significant weight loss, nutritional deficiencies, and the need for prescribed vitamins, nutritional supplements and eternal nutrition. Neurodivergent children, particularly those with confirmed diagnoses, showed higher rates of most ARFID symptoms compared to neurotypical or suspected neurodivergent cases.

The inter-item correlation analysis highlighted significant relationships among ARFID symptoms and child factors. Neurodivergence was significantly correlated with multiple severe ARFID symptoms, including avoidance based on sensory characteristics, family impact, fluid restriction, nutritional deficiency, prescribed vitamins, and enteral nutrition requirement. Older children showed significant correlations with weight loss, nutritional supplement drinks, and 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.

These findings underscore the complexity and interconnectedness of ARFID symptomatology, illustrating how multiple factors contribute to the presentation and severity of symptoms in affected children.

4.4 Is there any significant difference in the age of onset of ARFID symptoms based on neurodivergence and ARFID diagnostic status?

4.4.1 Age of Onset of ARFID Symptoms by Neurodivergence Status

A chi-square test of independence was performed to examine the relationship between the age of onset of ARFID symptoms and neurodivergence status. Age of onset was collected in categorical form to support recollection and ensure consistency in response specificity (Table 30).

Table 30 Crosstabulation of Age of Onset of ARFID Symptoms and 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

The results indicated that there was 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.

4.4.2 Age of Onset of ARFID Symptoms by ARFID diagnostic status

A chi-square test of independence was performed to examine the relationship between the age of onset of ARFID symptoms and ARFID diagnostic status (Table 31).

Table 31 Crosstabulation of Age of Onset of ARFID Symptoms and ARFID Diagnostic Status

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%)	32.23	<.001
	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%)		
	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

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, with a Cramer's V of 0.28, indicating a small to medium effect size. 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. Additionally, 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.

4.4.3 Summary

The analyses revealed no significant association between the age of onset of ARFID symptoms and neurodivergence status. However, there was a significant association between the age of onset of ARFID symptoms and ARFID diagnostic status, suggesting that children whose symptoms were noticed at younger ages were more likely to be diagnosed with ARFID.

4.5 Are there differences in the type of professional first contacted by parents about ARFID behaviours based on the child's neurodivergence status, and do the delays in receiving a diagnosis vary depending on the type of professional first contacted?

4.5.1 First Professional Contact by Neurodivergence Status

As shown in Table 32, 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.

Table 32 Descriptive Statistics for First Professional Contacted by Neurodivergence Status

First Professional Contacted	NT	SUS	DN	Total
GP (General Practitioner)	27 (37%)	59 (39.6%)	85 (39.7%)	171 (39.2%)
Health Visitor	33 (45.2%)	55 (36.9%)	64 (29.9%)	152 (34.9%)
Paediatrician	7 (9.6%)	9 (6%)	28 (13.1%)	44 (10.1%)
Dietitian	4 (5.5%)	15 (10.1%)	12 (5.6%)	31 (7.1%)
Other (e.g., teacher)	2 (2.7%)	6 (4%)	9 (4.3%)	17 (3.9%)
Speech and Language Therapist	0 (%)	3 (2%)	4 (1.9%)	7 (1.6%)
Clinical Psychologist	0 (%)	1 (0.7%)	5 (2.3%)	6 (1.4%)
Gastroenterologist	0 (%)	1 (0.7%)	2 (0.9%)	3 (0.7%)
Allergist/Immunologist	0 (%)	0 (%)	2 (0.9%)	2 (0.5%)
Psychiatrist	0 (0%)	0 (%)	2 (0.9%)	2 (0.5%)
Occupational Therapist	0 (%)	0 (%)	1 (0.5%)	1 (0.2%)
Total	73 (100%)	149 (100%)	214 (100%)	436 (100%)

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

4.5.2 First Professional Contact by ARFID diagnostic status

Table 33 reveals similar trends to those observed in Table 32, indicating no significant differences in whom parents first contact regarding their child's eating behaviours or ARFID symptoms. GPs were the primary professionals contacted by 39.4% of the sample, while Health Visitors were approached by 34.8%. This data highlights the prominent role that these primary care professionals consistently play as the initial point of contact for parents concerned about their child's eating difficulties.

Table 33 Descriptive Statistics for First Professional Contacted by ARFID Diagnostic Status

Professional Contacted	NO AX	NO DX	DX	Total
GP (General Practitioner)	87 (37%)	28 (54.9%)	57 (37.7%)	172 (39.4%)
Health Visitor	81 (34.5%)	15 (29.4%)	56 (37.1%)	152 (34.8%)
Paediatrician	23 (9.8%)	5 (9.8%)	16 (10.6%)	44 (10.1%)
Dietitian	20 (8.5%)	1 (2%)	10 (6.6%)	31 (7.1%)
Other (e.g., teacher)	11 (4.7%)	2 (3.9%)	4 (2.6%)	17 (3.9%)
Clinical Psychologist	5 (2.1%)	0 (%)	1 (0.7%)	6 (1.4%)
Speech and Language Therapist	3 (1.3%)	0 (%)	4 (2.6%)	7 (1.6%)
Gastroenterologist	3 (1.3%)	0 (%)	0 (%)	3 (0.7%)
Allergist/Immunologist	1 (0.4%)	0 (%)	1 (0.7%)	2 (0.5%)
Psychiatrist	0 (%)	0 (%)	2 (1.3%)	2 (0.5%)
Occupational Therapist	1 (0.4%)	0 (%)	0 (%)	1 (0.2%)
Total	235 (100%)	51 (100%)	151 (100%)	437 (100%)

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

4.5.3 Delays Based on First Professional Contacted

The ages at which children underwent their first assessment, received a diagnosis, and commenced treatment were compared based on neurodivergence status (Table 34).

Table 34 Comparison of Mean Ages at Key Stages of ARFID Care Pathway Based on 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

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.

To understand the impact of the type of professional first contacted on delays in the diagnosis and treatment of ARFID, ANOVAs were conducted comparing the mean delays across different professional groups.

Table 35 presents the comparison of mean delays in months. 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). However, no significant differences were found for diagnostic delay after first assessment (F (3, 145) = 1.67, p = .18) and treatment delay (F (3, 84) = 1.64, p = 1.9). 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).

Table 35 Comparison of Mean Delays (months) Based on First Professional Contacted by Parents About Eating Concerns

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)

Table 36 Post-Hoc Comparisons of Overall Diagnostic Delay Using Tukey HSD (Professional First Contacted)

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

4.5.4 Summary

The analysis revealed no significant differences in the type of professional first contacted based on ARFID diagnostic status or neurodivergence. The ages at which children underwent their first assessment, received a diagnosis, and started ARFID treatment were compared based on neurodivergence status, with no significant differences found. This suggests that the timing of these healthcare milestones in the ARFID care pathway does not vary significantly by neurodivergence status.

Moreover, the type of professional first contacted was found to significantly impact overall diagnostic delay, with specialist care professionals associated with shorter delays compared to primary care professionals. There were no significant differences in the time taken to receive a diagnosis after first contact or in the treatment delay, suggesting that the type of professional initially contacted does not influence the speed of subsequent diagnosis and treatment initiation once the first contact has been made.

4

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

An ANOVA was conducted to examine the effect of neurodivergence on parental satisfaction with various aspects of ARFID assessment, diagnosis, and treatment (Table 37). The results indicate no significant differences in parental satisfaction levels based on the neurodivergence status of the child.

Parental satisfaction scores were relatively low across all groups for NHS processes, including assessment, diagnosis, and treatment. Similarly, satisfaction with the available treatment options from the NHS, private sector, and third sector did not show significant differences across neurodivergence statuses. Overall, satisfaction levels were generally below the midpoint of the scale, indicating somewhat to extreme dissatisfaction with NHS ARFID processes and available somewhat dissatisfied to neither satisfied nor dissatisfied for the availability of ARFID treatment options through the NHS, Private Healthcare and Third Sector Organisations.

Table 37 Comparison of Mean Satisfaction Scores Based on Neurodivergence Status

Variable	Levene's Test	NT			SUS			ND			*df*	*F*	*p*
	(p)	*N*	*M*	*SD*	*N*	*M*	*SD*	*N*	*M*	*SD*			
Satisfaction with NHS Processes													
Assessment Process	.15	67	1.45	2.10	136	1.85	2.44	186	1.85	2.59	2,386	0.76	0.47
Diagnostic Process	.004	60	1.57	2.32	112	1.79	2.81	166	2.24	3.24	2, 335	1.48	0.23
Treatment Process	.095	58	1.00	1.75	112	1.42	2.47	166	1.45	2.55	2, 333	0.78	0.46

Variable	Levene's Test (p)	NT			SUS			ND			*df*	*F*	*p*
		N	*M*	*SD*	*N*	*M*	*SD*	*N*	*M*	*SD*			
Satisfaction With Available Treatment Options													
NHS	.03	14	1.79	2.12	22	3.95	3.47	56	3.18	3.19	2, 28	2.07	0.13
Private	.24	6	3.50	2.81	9	5.44	4.07	22	4.59	3.13	2,34	6.2	0.55
Third Sector	.40	6	2.33	2.25	2	4.50	3.54	20	5.40	3.47	2, 25	2.04	0.15

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

* Indicates significant at the 0.05 level

4.7 Summary

For a summary of the key findings related to the research questions, please refer to Table 38.

Table 38 Summary of Key Findings Related to Research Questions

Research Question	Findings Related to Neurodivergence	Findings Related to ARFID Status
1. How does child age and gender vary by neurodivergence and ARFID diagnostic status?	• 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 ($p < .001$). • Gender differences not significant.	• Children diagnosed with ARFID were statistically older than those not assessed or assessed but not diagnosed ($p < .001$) • Children who were assessed and not diagnosed were statistically significantly older than children who had not been assessed for ARFID (p = .006). • Gender differences not significant.
2. What differences exist in the prevalence of comorbidities between children diagnosed with ARFID and those who are not?	• the most prevalent diagnosed neurodivergences Autism (47% total sample, 56% diagnosed ARFID sample) and Sensory Processing Disorder (45% total sample, 60% diagnosed ARFID sample).	• Anxiety was the most prevalent mental health diagnoses (30% total sample, 44% diagnosed ARFID sample). • The most prevalent physical health diagnoses were constipation (28% total sample, 30% diagnosed ARFID

Research Question	Findings Related to Neurodivergence	Findings Related to ARFID Status
	• 65.6% of children diagnosed ARFID also had an Autism diagnosis (p = .034). • A substantial portion of Autistic children have not been assessed for ARFID (51.3%) despite having ARFID symptoms. • 71.1% of children diagnosed with ARFID also had a SPD diagnosis (p < .001). • No significant association between allergies and neurodivergence.	sample) and allergies (22% total sample, 30% diagnosed ARFID sample). • Significant associations between ARFID and mental health diagnoses (29.3% for those with ARFID vs. 14.4% without, p = .003). • 45.9% of children diagnosed with ARFID also had an anxiety diagnosis (p < .001). • Children diagnosed with ARFID had higher rates of EDNOS (9.8%, p = <.001) and OSFED (13.2%, p = <.001) diagnoses. • No significant association between allergies and ARFID status. • 29.2% of children diagnosed with ARFID were also diagnosed with constipation (p = .029).

Research Question	Findings Related to Neurodivergence	Findings Related to ARFID Status
3. What are the clinical presentations and correlates of ARFID symptomology based on diagnostic status and neurodivergence?	• Neurodivergent children exhibited higher prevalence rates for most ARFID symptoms. • Neurodivergent children, particularly those with confirmed diagnoses, showed higher rates of most ARFID symptoms compared to neurotypical or suspected neurodivergent cases. • Neurodivergence was significantly correlated with multiple severe ARFID symptoms, including avoidance based on sensory characteristics, family impact, fluid restriction, nutritional deficiency, prescribed vitamins, and enteral nutrition requirement.	• 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.
4. Is there a significant difference in the age of onset of ARFID symptoms based on	• No significant association between age of onset of ARFID symptoms and neurodivergence status.	• Significant association between age of onset of ARFID symptoms and ARFID diagnostic status (p = <.001).

Research Question	Findings Related to Neurodivergence	Findings Related to ARFID Status
neurodivergence and ARFID diagnostic status?		• A notable portion of children whose ARFID symptoms were first noticed before 1 year of age were more likely to be diagnosed with ARFID (39.5%, Z-Score = 3.2). • Children with an age of onset between 2 and 4 years had a higher likelihood of not being assessed for ARFID (34.4%, Z-Score = 2.2). • Children with an age of onset from 5 years and over had a higher proportion of children who were assessed for ARFID but not diagnosed (33.3%, Z-Score = 2.2)
5. Are there differences in the type of professional first contacted by parents about ARFID behaviours based on the child's neurodivergence status, and do the delays in receiving a diagnosis	• Parents first raised concerns about their children's eating behaviours and ARFID symptoms to GPs (39.2%) and Health Visitors (34.9%).	• Parents first raised concerns about their children's eating behaviours and ARFID symptoms to GPs (39.4%) and Health Visitors (34.8%). **Results based on professional first contacted:**

Research Question	Findings Related to Neurodivergence	Findings Related to ARFID Status
vary depending on the type of professional first contacted?	• No significant differences in the mean ages at first assessment, diagnosis, or commencement of treatment based on neurodivergence status.	• A significant difference in the overall diagnostic delay based on the type of professional first contacted (p = .02). • The post-hoc testing 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).
6. 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. • Overall, satisfaction levels were generally below the midpoint, indicating dissatisfaction with NHS ARFID processes and treatment options (NHS, Private and Third Sector).	NA

Chapter Five: Mothers' Experiences of Accessing Healthcare for their Autistic Child's ARFID

This chapter presents the IPA findings on mothers' experiences accessing the healthcare system on behalf of their Autistic children to obtain an ARFID diagnosis and support. Results are organised thematically (Table 39) and are illustrated with quotes, providing a vivid account of their experiences. The chapter concludes with implications and recommendations (Table 40).

Table 39 Master Themes and Subthemes

Master Themes	Subthemes
1. The Unseen Battle: Initial Identification and Experiences with Healthcare Professionals	Missed Opportunities for Early Intervention
	Diagnostic Overshadowing
	Overlooked Symptoms and Consequences of Delayed Intervention
	Professional Dismissal and Lack of Understanding
	The Emotional Toll of Early Struggles
2. The Merry-Go-Round of Navigating ARFID Care	Navigating a Pathway, What Pathway?
	Guinea Pigs and Pioneers: Forging New Paths
	Jumping Through Hoops
	Confronting Rejection and Enduring Delays
	Manoeuvring an Obstacle Race while Your Child Deteriorates
	Confronting Power Differentials and Engaging in the Interpersonal Dance

Master Themes	Subthemes
3. Harnessing the Power of a Diagnosis	Validation Through Diagnosis
	Empowerment Through Diagnosis
	Opening Doors and Access to Resources
4. Professional Advice and Interventions: A Double-Edged Sword	Positive Experiences and Neuro-Affirming Approaches
	Negative Experiences and Lack of Autism-Informed Care
5. Life-Saving Decisions and Ongoing Struggles: The Enteral Nutrition Experience	Encountering Professional Reluctance to Enteral Nutrition
	Transformation through Enteral Nutrition
	Enteral Nutrition: Lifesaving Yet Laden with Struggles
6. The Emotional Undercurrent: Navigating the Psychological and Emotional Challenges	Hope and Hopelessness
	Loneliness and Lack of Support
	Fear and Desperation
	Guilt, Regret, and Shame

Theme 1: The Unseen Battle: Initial Identification and Experiences with Healthcare Professionals

The journey often began with mothers recognising early signs that something was different with their child's eating behaviours and bringing this to the attention of HCPs. This theme explores their early interactions with HCPs and the challenges they faced in getting their concerns taken seriously. For many mothers, these initial stages were characterised by a sense of battling to be believed and struggling to compel HCPs to take action. Their stories reveal a pattern of missed opportunities for early intervention, frequent dismissal by HCPs, diagnostic overshadowing, and illuminates the emotional toll that comes with feeling unheard and unsupported.

Missed Opportunities for Early Intervention

Many mothers described a frustrating lack of recognition and early intervention from HCPs. Despite raising concerns repeatedly, they felt dismissed, adding to their sense of helplessness and frustration. The early signs of ARFID were often subtle and easily mistaken for typical picky eating, which contributed to delayed interventions. Marigold's experience is illustrative of this struggle.

> **Marigold**: "I've spoken to the Health Visitor. He wasn't concerned and I'd raised it a few times but obviously then we were under the Dietitians purely because of the CMPA [Cow's Milk Protein Allergy]. [...] The dietitians were involved but again there was no concern there. I was constantly saying you know *'this doesn't seem to be you know a normal pattern of like baby behaviour'* and very often it's just kind of shut down."

For Marigold, the lack of concern from HCPs despite her persistent efforts to highlight her child's abnormal eating patterns created a feeling of frustration. Her worries were frequently dismissed, contributing to a growing sense of helplessness.

Violet also faced similar challenges. Health Visitors consistently downplayed her concerns, attributing her daughter's lack of weight gain to a phase that would resolve itself.

> Violet: "[…] she wasn't really putting on weight and I was a bit concerned about that […] from early doors even the Health Visitors were you know it's the usual thing *'she'll pick up as she goes along'. 'She'll get used to this'. 'Just try giving her a little bit more of this that and the other'.*"

Both Marigold and Violet believed these early experiences were crucial, and professional intervention could have made a significant difference if offered. Instead, their concerns were dismissed as overreactions, typical of new mothers or as temporary phases their children would outgrow. This dismissal not only delayed necessary interventions but also compounded the mothers' stress and anxiety.

Ivy echoed a similar story of dismissal:

> Ivy: "I remember listing off the foods that he would eat and the doctor's like 'well, it's not too bad' [...] it's not great but it's not bad."

This response minimised the severity of the situation, leaving Ivy feeling invalidated and her son's issues unaddressed. The common thread in these narratives is the missed opportunities for early interventions due to HCP dismissal.

Diagnostic Overshadowing

Mothers often faced diagnostic overshadowing, where the presence of an Autism diagnosis, led to the minimisation or misattribution of ARFID symptoms. This phenomenon further complicated their efforts to secure appropriate ARFID care.

Violet expressed frustration with HCP dismissal of ARFID symptoms as merely extensions of her daughter's Autism, which led to a lack of targeted interventions.

> Violet: "any other condition, illness, whatever it may be is lumped together with Autism […] It's almost as if it's quite convenient for them to say *'well that's part of the Autism. So, we won't focus on that'*. And then you *think 'well actually no that's actually a really big deal. And we need a bit of help with that'*."

Violet's narrative highlights the critical issue of misattribution, where the distinct and significant nature of ARFID is overshadowed by the more familiar Autism diagnosis. This misattribution resulted in what mothers perceived to be inadequate care and exacerbated the mother's frustration. Fern echoed this sentiment.

Fern: "everything is blamed on the Autism. *'It's the Autism why he's not eating. It's just his flaws'* and it's not. Although it's highly linked to Autism it's separate."

Erica offered a nuanced perspective on how her son's Autism diagnosis both hindered and facilitated the ARFID diagnosis. While it sometimes led to dismissive attitudes, it also made the ARFID diagnosis more accessible in certain contexts.

Erica: "it could have gone one or two ways I think without the Autism I think it could have just been perceived as a fussy eater and therefore nothing much coming about that until the physical side of things got so severe. But on the other hand, I think maybe ARFID it was more easily diagnosed because he was already Autistic and had anxiety. You know that all happened in that one appointment. Being given the ARFID diagnosis, there wasn't a big battle to get it."

Mothers perceived diagnostic overshadowing to cause delays in obtaining appropriate ARFID care and to exacerbate their emotional strain by complicating their efforts to secure appropriate treatment.

Overlooked Symptoms and Consequences of Delayed Intervention

As the early signs of ARFID were often subtle and easily mistaken for typical picky eating, many children's symptoms went unrecognised until they became severe. The weight-centric approach of HCPs often led to a focus on measurable indicators, missing the true severity of the disorder. An approach, intended to normalise and reassure, instead heightened maternal worry, as mothers felt that reassurance was based on the wrong metrics. They felt dismissed and more anxious, fearing that their valid concerns were not being taken seriously and worrying about the consequences of delayed interventions.

Marigold's story of a coincidental X-ray due to an accident on holiday highlights the hidden consequences of delayed intervention.

> Marigold: "they said she had growth arrest lines[13] all through her bones. [...] I thought that there was damage. We knew there was damage now [voice breaks] [...] Damage that goes on internally that goes on internally that isn't seen and that poor boy [Alfie[14]] obviously you know ended up having a cardiac arrest you know because of he didn't have the nutrients in him and you just think that it that's so easily could've been us at any point and it's just it's/ we have to do better."

[13] Growth arrest lines, also known as Harris lines, are horizontal lines visible on X-rays of long bones. They indicate periods of interrupted bone growth, often due to malnutrition or other severe stressors during a child's development. These lines can serve as markers of past nutritional deficiencies or other health issues affecting growth.

[14] Alfie Nicholls was a 7-year-old boy with Autism who tragically died in December 2021 from undiagnosed and untreated ARFID. An inquest into his death was conducted, resulting in a report published in February 2024 that highlights the severe risks associated with this condition. For more information, you can refer to the report: https://www.judiciary.uk/wp-content/uploads/2024/02/Alfie-Nicholls-Prevention-of-future-deaths-report-2024-0084_Published.pdf

For Marigold, the discovery of growth arrest lines was a stark and painful realisation of the damage that had been accumulating unnoticed. The emotional weight of knowing the internal damage caused by years of inadequate nutrition added to Marigold's sense of urgency and frustration with the healthcare system.

Fern's son experienced similar long-term consequences of delayed intervention:

> Fern: "Because of all the years of not having the right nutrition we don't know if a problem with his joints is a malnutrition effect or not. He's really struggling with pain."

Fern's son's joint pain illustrates another dimension of the severe consequences of overlooked symptoms. The uncertainty about whether his joint issues were caused by malnutrition adds another layer of complexity and worry for Fern.

Jasmine provided a crucial insight into the limitations of standard medical metrics in detecting eating disorders early.

> Jasmine: "he's really still not eating anything, and his weight doesn't drastically drop. Now the Paediatrician has told me that that can be quite common in eating disorders, and it only drops when it really becomes the end […] In fact sometimes it doesn't drop, they just don't make it."

The Paediatrician's acknowledgment that weight metrics can fail to indicate the severity of an eating disorder until it is almost too late highlighting a critical gap in the current healthcare approach. This lack of early intervention and subsequent overlooked symptoms had a cascading effect on both the child's health and the family's emotional well-being. The result was a deep sense of frustration and helplessness for the mothers, who felt that their concerns were diminished until the consequences became acute.

Professional Dismissal and Lack of Understanding

Mothers frequently recounted encounters with HCPs who either did not understand ARFID or dismissed it as unimportant. Professional dismissal compounded the emotional toll, making mothers feel as if they were fighting an uphill battle with little support.

Jasmine's frustration stemmed from a pervasive disbelief among HCPs about the severity of her son's eating issues, reinforcing a sense of isolation and desperation.

> Jasmine: "What I felt through the whole journey is that people don't believe you. Don't believe me and they think that he's eating more than he is."

This pervasive disbelief not only left Jasmine feeling unsupported but also heightened her anxiety, as she was constantly battling to be heard.

Feeling dismissed and invalidated by HCPs, mothers had to navigate their child's health issues largely on their own. This lack of professional support exacerbated their stress and anxiety, as they worried about their child's health deteriorating amid a lack of containment for their concerns.

Fern experienced a similar situation where her son's symptoms were not given due consideration by HCPs, which added to her frustration and helplessness.

> Fern: "Every time we went to see the Paediatrician, it felt like they just weren't taking it seriously. They'd look at his growth chart and say he's fine, but they weren't seeing the daily struggles we faced at home."

The emotional toll of being repeatedly dismissed by HCPs cannot be overstated. Mothers described deep frustration and helplessness, as their legitimate concerns were persistently brushed aside.

The Emotional Toll of Early Struggles

Lack of early recognition and intervention had a significant emotional impact on mothers, who often felt isolated and judged. The constant battle to be heard and taken seriously by HCPs contributed to frustration and emotional exhaustion.

Marigold's narrative captures the emotional toll of feeling like a *"neurotic"* mother, constantly second-guessing her parenting decisions.

> Marigold: "I very much felt like that neurotic kind of mother. You know first time mother that just got it wrong, and I just didn't know what I was doing, and I wasn't weaning her properly and I wasn't having the confidence in my decisions. You know so that that was kind of was how I was left to feel."

This self-doubt, compounded by the ongoing struggles to manage her child's eating disorder, led to a profound sense of emotional fatigue. The lack of validation from HCPs not only undermined her confidence, but also heightened her anxiety, leaving her to navigate the complex and demanding situation alone.

Violet also expressed the intense emotional strain of trying to secure the necessary care for her child while feeling unsupported and judged.

> Violet: "Deflated, I think very deflated. […] you're constantly having to explain yourself all the time and they're kind of looking at you as if to say *'hmmm'*, it's as though you're over-egging the pudding a bit and then you kind of without meaning to, you're kind of feeling yourself getting a bit annoyed because you just think *'you're really underestimating what we're going through all the time at home'.*"

For Violet, the emotional toll of feeling judged and unsupported made the already challenging task of managing her child's health issues even more difficult.

Fern's experience further illustrates the profound emotional impact of these early struggles. The relentless efforts to seek help and the lack of responsive support took a significant toll on her mental health.

> Fern: "we had a Health Visitor come around the house and he said *'oh you just need to starve him. He'll eat when he's hungry'* and I said, *'he will not'*. I said, *'you clearly don't know anything about it'*. I said, *'he will not eat this stuff'*. And I said, *'I refuse to do it'.* He was like *'well if you're not following our advice, we can't help you'*."

The combination of feeling judged, unsupported, and responsible for their child's well-being created an overwhelming emotional burden for mothers. The consistent invalidation heightened their struggles.

Theme 2: The Merry-Go-Round of Navigating ARFID Care

The journey through the healthcare system for mothers often felt like being on a merry-go-round, a relentless cycle of challenges with no clear path forward. Mothers found themselves on a metaphorical carousel, encountering obstacles and delays while striving to secure appropriate care for their children. Each rotation symbolised a new hurdle, and the sense of

disorientation was compounded by the lack of a clear roadmap. Mothers also described feeling like pioneers, navigating uncharted territory, often forced to act as guinea pigs in a system still learning how to identify and treat ARFID.

Navigating a Pathway, What Pathway?

Mothers frequently spoke of the absence of a clear, structured pathway to follow in seeking care for their children. This lack of direction often left them feeling lost and frustrated, having to rely on their persistence and resourcefulness to make any progress.

Marigold, a HCP herself, described her struggle despite having some insider knowledge.

> Marigold: "I think the fact that because I work in the industry it kind of [helped] […] push forward and I guess mapped out that route […] But it wasn't a case of just going and asking for a referral and we got it. It was like pulling teeth to get to that. It was very hard to get through the walls to get to the Community Paediatrician and then it was very hard to get to [specialist feeding clinic A] but we got there in the end. But the whole process took a year and a half with both those things combined and anything could have happened in that time."

For Marigold, even with her background in healthcare, navigating the system was like *"pulling teeth,"* illustrating how convoluted and obstructive the process could be. While Marigold had the knowledge needed to create her own map, other mothers had to rely on the knowledge of

professionals. Sadly, often the onus was on parents to figure out where to request a referral to or to not accept no for an answer.

> Fern: "we'd managed to see a Paediatrician after waiting 10 months, and he said *"I don't know anything about ARFID. What do you want me to do?*" So, I asked to be referred to [Area], to the Gastro clinic cause I'd heard that the consultant there really understood ARFID, and she really does get it."

> Jasmine: "the GP had already said *'there's nothing I can do. You know I can't. It's not my area of expertise. I don't know what to offer'*."

As evidenced in the quotes, mothers frequently encountered a pervasive lack of ARFID awareness among HCPs, with many not knowing where to refer patients or what to do with them. This issue spanned the entire healthcare system reflecting the systemic gaps in knowledge and referral pathways for ARFID.

Jasmine' spoke to the need to be forceful to ensure her son received the necessary care and was not abandoned by HCPs.

> Jasmine: "*'You can't just drop him. He's got an eating disorder. You're not saying he hasn't got an eating disorder. You're just saying you don't deal with ARFID so tell me who does and refer to who does'* […] but I had to be really forceful. Like really forceful."

For many mothers, the journey felt chaotic, more like a battlefield than a structured pathway. Erica described this feeling aptly.

> Erica: "A pathway sounds like you know you complete steps and you get to an end, but it's just called a pathway. I wouldn't actually describe it as a pathway. If it is, it's a very disjointed chaotic pathway. [...] I describe it as a battle [...] it's almost like trying to follow a route with no map. No one tells you what the next step is. No one tells you where you should go next or what you need know or who you need to speak to. It's just lots of you know finding out on your own really. And depending on who you speak to, if they happen to be competent, and you know, care basically, then you might get a step further."

Erica's depiction of the pathway as a battle rather than a structured route highlights the systemic disorganisation and lack of support. Her description of navigating *"a route with no map"* powerfully conveys the confusion and frustration experienced by mothers as they try to secure appropriate care for their children.

Overall, these narratives reveal a common thread: the healthcare system's lack of a clear, supportive pathway for ARFID care leaves mothers feeling isolated, desperate, and constantly battling to make progress.

Guinea Pigs and Pioneers: Forging New Paths

Navigating ARFID care often made mothers feel like they were pioneering uncharted territory, serving as guinea pigs in a system still developing its understanding. Their experiences helped pave the way for future families, creating a path through their trials and advocacy.

Fern described being explicitly told that she and her son were guinea pigs during a conversation with a commissioner.

> Fern: "She said *'you're a bit like a guinea pig because we're trying to work out what works, what doesn't work for a pathway'."*

This statement encapsulates the uncertainty and experimental nature of navigating ARFID care, where mothers often felt that their experiences were being used to inform future practices rather than receiving established and effective treatment protocols. Due to the emerging evidence-base, this is sadly the reality they find themselves in. Despite this, many mothers accepted the role of pioneers with a sense of purpose and resilience. They understood that their struggles and the resistance they faced were paving the way for better ARFID care. There was a collective hope that their trials would not be in vain.

Marigold found solace in seeing progress made due to her efforts, feeling overjoyed when professionals brought ARFID to the attention of parents.

> Marigold: “I literally punch the air when I see people come on and they're *like ‘oh I found this group because my dietitian or my GP’* or you know somebody in a professional capacity and said *‘I think your child might have ARFID’* which is just something that none of us earlier people ever had access to. Everything has been absolutely fought for.”

Marigold’s reaction highlights the sense of accomplishment and validation that comes from knowing her advocacy and efforts were making a difference for others.

Jasmine reflected on how her persistence paid off, benefiting her younger child:

> Jasmine: “When I first went, she said *‘you could teach me about it’.* When I went the second time six months later, she was very much informed of what was what. […] I felt happy because I didn't have to fight. Honestly, I feel absolutely knackered from the last two or three years. I'm exhausted from it."

Jasmine’s experience illustrates the progress that can be made through persistent advocacy. Seeing HCPs become more informed about ARFID over time provided many mothers with a sense of relief and validation. Jasmine’s exhaustion underscores the intense effort required to bring about this change, highlighting the need for a more informed and responsive healthcare system. These narratives reflect the dual role mothers often played: not only seeking care for their own children but also forging new paths for others.

Jumping Through Hoops

The process of securing appropriate care was frequently likened to jumping through hoops. Mothers shared stories of the complex and often repetitive steps they had to take to get referrals and appointments with the right specialists. The numerous hurdles they had to overcome added to their frustration and sense of being stuck in an endless cycle of bureaucratic challenges.

Jasmine illustrated the frustration of unnecessary hurdles.

> Jasmine: "I went through hoops that I didn't need to go through. […] I've had to go backwards and forwards, backwards and forwards."

For Jasmine, the repetitive and seemingly pointless steps made the journey feel even more daunting. Her experience highlights how the inefficiencies in the system added unnecessary stress and delays to an already difficult process.

Erica also described the extensive effort required to secure even basic appointments (weight monitoring), providing context to the arduous process.

> Erica: "I had to fight and fight and fight for an appointment that takes 2 minutes. I was told *'we don't offer that as a service', 'our nurses don't do that'*. […it] took several months and finally they came back and agreed."

Erica's comment underscores the exhausting nature of the process, where every step felt like climbing a steep hill.

Marigold captured the necessity of prioritising certain battles over others to reach her goal.

> Marigold: "I just thought *'well you know I'm not/ that's kind of not my battle right now, that I'll do that one later. This is an issue about the feeding. You're just kind of a you know a step on the chain to where we need to get to'*."

Marigold's strategy of prioritising specific issues highlights the pragmatic approach many mothers had to adopt. By focusing on immediate concerns and conserving their energy, they managed to make incremental progress despite the system's complexities.

The necessity of navigating multiple layers of bureaucracy and complex referral criteria often left mothers feeling like they were running in circles without making tangible progress. The metaphor of jumping through hoops encapsulates the exhausting and often frustrating experience of trying to secure appropriate care.

Confronting Rejection and Enduring Delays

Mothers frequently described their frustration with the systemic obstacles and the emotional toll of waiting for necessary interventions. Mothers spoke of frustration with rejected referrals and created unnecessary delays. They faced challenges getting the right HCPs to take their concerns seriously enough to make a referral.

Marigold's Health Visitor was *"non-believing"* and thus wrote *"wishy washy"* referrals that kept being rejected. Marigold felt that she was only accepted to appease her, imagining HCPs seeing her fourth referral and thinking*: "'Let's just see this woman (laughs) so that if nothing else, we can just reassure and send her off."*

For Fern, her GP was willing to refer, however, the referrals were rejected because the specialist clinic only accepted referrals from Consultants. Fern felt that had they accepted her earlier referrals, things might not have deteriorated to the point where her son required enteral nutrition.

> Fern: "Our GP is fantastic for referrals. They're really supportive, our GP, but it's everywhere else that lets it down (laughs). Our GP actually referred us to [area] three times, but [area] kept declining it because it didn't come from a Consultant. So, if they'd accepted it years before, we might not have needed the MIC-KEY button. If they provided the support early, like they should be, we might not be in this position."

Other delays noted related to a lost referral and being immediately referred onto another professional because they are not equipped to manage the case.

> Marigold: “We were waiting for 18 odd weeks, and I hadn't heard anything and then I got in touch with them, and they said they'd never received anything. So, it's that situation where you think you're in the waiting list for something, a service that you know has got a long waiting list, and then actually you never were."

> Jasmine: "she [Paediatrician] was lovely, she'd read all the medical history she could see everything that had gone on and she said to me*, 'I'm not going to take this, I'm going to pass you to the Head Consultant, the Consultant Paediatrician because it's over my head. I don't know what to do.*'"

These narratives illustrate the impact of systemic delays and rejections on families dealing with ARFID. The emotional toll of navigating a fragmented and unresponsive healthcare system adds to the already significant burden faced by these mothers.

Manoeuvring an Obstacle Race while Your Child Deteriorates

Mothers shared moving accounts of the fear they endured while waiting for support and navigating the uncertainty of waiting lists.

Ivy: "there's like so much time on waiting lists and you know when your child is young and not eating and dropping weight, it's concerning."

The situation was compounded by being shuffled between services, perpetuating a cycle of waiting lists. It felt akin to an obstacle race as they weaved, jumped, and sidestepped their way to the care their child needed. In Jasmine's case, she went to her GP for support when Jeremy stopped eating. The GP referred to CAMHS, who called within a couple of days and offered an appointment a month later, despite the urgency.

Jasmine: "I hadn't even sat on the seat and the chap said to me *'there's no therapies for at least two years. I'm not really sure what we can offer'*. […] which wasn't a great start to our journey with CAMHS (laughs) and so yeah, that's where we began. That wasn't very helpful, so we left there, with no help, not knowing what to do. No discussion about eating disorders. [...] I went away from there and he continued to not eat and days with nothing. […] week three I was really panicking, really panicking, which I thought, *'we can't leave him like this'*. I went back to the GP and the GP said I'll refer you to the Dietician. So, the GP was really frustrated too, but had no idea honestly, no clue of what it was".

Seemingly, the GPs sense of helplessness may have immobilised them, doing little within the realm of their control, and duty and instead hoping that the referral will be picked accepted, and another professional would take responsibility.

Jasmine: “in hindsight, they should have seen him. They should have said, *‘bring him in*’ and they didn't. They didn't ask me to, they didn't even mention it […] the GP had already said *‘there's nothing I can do. You know I can't. I'm not. It's not my area of expertise. I don't know what to offer’*, so I think he was quite clearly saying there's no point in bringing him here. And I think he just assumed that whoever he referred to would see him.”

Ultimately, the onus was on Jasmine to ensure Jeremy was seen as soon as possible. Understandably, this evoked a lot of fear in Jasmine, and the lack of containment was traumatic.

Jasmine: “an urgent appointment for 11 months. So yeah, you can imagine, you can imagine my fear at that point […] I remember it vividly. I was crying on the phone. I was phoning people up and crying, *saying ‘I think he's going to die, you know, no one's listening. I can't wait four weeks. I can't wait a week for an appointment. It's just kind of somebody's got to take this seriously*.’”

In Marigold's case, by the time her daughter reached the feeding clinic, her condition had deteriorated to the extent that feeding therapy was no longer viable, prompting the team to advocate for enteral nutrition.

Marigold: "she was now starting to quite quickly deteriorate […] She was so lethargic. She just had nothing in her. She was ghostly white. Her hair was like spindly, you know,

like she's got really thick, full hair now. [*visibly crying*] But she just looked like this little old woman. She had black eyes. And they just said *'she just can't engage. This is/ there's no, we can't even begin to do feeding therapy on a on a child that for all intents and purposes just needs to be fed'."*

While upset about the delay in reaching the feeding clinic, Marigold also expressed gratitude that she reached them when she did and no later, fearing the alternative scenario of remaining in the limbo of waiting lists and having to visit A&E; a situation feared and faced by many other families.

Marigold: "thankfully we were under them. […] I think God knows what I would have done […] I see this all the time [on Facebook], parent that are just sitting in A&E with their children and being sent away and their kids are literally curled up like skeletons. They're so malnourished and being told there's nothing we can do, and you just think it's, it's barbaric, like, just feed them. They just need feeding."

Fern found herself in a frustrating situation where care coordination was lacking, leaving her feeling overwhelmed by the responsibility. Recognising her own limitations in taking on such a role, she sought assistance from social services to establish a Child in Need Plan. Despite initial reluctance, this step ensured that responsible parties were involved and accountable.

Fern: "NHS parties weren't coming together, school weren't coming together, and it was to get everybody around the table to discuss it. [...] social services didn't want to be involved and said there's no need to be involved but I begged them to be involved (laughs) because we just weren't getting anywhere".

These narratives reveal the exhausting and often traumatic experience of navigating the healthcare system. The lack of coordination, frequent rejections, and long waiting times not only delay essential care but also exacerbate the emotional and physical toll on children and their family. The constant struggle to secure appropriate care left mothers feeling helpless, anxious, and overwhelmed.

Confronting Power Differentials and Engaging in the Interpersonal Dance

Mothers were acutely aware of the power differentials between them and HCPs. They spoke about the delicate balance of advocating for their children while remaining in the good graces of HCPs. This dynamic often required mothers to traverse interactions with strategic politeness, even when faced with contemptuous attitudes.

Violet encapsulates this struggle, expressing the frustration of having to *"bite my tongue"* and remain *"polite"* even in the face of *"eye rolls"* and what felt like a conscious effort to misunderstand. Made to feel she was *"being too much".*

Violet: "as a parent they question your knowledge or what you're telling them or, you know, and sometimes I've had rolls of the eyes given to me before, and you know, you're kind of like, *'okay',* obviously they're not understanding it from my perspective."

Violet: "I have to kind of bite my tongue with certain things […] It can be hard not to say something. Continually sort of be polite when actually you want to say *'no. I don't want to do that'* […] they're very kind of rigid in what they want to do, a tick box kind of exercise."

Other mothers also echoed the sentiment that maternal expertise was frequently overlooked, and professionals were too rigid in their approach. Mothers had to find ways to flex and bend around professionals who were not willing to do the same.

For Marigold, the journey involved resisting the urge to appease and embracing the role of *"that mum"* who persistently advocates for her child, despite the social discomfort it brings. She recognised that while she could endure the *"horrible feeling"* of being a nuisance, not all parents could, highlighting an unfair disparity in the system.

Marigold: "You're the only advocate for your child who cannot advocate for themselves. […] A lot of other people just fall at the first thing and go, *'oh, well, you know, it's not a problem. Then I'll just go away'* (shakes head)."

Marigold initially approached her interactions passively, typical of a "*new mum*" trusting in professional opinions. Over time, necessity and desperation transformed her approach, empowering her to challenge decisions. Being a HCP herself, Marigold felt less intimidated, recognising that doctors are not beyond reproach.

> Marigold: "You're brought up to believe that if a doctor says, then a doctor knows and because I work in the industry [...] I see it all the time (laughs), you know, that they get it wrong as well [...] they're not on some pedestal and that everything they say is gospel."

Similarly, Jasmine felt confident in challenging *"the powers that be"* due to her familiarity with the medical profession.

> Jasmine: "Some people won't challenge a doctor. I've worked with doctors for quite a long time, and I'm not fazed by that."

These narratives highlight the intricate interpersonal dance mothers must perform, balancing advocacy with diplomacy.

Theme 3: Harnessing the Power of a Diagnosis

Most mothers spoke to the power of a diagnosis, noting its significance both for themselves and others. For many, receiving a diagnosis brought validation and empowerment, offering a framework for understanding their child's challenges and a tool for advocacy. For others, it was more of a necessity.

Validation Through Diagnosis

Receiving an ARFID diagnosis often served as a turning point, offering validation for the mothers' concerns and experiences. The diagnosis confirmed that their children's eating issues were real and significant, serving as a balm for wounds inflicted by previous dismissals from HCPs.

Violet spoke to feeling empowered by the diagnosis. She mused that while *"ammunition"* might feel like the wrong word, it nonetheless encapsulated the assertiveness and conviction it provided. In many ways, ammunition felt befitting, creating a visual of having a diagnosis in her back pocket, ready to shoot down disbelief and judgement.

> Violet: "It's nice almost to have it recognised, so when you do want to go and speak to someone you can say she actually does have ARFID, it is diagnosed, you know it is an eating disorder. It kind of just makes you feel like you've got a bit more... I think ammunition is the wrong word, but a bit more gumption to kind of make people realise what you're trying to explain."

Fern mirrored this sentiment, emphasising the internal and external validation that comes with having a diagnosis.

> Fern: "I think having a diagnosis validates your feelings and it validates what you're going through."
>
> Fern: "I've also found since we've got my diagnosis for both of them, people listen more."

While some, like Fern, found validation in the diagnosis provided by professionals, others, like Erica, felt they did not need professional verification.

> Erica: "It wouldn't have mattered if 100 professionals had told me Elijah doesn't have ARFID. I knew he had ARFID."

> Erica: " I wasn't necessarily looking for a diagnosis. I just needed help and support. [...] I had absolutely no doubt whatsoever [...] I was telling people that he had ARFID before I got a diagnosis anyway."

Thus, the diagnosis acted as ammunition for some mothers, empowering them to assert their child's condition confidently, while for others, it was a necessary step to gain access to support and recognition from others.

Empowerment Through Diagnosis

The diagnosis not only validated mothers' concerns but also provided a framework for understanding their children's behaviours and needs. This understanding empowered mothers to seek appropriate interventions and support.

In a different but related context, Jasmine spoke to the importance of a label for Jeremy and how sharing her suspicions that he has ARFID offered much-needed containment for him.

> Jasmine: "I said to him '*I think I think you've got an eating disorder and I think this is what it is'* and he listened. He was really interested. He wanted to know if I knew anyone else that had it. He wanted to see the people that got tubes and, you know, I did say to him, you know, *'that I'll just, I'll show you stuff'* and he said, *'well, how do people eat?'* And I told him there were different options and he didn't seem scared. And I think from that, from there, I noticed a difference in his anxiety. It started to reduce."

By sharing her suspicions with Jeremy, Jasmine provided him with a sense of containment and understanding. Jeremy's interest and curiosity about the condition, along with Jasmine's reassurance and information sharing, contributed to a noticeable reduction in his anxiety. Highlighting the potential therapeutic impact of labelling and discussing ARFID openly within the family dynamic.

Opening Doors and Access to Resources

Alongside validation, a diagnosis was also able to open doors to resources and support that were previously inaccessible. However, the type of diagnosis (private vs. NHS) and the specific conditions diagnosed affected the availability and type of support received. Ivy commented on the difference between a private diagnosis and an NHS diagnosis.

> Ivy: "I felt that an NHS diagnosis opens up doors that a private one doesn't."

While an ARFID diagnosis appeared to support access to ARFID care, an Autism diagnosis was seen by some to close certain doors, as detailed in 'diagnostic overshadowing'.

Jasmine pointed out the systemic reluctance to address ARFID in the presence of an Autism diagnosis, which can discourage families from seeking help.

> Jasmine: "There's a lot of people saying 'don't bother. Don't go'. Which is why I think this/ the figures will always be skewed because you know how hard it is to get help. If you think that an Autism diagnosis is going to hinder your chances of getting help, then you wouldn't go."

This observation reveals a fear that fuels diagnostic reluctance among those yet to be diagnosed with Autism, forcing families to be strategic and prioritise which diagnosis they pursue.

The overall experiences underscore the differing influences a diagnosis can have. A diagnosis can serve as a pivotal tool that can transform or contain uncertainty, as well as open or close doors.

Theme 4: Professional Advice and Interventions: A Double-Edged Sword

The quality of professional advice and interventions varied widely, with some mothers receiving lifesaving support while others encountered harmful or dismissive attitudes. This theme explores the dual nature of these experiences, highlighting the critical impact of HCPs' understanding and approach.

Positive Experiences and Neuro-Affirming Approaches

Positive experiences where HCPs provided empathetic, informed, and effective advice were deeply valued by mothers. These moments of support made significant differences in their children's health and well-being.

Fern appreciated the anxiety support provided by CAMHS, even though it was not specifically around eating:

> Fern: "The anxiety support for CAMHS not around for eating but anxiety support has been really useful."

Erica recounted a particularly impactful appointment where clear, numbers-based guidance resonated with her son who was *“very numbers based”* and *“good at maths”.* The professional's approach, though alarming, was effective in ensuring Elijah adhered to the necessary dietary supplements.

> Erica: " It's probably the most horrific appointment either of us have been in because I just couldn't quite comprehend what he was telling me […] *‘You're still at risk of a heart attack if you don't take these vitamins’*. But in one way I think Elijah's intelligence worked for him in that because he had understood perfectly what was being said to him and he has taken that every day since. So that was good."

Negative Experiences and Lack of Autism-Informed Care

Conversely, many mothers encountered professionals who lacked an understanding of ARFID and Autism, resulting in harmful advice and interventions. These negative experiences often exacerbated the challenges faced by families. Marigold reflected on the detrimental advice she received, which did not account for the complexities of her child's condition.

> Marigold: "you've probably heard this, *'no child would starve themselves'* and you know *'she's just learning that you're going to give her crisps all the time'.* So, you know *'you've just kind of got to batten down the hatches and be prepared that she'll dig her heels in for a couple of days but then she will eat, and this will all be better'*. Which we did and it was the worst thing we ever did."

Violet experienced intrusive and counterproductive interventions from HCPs, which only increased her daughter's anxiety and worsened her condition.

> Violet: "We found the doctors would come over to her and they would literally bombard her at all hours of the day. *'You need to start eating Vanessa. Why are you not eating?*' and being really quite intrusive with the way they were doing it. And I was just thinking *'gosh this is a really anxious Autistic girl, and you are coming at her standing over the bed sometimes in a group'* and sort *of 'why? Why, why, why?*' And of course, she was withdrawing more and more and more, and she ended up getting really unwell and lost further weight and we had to go."

These narratives illustrate the significant impact that the quality of professional advice and interventions can have on families navigating ARFID. The contrasting experiences underscore the importance of informed, empathetic, and Autism-informed approaches in providing effective care and support.

Theme 5: Life-Saving Decisions and Ongoing Struggles: The Enteral Nutrition Experience

This theme delves into mothers' encountering professional reluctance, and enduring delays in accessing a life-saving treatment. The transformative power of enteral nutrition was evident, with mothers expressing gratitude for its lifesaving effects, yet also speaking to the new challenges it introduces. Through shared experiences and personal narratives, this theme highlights both the hope and hardship inherent in enteral nutrition.

Encountering Professional Reluctance to Enteral Nutrition

Mothers reported encountering significant professional reluctance initiating enteral nutrition. While they understood the gravity of such decisions, they also felt a profound sense of desperation, viewing reluctance as another obstacle to overcome.

Marigold articulated the complex position of HCPs, who must balance the potential benefits and harms of medical interventions for what is fundamentally a psychological issue.

> Marigold: “It's in the DSM manual so it falls under a mental health condition so no healthcare professional wants to be the person that whacks a mental health label on a child particularly a young child and put them through a procedure that might ultimately harm them […] when they think that this is just for a kid who is just choosing to eat crisps and not you know not proper food."

Nevertheless, Marigold stressed the crucial need for professionals to weigh the consequences of not providing enteral nutrition, emphasising the stark possibility of a *"preventable death."* She posed a pertinent question about whether they could live with such an outcome on their conscience.

> Marigold: "As much as you might be uncomfortable making a decision to feed that child, is that worse than having the death of a child on your conscience because you didn't

intervene? To me, that's ultimately got to be the worst thing. [...] a child's death... a preventable death."

Jasmine's account vividly illustrates the immense panic and frustration experienced by parents while professionals deliberated. In her case, there was a profound sense of anger at the perceived lack of urgency given the clear threat to her son's life and the distressing sight of him *"disappearing"* before her eyes.

Jasmine: "I was angry. I'm not going to lie (laughs). I think after the journey that I've been on, I think I've never got angry with anyone until that point, and he was literally just disappearing before my eyes. And everyone was seeing him. I was being told that the intervention for tube feeding wasn't being highlighted because of the trauma [...] That's a really hard thing to hear when you can see him disappearing. So, I was saying to her, *'where do we get to? Where's the point? What? Who chooses this point? Is it me? Is it until he collapses?*'"

Poignantly, within days of a meeting where Jasmine raised questions about the necessity of enteral nutrition, Jeremy became unresponsive and required an ambulance.

Jasmine: "I couldn't wake him up the next morning. He was unresponsive. He was clear. He was freezing cold. I am going to get upset [*becomes visibly distressed*] and I phoned an ambulance."

Jasmine recognised that the professionals were also afraid, saying *"I could feel their fear. They're scared. They are all scared. All of them,"* but ultimately felt the priority in this instance was to keep him alive.

Transformation through Enteral Nutrition

Despite the initial reluctance and hurdles, once enteral nutrition was initiated, mothers reported significant positive changes in their children's health and well-being. The transformation was often described as lifesaving, bringing immense relief to families who had been struggling for years.

Marigold highlighted both the severe deterioration her daughter experienced before starting enteral nutrition and the immediate and profound impact it had on her child's health.

> Marigold: "they rang me from the appointment, and they just said this. *'We can't/ this is completely inappropriate. Like Maya just climbed up on her dad's lap and just went to sleep […] we can't even begin to do feeding therapy on a on a child that for all intents and purposes just needs to be fed. Like this has become quite a critical thing now.'* So, because thankfully we were under them […] within three weeks we were in for a tube at our local hospital, but I've been asking for that for sort of a year (scoffs)."

Marigold: "The mental alertness I can't tell you. She just lit up like she had all this energy. She was bounding around. We actually saw for the first time her personality when she was three."

For Marigold, the decision to start enteral nutrition marked a turning point. Her daughter's rapid improvement underscored the critical importance of timely intervention. The positive changes not only alleviated her physical health issues but also significantly improved her overall quality of life.

Fern also shared the severe deterioration her son experienced before starting enteral nutrition, followed by a transformation after the intervention.

Fern: "We were having MDT meetings by this point, and I think within two weeks he'd deteriorated that much, he'd got, he'd lost that much where he was quite in danger. So, we had an MDT. They all agreed he needed the MIC-KEY button and then he had the MIC-KEY button fitted 6 weeks later and it's changed his life. [...] It's saved his life."

Fern's narrative highlights both the urgency and the life-saving impact of enteral nutrition.

Enteral Nutrition: Lifesaving Yet Laden with Struggles

While enteral nutrition proved to be a transformative and life-saving intervention, it also came with its own set of ongoing struggles. Mothers faced numerous challenges related to the care and maintenance of feeding tubes, dealing with frequent infections, and managing the emotional toll of regular tube changes. This sub-theme delves into the complex reality of living with enteral nutrition, highlighting both the relief it brought and the new battles it introduced. The focus is primarily on Marigold, who had almost four years of experience with enteral nutrition, compared to Fern's six months.

Marigold spoke to the ongoing challenges she faces in caring for Maya's G-tube and the new limbo they find themselves in. Feeling as though she's reached a *"wall"* where *"everybody's like 'well I've done my part'"* yet the struggle for her continues. Indefinitely.

Marigold feels alone in navigating Maya's care, confronting repeated infections, hyper-granulation[15], and traumatic tube changes every four months. Weary from the last, this new battle felt gruelling with no end in sight as *"there is absolutely nothing in terms of weaning her."*

> Marigold: "no one no one said to me *'hey you don't have to pin your child down every four months. Like why don't we try this?'* It was me actually cracking, after doing this for the last three years to her regularly and saying/ just sobbing and saying *'I can't do this anymore. Like can we do this is there another way?'* […] I'm orchestrating all of this […]

[15] [15] Hyper-granulation occurs when excess tissue forms around a stoma site, leading to complications such as bleeding, irritation, significant discomfort, and challenges in managing the stoma site.

> And it's just baffles me that every single thing has had to come from me. It's exhausting."

Marigold's experiences underscore the ongoing struggle mothers can face even after securing enteral nutrition for their children. The life-saving nature of the intervention does not diminish the day-to-day difficulties and emotional toll it takes on families. The need for continuous care, dealing with medical complications, and the emotional strain of seeing their children go through regular traumatic procedures highlight the complex reality of living with enteral nutrition.

Theme 6: The Emotional Undercurrent: Navigating the Psychological and Emotional Challenges

While sprinkled throughout, this theme is dedicated to the multifaceted emotional experiences that accompany mothers' journeys. The emotional undercurrents illuminate the profound psychological impact on mothers as they advocate tirelessly for their children.

Hope and Hopelessness

Journeys were punctuated by fluctuations between moments of hope and deep despair. Mothers frequently expressed a yearning for a definitive solution while simultaneously grappling with the reality of ARFID. The dichotomy of hope and hopelessness was a persistent theme in their narratives, revealing the emotional complexity of their experiences.

Marigold spoke to a sentiment shared by many mothers.

> Marigold: "there's always that hope there. I think that you think that someone is gonna be able to just magically tell you what you need to do, and it will all go away. So, I suppose I still held a bit of that [...] the end site was always [feeding clinic A] and at that point I thought that they would have all the answers and there would be this magic wand that they could wave and that she would be cured."

The hope that HCPs could offer a straightforward solution provided the motivation to continue seeking help despite numerous setbacks. However, the harsh reality that there is no *"magic wand"* often led to profound disillusionment and despair, leaving mothers to grapple with this and the grief that follows.

Erica's account highlighted the depths of hopelessness when faced with an uncertain future. Her narrative underscored the emotional burden of not seeing a clear path forward.

> Erica: "I have currently no hope for my son getting better. And that is really terrifying. And as a parent it's an enormous weight to carry. Enormous."

Jasmine described the emotional *"roller coaster"* and the lack of clear solutions, which further compounded her feelings of frustration and helplessness.

> Jasmine: "it's been a proper roller coaster […] I feel very lucky we've got a full team more than most people have got but what's happening? No-one knows what to do. Nobody knows what to do."

Jasmine's experience illustrates the volatility of emotions that mothers go through. While she felt fortunate to have a supportive team, the persistent uncertainty and lack of clear answers undermined her sense of hope.

These narratives illustrate the emotional pendulum mothers experience, swinging between the optimism for a breakthrough and the despair of an uncertain future. The persistent search for answers and the frequent encounters with uncertainty create a complex emotional landscape where hope and hopelessness coexist.

Loneliness and Lack of Support

The journey with ARFID can be an isolating experience for mothers, who often find themselves without adequate support or understanding from HCPs and their community. The lack of support exacerbated their sense of isolation.

Erica shared the profound loneliness she felt, emphasising the lack of support specifically for parents.

Erica: "to be honest there has never been any support for me as a parent for Elijah with Autism or ARFID […] it's very lonely, lonely journey. I have been in some very dark places."

Erica's account underscores the impact of feeling unsupported and the rare moments where small gestures can a significant difference.

Erica: "Elijah has an early help worker […] She's about Elijah but obviously Elijah and I are family […] and she has phoned just to check in and, in the conversations, especially the last year when things have been so bad, she will then say, *'and how are you?'* You know and that's been it. That/ and that's been that's been huge! Just for even for someone to ask you that question. You know just for someone to actually recognise how unbelievably difficult it is. It's yeah it's just so isolating."

Jasmine described the compounded stress of feeling judged and unsupported by others, leading her to withdraw from sharing her experiences.

Jasmine: "I got to a point where I didn't talk to anyone about it. I just didn't tell people because it was easier not to tell people and have those judgements. To have those judgements on top of what was already a really stressful situation that was hard. That's hard because then not only do you are you in that situation with that level of stress you also feel unsupported and judged and you know it's just yeah, it's not nice. It's not nice."

Jasmine’s experience illustrates the double burden of managing her child’s condition while also dealing with societal judgement and lack of understanding. This added layer of stress led to increased isolation.

Fear and Desperation

The pervasive fear and desperation felt by mothers as they watch their children grapple with ARFID was evident. These emotions drove their relentless advocacy and contributed significantly to the emotional toll of their journey. The following narratives illustrate the intense fear and desperation that mothers experienced while trying to secure appropriate care for their children.

Jasmine captured the desperation to secure appropriate care and the intense fear that accompanied her child's deterioration.

> Jasmine: "At the time I was sooo panicked. I was so desperate to get him to the right people."

Jasmine’s urgency was rooted in an acute awareness of the need for timely and effective intervention. The anxiety and desperation were compounded by the uncertainty and lack of clear guidance from HCPs. She also described the terror of dealing with her son's starvation.

> Jasmine: "very, very restricted and scared the shit out of me. I'm not going to lie sorry. Excuse my language (laughs). It was terrifying because I dealt with him not eating. I dealt with the very restricted food and the lack of calories and that the impacts that that has but this was something so out of my comfort zone and so against your parental instinct."

This visceral description highlights the intense fear that mothers can feel when faced with their child's severe dietary restrictions and the potential health consequences.

Erica shared her deep-seated fears about her son's health, particularly when his physical condition deteriorated.

> Erica: "I became really worried about him because he was, he was just skin and bone. I could see his ribs. And the anxiety around eating was just becoming harder and harder and harder."

Erica's fear illustrates the acute anxiety that accompanies the visible signs of malnutrition. This fear was a powerful motivator for mothers to seek urgent and effective care.

Ivy highlighted the need for emotional support for parents to help contain their fear.

Ivy: "for the parents or family there probably needs to be at least some emotional support or help because it does create a lot of stress […] when he was below the first percentile, you know, we were terrified."

Marigold spoke to the ever-present fear of severe consequences, referencing a tragic case that deeply affected her and most of the ARFID community.

Marigold: "there was that awful case of that lad [Alfie] that died [...] I think every parent of a child with ARFID who is significantly malnourished […] that is the fear, and I just think that you know that could so easily have been us [visibly tearful]. So easily."

Marigold's narrative captures the deep fear that underlies the daily experiences of mothers managing ARFID. The possibility of severe and life-threatening consequences is a constant source of anxiety, driving mothers to persistently advocate for their children despite numerous challenges.

Guilt, Regret, and Shame

Mothers were also confronted with guilt, regret, and shame along their journeys. These emotions added another layer of complexity, amplifying the psychological burden they carried.

Erica's spoke to feeling *“such guilt and regret”* and described the self-blame as *a “constant weight on my shoulders”.* Her experience further illustrates the depth of regret and the emotional toll of perceived failures.

> Erica: "unless you're living with it, you can't, you can't really imagine to desperately want your child to eat. As a mum it is the most basic function you can do, you know is to feed your child and there is definitely a sense of guilt there that somehow you must have done something wrong that you've caused this or you/ You could have done more, or you're inadequate. You know because you're not giving your child the basic nutrients that they need some nutrition. [...] All those thoughts I just need to just push them to the back of my mind because I know it's not my fault”.

Erica’s account highlights how the ongoing challenges and lack of progress in her son’s condition led to persistent self-blame and regret, adding to her emotional burden.

Marigold’s narrative poignantly captured her deep sense of regret over following misguided advice and the harmful impact it had on her daughter. She reflected on the well-meaning but ultimately damaging actions taken due to this advice (force feeding with escape extinction), which only exacerbated her daughter's anxiety around food.

> Marigold: "She just established her own little set of kind of safe food. But we were doing bad things alongside that because that's the narrative of, you know, *'you've got to feed*

your child the good stuff'. It's always there. [...] We were force feeding her and it was hard."

Compounding the guilt of not being able to adequately feed their children was the additional guilt from following *"bad advice"* that often made the situation worse. Several mothers noted that interventions and professional advice sometimes backfired, particularly due to their child's Autism.

Violet: "because Vanessa is Autistic, she's so inflexible and set in her ways often that would backfire and then we wouldn't get anywhere, and it'll make it worse in some way. So, we couldn't always do it."

Violet's recognition of this prompted her to take a different approach.

Violet: "the more we try to do, the worse she kind of got. So, I think sometimes you have to kind of come away and let her make the decisions rather than being guided by what they [professionals] say all the time."

While Violet was able to pivot to a child-led approach as opposed to a professional-led one, this realisation came a bit later for Marigold. The nature of the experiences that followed further embedded her sense of guilt. Marigold tearfully reflects on the *"huge regret"* she feels about her earlier approach and the lasting impact it has had on her and her family.

Marigold: "now we know and learnt about ARFID, that was the worst things that we could have done [...] I wish I hadn't have done that, but then I don't know what else we would have done."

Marigold went on to refer to her regretful thoughts as "*shoulda, woulda, coulda*," in some ways downplaying the impact, but it was evident that these memories plague her. Highlighting an ongoing struggle to reconcile her past actions with the current reality, and the persistent questioning of whether different choices might have led to better outcomes.

These narratives underscore the significant emotional burden that guilt, regret, and shame place on mothers navigating ARFID. The lack of validation and support from HCPs, combined with the persistent struggle to secure appropriate care, exacerbates these feelings, and adds to the psychological toll.

Summary

Table 40 presents a breakdown of key findings, implications and recommendations, serving as an essential reference point.

Table 40 Summary of IPA Results: Key Findings, Implications, and Recommendations

Master Themes	Subtheme	Implications	Recommendations
1. The Unseen Battle: Initial Identification and Experiences with Healthcare Professionals	• Missed opportunities for early intervention	• Delayed intervention can lead to worsening symptoms and increased emotional toll on families	• Increase training for early recognition of ARFID symptoms among HCPs, especially those who come into frequent contact with younger children (e.g., Health Visitors)
	• Diagnostic overshadowing and overlooked symptoms	• Diagnostic overshadowing can cause misdiagnosis or no diagnosis	• Develop aids to support HCPs in differentiating ARFID from other conditions. • Promote awareness among HCPs of the harms of diagnostic overshadowing
	• Professional dismissal and lack of understanding	• Lack of understanding can lead to frustration and helplessness among parents	• Promote awareness and education programmes about ARFID for HCPs

Master Themes	Subtheme	Implications	Recommendations
	• Emotional toll of early struggles	• Lack of understanding can lead to frustration and helplessness among parents	• Provide support resources and counselling for families during the diagnostic process • Ask parents about their wellbeing during all contact and signpost to support
2. The Merry-Go-Round of Navigating ARFID Care	• Navigating a pathway, what pathway?	• Frustration and confusion due to lack of clear care pathways	• Establish clear and consistent care pathways for ARFID
	• Guinea pigs and pioneers	• Families may experience trial-and-error treatments, leading to inconsistent care	• Develop standardised treatment protocols for ARFID, but avoid generalising. Recognise the heterogeneity of ARFID and thus the importance of being formulation led as opposed to diagnosis led.

Master Themes	Subtheme	Implications	Recommendations
	• Jumping through hoops, confronting rejection and enduring delays	• Delays in receiving appropriate care can exacerbate ARFID symptoms	• Streamline referral and treatment processes to reduce delays
	• Manoeuvring an obstacle race while your child deteriorates	• Lack of care-coordination and joint-up ARFID care means that patients can fall between the gaps of services. This has health implications and can lead to hospitalisations and also is an additional source of stress for parents	• Referrers should maintain clinical oversight, including physical health monitoring, while awaiting further support from specialist services
	• Confronting power differentials and engaging in the interpersonal dance with HCPs	• Power imbalances can hinder effective communication and advocacy	• Train HCPs on collaborative and empathetic communication technique • Be aware of power differentials and remember to bring a dose of kindness to ARFID by listening to parents and maintaining humility around expertise.

Master Themes	Subtheme	Implications	Recommendations
3. Harnessing the Power of a Diagnosis	• Validation through diagnosis	• Diagnosis provides validation and relief, helping some families understand and address their child's needs	• Ensure timely and accurate diagnosis to support families effectively • Recognise the validation and empowerment that a diagnosis can provide to families. • In instances where a diagnosis is not provided, ensure that this is communicated with sensitivity and accompanied by adequate support and resources to help families navigate their child's challenges without feeling dismissed or invalidated.
	• Empowerment through diagnosis	Diagnosis empowers families to advocate more effectively for their child's care	• Provide resources and support for families post-diagnosis

Master Themes	Subtheme	Implications	Recommendations
	• Opening Doors and Access to Resources	• Receiving a diagnosis can significantly open doors for families, providing access to necessary resources, services, and support systems that might otherwise be unavailable. This underscores the critical role of timely and accurate diagnoses and highlights a barrier to support for those unable to obtain a diagnosis • The disparity between NHS and private diagnoses can impact the timeliness of care received and waste resources by re-confirming private diagnose	• Advocate for policies and practices that ensure all families, regardless of whether a diagnosis is confirmed, have access to necessary resources and support services. This includes providing clear information, referral pathways, and consistent follow-up to help families navigate the healthcare system effectively • Increasing funding, reducing wait times, and improving diagnostic processes within the NHS will reduce the need for private diagnoses

Master Themes	Subtheme	Implications	Recommendations
			• Support should not be contingent on whether a diagnosis was provided via the NHS or private HCPs
4. Professional Advice and Interventions: A Double-Edged Sword	• Positive experiences and neuro-affirming approaches	• Positive, informed advice can significantly improve child outcomes	• Promote neuro-affirming training and education for HCPs
	• Negative experiences and lack of Autism-informed care	• Negative or uninformed advice can harm the child and increase parental stress	• Implement mandatory Autism-informed training for HCPs
5. Life-Saving Decisions and Ongoing Struggles: The Enteral Nutrition Experience	• Encountering professional reluctance to enteral nutrition	• Reluctance can delay critical nutrition support	• Create spaces for reflective practice to enable HCPs to speak with peers on the dilemmas that arise when making decisions about enteral nutrition
	• Transformation through enteral nutrition	• Enteral nutrition can be lifesaving but comes with its own set of struggles	• Provide support and guidance for families considering or undergoing long-term enteral nutrition

Master Themes	Subtheme	Implications	Recommendations
	• Enteral nutrition: lifesaving yet laden with struggles	• Families face ongoing challenges managing enteral nutrition at home	• Develop robust follow-up and support systems for families using enteral nutrition. Including an exit strategy when starting enteral nutrition • Be proactive in considering care needs when eternal nutrition is ongoing and consider trauma-informed approaches to improve tube change experiences
6. The Emotional Undercurrent: Navigating the Psychological and Emotional Challenges	• Hope and hopelessness	• Emotional fluctuations can impact the mental health of both the child and family	• Offer psychological support for families and signpost to appropriate services. • Consider whether it is appropriate to conduct a carers assessment to support the family
	• Loneliness and lack of support	• Isolation and lack of support can exacerbate stress and anxiety	• Establish support groups and community resources for families.

Master Themes	Subtheme	Implications	Recommendations
			• During all contact with family members, assess their wellbeing and signpost accordingly
	• Fear and desperation	• Persistent fear and desperation can lead to burnout among parents	• Provide accessible mental health support and resources. • Use trauma-informed approaches when working with families who may have had traumatic experiences
	• Guilt, regret, and shame	• Negative emotions can impact parental well-being and their ability to care for their child	• Establish support groups and community resources for families that focus on the experience of parenting a child with ARFID and attend to the difficult emotions that arise. • Be mindful of perpetuating harmful messaging that can reinforce feelings of

Master Themes	Subtheme	Implications	Recommendations
			guilt, shame, and regret and cognisant of the socio-political landscape surrounding eating and feeding.

Chapter Six: Discussion

6.1 Overview

The primary aim of this study was to explore the journey parents of children with ARFID undertake in seeking a diagnosis and accessing treatment. Additionally, the study aimed to improve healthcare access for these children and their families by identifying gaps, opportunities, and shortcomings in the current healthcare system. This chapter thematically integrates findings, addressing issues parents encountered along their healthcare journey. Towards the end of the chapter, limitations, strengths, implications, and recommendations are detailed (Tables 41 and 42).

6.1.1 Widespread Lack of Awareness

The literature review revealed a pervasive gap in HCPs' awareness and confidence in understanding ARFID (Dinkler et al., 2023; Harrison, 2021; Jackson et al., 2022; Seike et al., 2016). This finding was echoed in the qualitative accounts of mothers of Autistic children with ARFID, who frequently described frustrating encounters with HCPs due to a fundamental lack of understanding of ARFID. Mothers often had to educate HCPs about ARFID, hoping they would be listened to. Unfortunately, mothers reported being dismissed and disbelieved.

In a persuasive commentary, Bryant-Waugh (2020) emphasised the need for HCPs to remain open to learning, especially with conditions that are not fully understood, HCPs' knowledge base could be enriched by respecting the expertise of mothers and their valuable intimate

insights. This is particularly pertinent considering the judgement and shame often associated with mothering (Jackson & Mannix, 2004) and feeding (Knapp, 2021), which were echoed in the accounts shared. Where knowledge voids exist, personal values and judgements can influence care, potentially perpetuating harmful societal messages (Thomson et al., 2015).

The review also highlighted that many HCPs lack formal training and experience (Dinkler et al., 2023; Magel et al., 2021). In the current study, the absence of appropriate training was also considered a contributing factor to misdiagnosis or delayed diagnosis, as well as adversely affecting the timely and appropriate care that families received. Mothers reported that some HCPs were willing to acknowledge their lack of, or limited awareness of ARFID and to learn alongside them. The mothers in our study appreciated this and hoped it would contribute towards better experience for future families. This willingness to learn was better received than being offered generic advice, compounding frustration when specialists, who were expected to be more knowledgeable, proved to be just as uninformed as primary care providers (Young et al., 2024).

Given the widespread lack of awareness of ARFID among HCPs globally and its significant clinical implications, all studies highlighted the urgent need for targeted education and awareness initiatives. In the current study, while mothers understood that it was unrealistic for every HCP to be familiar with all conditions, they felt that certain professionals, particularly Dietitians, should have a better awareness and understanding of ARFID. This expectation was consistently unmet, adding to the frustration of navigating the medical system and the additional responsibility of educating HCPs.

6.1.2 HCPs' Approach and Interactions with Mothers

In addition to the lack of awareness, the approach, and interactions of HCPs with mothers of children with ARFID were also found to be challenging. Instead of approaching interactions with humility and curiosity, HCPs' dismissive attitudes often invalidated mothers' concerns, deepening their mistrust and frustration with the healthcare system. This dismissive attitude was especially detrimental given the judgement and shame often associated with mothering and feeding practices more generally (Jackson & Mannix, 2004; Knapp, 2021) and in relation to ARFID (LaMarre et al., 2023; Young et al., 2024).

Mothers' experiences highlighted how their identity is strongly tied to their role as feeders. Zivkovic et al. (2010) noted that morally responsible mothers are expected to prioritise their children's health and wellbeing, starting from pregnancy. This responsibility extends as children grow, where mothers are entangled in societal norms and expectations, and their child's body becomes a visible metric of their ability to feed and care for them (Elliott & Bowen, 2018). Mothers internalise these societal expectations (Ristovski-Slijepcevic et al., 2010) and confront judgement and condemnation in interactions with HCPs, leading to feelings of shame, guilt, inadequacy, and isolation. The politicisation of children's diets and the intertwining of maternal identity with feeding practices mean that the challenges faced by mothers, especially those with children with chronic conditions like ARFID, are exacerbated (Tabatabai, 2020).Taking this socio-political context into account and maternal narratives, the findings underscore the critical need for HCPs to adopt a more empathetic and informed approach. By approaching interactions with humility, respect, and kindness, HCPs can significantly improve the experiences of families dealing with ARFID (Bryant-Waugh, 2020).

6.1.3 Diagnostic Overshadowing

The systematic literature review revealed significant challenges that HCPs face in identifying and diagnosing ARFID (Coelho et al., 2021; Dinkler et al., 2023; Harrison, 2021; Katzman et al., 2014; Magel et al., 2021) differentiating ARFID from common co-occurring conditions such as selective eating and normative picky eating, due to their overlapping presentations (Desalesa & Mejía-Buenaño, 2024).

Diagnostic overshadowing often leads to delays in appropriate care being provided. It also highlights the lack of specific training and awareness among HCPs regarding the nuances of ARFID, particularly in the context of Autism due to an overlap in presentation; rigid obsessive, or repetitive behaviours and sensory sensitivities (Magel et al., 2021). ARFID and Autism often coexist (Farag et al., 2022; Koomar et al., 2021); therefore, diagnostic overshadowing significantly hampers the diagnostic process for ARFID.

Mothers in our study perceived HCPs' reluctance to diagnose ARFID in their Autistic children as causing unnecessary delays and being a source of profound frustration. They felt that HCPs dismissed their insights, not recognising that they had intimate knowledge and experience navigating both the Autism and eating disorder spectrums. These mothers spoke of the fear and worry that uniquely characterises ARFID. While Autism and picky eating presented challenges, there were feasible workarounds. However, with ARFID, mothers felt this was not the case, solidifying their conviction that their child's presentation was clinical. Despite maternal confidence, HCPs often dismissed these observations, which further delayed the diagnosis and appropriate intervention for their children.

Findings from the survey further indicated that a significant majority (83%) of children with ARFID symptoms were identified as neurodivergent, with 47% of the sample having a formal Autism diagnosis. Among those diagnosed as neurodivergent, a majority (75.2%) received their diagnosis prior to their ARFID assessment, highlighting the importance of Autism not overshadowing ARFID. Notably, 65.6% of diagnosed Autistic children also had an ARFID diagnosis (p = .034), but a substantial portion of Autistic children (51.3%) had not been assessed for despite exhibiting symptoms. When considered alongside Jasmine's comment that parents have begun advising one another not to seek an Autism diagnosis due to fear it might hinder their chances of getting help for ARFID, it becomes evident that diagnostic overshadowing and dismissal of symptoms are significant barriers to appropriate care. To prevent perpetuating this perception and in line with best practices, HCPs should clearly explain why an ARFID diagnosis is not given, particularly in cases where Autism is comorbid and there is a risk of perceived diagnostic overshadowing if the decision is not explicitly communicated.

Desalesa and Mejía-Buenaño (2024) emphasise that the overlapping symptoms of ARFID and Autism require a nuanced understanding and approach, which is often lacking in current healthcare practices. Importantly, they also found that parents of children with intellectual and developmental disabilities reported similar issues with diagnostic overshadowing, further complicating efforts to secure appropriate ARFID care. This situation calls for a more integrated and informed approach to diagnosing ARFID, one that acknowledges the complex interplay of co-occurring conditions and values the insights of caregivers.

6.1.4 Diagnostic challenges

The recent updates to diagnostic manuals, such as the DSM-5-TR (APA, 2022) and ICD-11 (World Health Organization, 2019), aim to improve the accuracy of ARFID diagnoses by recognising the variety of ways ARFID can manifest. However, the lack of familiarity with these updates among HCPs continues to pose a significant barrier (Claudino et al., 2019; Harshman et al., 2021). For example, Coelho et al. (2021) found ambiguity in HCPs' judgement in relation to ARFID presentations with psychosocial impairment as the sole impact, not always recognising that this was sufficient to meet the diagnostic criteria.

Furthermore, when assessing a person for ARFID, HCPs must consider and rule out other medical and mental health conditions that could explain their symptoms. For example, some children were initially diagnosed with other eating disorders before receiving an ARFID diagnosis. Our survey study revealed that the most prevalent initial diagnoses among these children were EDNOS and OSFED. This trend aligns with the findings of Claudino et al. (2019), which showed that the introduction of ARFID in the ICD-11 has led to a decrease in the number of individuals diagnosed with residual eating disorders.

Taken together our findings highlight that the challenge of distinguishing ARFID from other eating disorders can lead to misdiagnosis or delayed diagnosis. This demonstrates the need for enhanced training and widespread dissemination of the updated diagnostic criteria are essential to reduce these diagnostic challenges and ensure timely and accurate identification of ARFID.

6.1.5 Referral Pathways and Lack of Care Coordination

The literature review also highlighted lack of clear referral pathways and multidisciplinary collaboration as significant barriers in the diagnosis and treatment of ARFID (Jackson et al., 2022; Magel et al., 2021). HCPs report confusion about the availability of services, and referral processes, compounded by stringent specialist service exclusion criteria and commissioning gaps (Harrison, 2021). These issues resulted in rejected referrals, particularly for children with Autism, leaving patients without any structured support (Harrison, 2021).

Survey findings further support this narrative of a lack of clear direction and revealed low parental satisfaction with NHS care processes. The mothers expanded on this narrative, describing the process as a merry-go-round to capture the dizzying feeling of constant movement but little to no progress. Additionally, navigating the system often felt like an obstacle race, requiring parents to jump through hoops to gain access to support.

Maternal accounts also mirror previous findings revealing challenges in care coordination (Desalesa and Mejía-Buenaño (2024). Unfortunately, these experiences erode trust in the system, highlighting both the individual and systemic barriers in access to assessment and treatment, limited services and referral pathways. This dual burden meant that mothers had to navigate not only the reluctance or inability of individual HCPs to provide appropriate care but also the broader, entrenched issues within the healthcare system.

The systemic barriers were characterised by inadequate training and awareness among HCPs about ARFID, leading to miscommunication and inconsistent care. The absence of established referral pathways and the limited availability of specialised treatment services compounded these challenges, leaving HCPs with few options to offer besides referrals. Survey findings indicated that parents who first raised concerns with a specialist professional experienced shorter overall diagnostic delay than those who first raised concerns with a primary care professional. Children whose parents initially consulted a specialist experienced overall diagnostic delays (from the onset of symptoms to age at diagnosis) of approximately 60.73 months, whereas those who consulted primary care professionals faced delays averaging 90.83 months. Insights from interviews in this study, along with other qualitative research, suggest that part of this delay may be linked to the additional burden placed on mothers to identify appropriate referral sources and advocate persistently for their child's needs (Harrison, 2021; Jackson et al., 2022). However, some of this delay might be attributed to help-seeking delays.

Ultimately, these barriers created a situation where even well-meaning HCPs found themselves helpless, unable to navigate the fragmented and under-resourced system to secure timely and appropriate care for their patients. The necessity for mothers to persistently chase and advocate for their child's needs ultimately led to feelings of exhaustion and deflation. The lack of clear pathways further hampered their efforts and left them feeling overwhelmed, a sentiment echoed in LaMarre et al. (2023), who noted the unrecognised labour that parents undertake when navigating the healthcare system. Shared sentiments are reported in the literature, parents reporting hope and promise of care to rarely materialise with no clear

pathway to care for ARFID (Desalesa & Mejía-Buenaño, 2024; LaMarre et al., 2023; Young et al., 2024).

Considering the lack of established care pathways for ARFID (Bryant-Waugh et al., 2021), it was understandable that mothers felt like guinea pigs and pioneers, forging new paths through the healthcare system. They expressed hope that their struggles would pave the way for improvements, leaving a trail of changes that might benefit others in the future. This hope was echoed by parents in Desalesa and Mejía-Buenaño (2024). Mothers encountered resistance as they had to force and fight their way through the system, often to their own detriment, an issue compounded by inadequate support and resources as highlighted by Harrison (2021).

The complexity of ARFID and its common comorbidities further complicated the journey to diagnosis and support. Despite, not being the focus of this study, it was noted that mothers spoke of the many challenges they also encountered in their journey towards an Autism diagnosis, fighting parallel and simultaneous battles. Desalesa and Mejía-Buenaño (2024) emphasised that diagnostic overshadowing was a significant issue not only for Autism but also for intellectual and developmental disabilities, further complicating efforts to secure appropriate ARFID care. It also provided some context to show just how difficult it was to gain a diagnosis of ARFID. For example, many felt for many ARFID was a harsher journey, by the very nature of having to navigate without a map, being dismissed or not believed. The absence of national guidelines and the emerging nature of ARFID research contribute to varied care provision and early intervention challenges. Furthermore, the systematic review underscored the need for increased awareness and understanding among HCPs, emphasising how these

gaps lead to miscommunication and inconsistent care. These factors collectively underscore the systemic nature of the issues faced in the referral pathways and care coordination for ARFID.

The need for multidisciplinary collaboration and clear referral pathways was evident in the systematic review findings (Jackson et al., 2022; Magel et al., 2021), aligning with mothers' qualitative accounts of feeling like their child was a 'hot potato' no one wanted to catch. This was likely due to inadequate support and resources, with HCPs abdicating responsibility to another professional they hoped would be better equipped to help, thus mirroring the experiences of the families they are trying to help.

6.1.6 Impact on Children

Existing literature highlights the severe physical health complications associated with ARFID, such as electrolyte imbalances and dependence on enteral nutrition, which align with these findings (Nitsch et al., 2021). The survey data revealed that certain ARFID symptoms and clinical presentations correlated with parent-reported child distress. Namely, sensory-based fluid restriction ($p < 0.01$) and experiencing significant nutritional deficiencies ($p < 0.01$). These factors relate to physiological issues—specifically, dehydration and a myriad of symptoms related to nutritional deficiencies, and highlights the importance of considering fluid intake, not just food intake, when assessing and addressing ARFID.

The significant impact of nutritional deficiencies and fluid restriction on their children’s health, also featured in the maternal accounts. For example, several children experienced severe

consequences such as dehydration and required medical interventions including enteral feeding. Additionally, the impact of hospital stays, and medical interventions were particularly profound and distressing as hospitals can be a challenging environment for Autistic children due to heightened sensory sensitivities (Muskat et al., 2015). This underscores the critical need for healthcare environments to be adapted to the sensory needs of these children to mitigate additional stress and trauma, further complicating their eating difficulties (Thom et al., 2020).

A few mothers shared that their child had been hospitalised repeatedly due to dehydration, and another described the long-term use of enteral nutrition as both a critical and painfully traumatic part of her child's treatment. This algins with research documenting the reliance on hospitalisation for medical stabilisation as well as enteral nutrition in ARFID (Sharp et al., 2017). Within the survey component, 10% of the sample reported eternal nutrition, with higher rates among those diagnosed with ARFID (18%) and neurodivergent children (16%).

Although this study did not focus on children's experiences of ARFID, mothers made reference to how ARFID limits quality of life for their children, detailing pain, fatigue, and social isolation. In one case, a child was suicidal due to their ARFID, emphasising the severe psychological impact of this condition. Currently, the only study reporting the prevalence of suicidality in ARFID suggests current and lifetime prevalence rates of 9% and 13%, respectively (Kambanis et al., 2020). As this study included threshold and subthreshold children and adolescents with ARFID, it is possible that the rate is higher among treatment-seeking populations. It is also important to note that the suicidal prevalence of Autistic children is one in four (O'halloran et al., 2022) suggesting the true figure may be even higher in this population. More about the

lived experiences of children with ARFID can be found in Doleman (2023), who highlights the complex interplay between ARFID and mental health issues, including significant distress and social isolation.

A systematic review by Sanchez-Cerezo et al. (2023) exploring the epidemiology of ARFID in children and adolescents found that psychiatric comorbidity was common, notably anxiety disorders (9.1% to 72%) and Autism (8.2% to 54.75%). In line with these findings, children diagnosed with ARFID in our study were more likely to have a psychiatric comorbidity (64%) than children who were not assessed or not diagnosed, reflecting the significant challenges faced by this population. Our findings align with Kambanis et al. (2020), who found that 45% of their sample of children and adolescents with ARFID met criteria for a current comorbid psychiatric diagnosis, increasing to 53% when considering lifetime comorbid diagnoses. In clinical samples, these rates are even higher, with studies reporting comorbidity rates as high as 95% (Bryson et al., 2017). Moreover, there was a significant association between anxiety and ARFID diagnosis ($p < 0.001$), with children diagnosed with ARFID being more likely to also be diagnosed with anxiety.

Alongside battles to secure ARFID care, parents also reported struggling to get their child's Autism diagnosed and to access appropriate mental health services for psychiatric comorbidities. Jackson et al. (2020) illustrate how mothers of children with Autism and comorbid mental health conditions often faced significant barriers in accessing mental health services, leading to feelings of isolation, self-blame, and powerlessness. This struggle was compounded by the need for continuous advocacy to secure necessary support, often at the

expense of their own mental health. These experiences parallel those of the mothers in our study, who had to contend with ARFID and secure appropriate support.

6.1.7 Impact on Parents

Survey findings revealed a significant association between a child's eating difficulties impacting their life and well-being and the well-being of their family ($p < 0.01$). Although no specific clinical presentation factors were found to significantly correlate with the impact on family well-being, clearer underlying factors between ARFID and impact on well-being emerged from the mothers' qualitative accounts. For example, mothers reported significant emotional strain due to the constant need to manage their child's dietary restrictions and medical needs. The lack of clear guidance and support from HCPs exacerbated these challenges, leaving many parents feeling overwhelmed and isolated (LaMarre et al., 2023).

As stated above, this referral merry-go-round and the constant obstacles and delays experienced by mothers left many mothers feeling exhausted, disheartened, and afraid. The psychological impact of their caregiving responsibilities was profound, with several mothers reporting resultant symptoms of anxiety and depression as well as experiencing trauma and fear. The emotional toll was characterised by feelings of guilt, regret, and shame, as they continually battled the system to get the necessary care for their children. Mothers were fatigued from constantly having to be vigilant and proactive in seeking help, often without success. They often felt that no one was taking responsibility for their child's care, thus leaving them to drive things forward. The obstacle race was further heightened due to their child often deteriorating in front of their eyes, compounding a sense of desperation.

6.1.8 Impact on HCPs

The systematic review underscored the challenges HCPs face, including limited awareness and lack of training and experience in diagnosing and treating ARFID, which naturally resulted in a lack of confidence as well as feelings of frustration (Dinkler et al., 2023). This lack of preparedness can result in misdiagnoses or delayed diagnoses, further complicating the care pathway for children with ARFID (Harrison, 2021). HCPs were aware of these issues, which increased the pressure to make the right call. These findings resonated with the observations from mothers, who at times commented on the tangible stress and frustration of the HCPs involved in their children's care.

Mothers' interviews provided additional context to these professional struggles. One mother described feeling the palpable fear among the HCPs involved in treating her son and their uncertainty about how to proceed with her child's care. Another recounted the frustration of her GP whose repeated referrals had been rejected, leaving both the HCPs and the family feeling stuck. This sense of professional helplessness was echoed in other accounts, highlighting the impact of systemic shortcomings on both families and HCPs (Magel et al., 2021). Considering the findings of the systematic review, it appears this was likely due to inadequate support and resources, with HCPs abdicating responsibility to another professional they hoped would be better equipped to help. This mirrored the desperation and feeling of being beyond one's depth experienced by the families they were trying to help. For instance, in Jasmine's case, her GP referred her son Jeremy to CAMHS due to his refusal to eat, but the referral led to a long wait time and an inappropriate initial assessment. The GP, feeling helpless, continued to make referrals but failed to monitor Jeremy's risk adequately, leaving Jasmine to

navigate the crisis largely on her own. The GP's sense of helplessness may have immobilised them, doing little within the realm of their control and duty, instead hoping that the referral would be picked up by another professional who would take responsibility.

The theme of professional reluctance towards enteral nutrition also emerged. A mother who was also an HCP noted the dilemmas faced by fellow medical professionals, experiencing a reluctance to give a child a psychiatric label or to initiate physical interventions for what is considered a psychiatric condition. While she understood the plight, it became less of a dilemma when situating the decision within the context of life or death. These experiences provided insights into the dilemmas HCPs faced as they too tried to navigate ARFID care. Research more generally on barriers to enteral nutrition in children notes lack of education and training on optimal feeding as a global barrier alongside service provision challenges (Tume et al., 2020).

Additionally, the review highlighted instances where HCPs felt a duty of care to deliver treatment outside the realm of their expertise and training, driven by a sense of desperation (Magel et al., 2021). This often resulted from systemic shortcomings and a lack of specialised resources, further illustrating the broader context of professional struggles and the parallel desperation faced by HCPs and families alike. Importantly, many mothers expressed empathy for HCPs, recognising their limited training and the systemic challenges they faced.

6.1.9 Parental Advocacy

Qualitative data from mothers' interviews provided deep insights into the realities of parental involvement and the necessity for advocacy. Mothers described their experiences as a continuous battle, where they had to be persistent and proactive to secure appropriate care for their children. This advocacy often involved extensive research, numerous phone calls, attending multiple appointments, and educating professionals and their loved ones about ARFID.

The interviews also highlighted the emotional toll of advocacy. Mothers described feelings of exhaustion, frustration, and isolation as they navigated the healthcare system. The need to constantly fight for their child's needs left many feeling overwhelmed and unsupported. Despite these challenges, mothers expressed a strong sense of duty and determination to continue advocating for their children, driven by the hope of securing better outcomes. This aligns with findings from Boshoff et al. (2019), who described parental advocacy as a persistent and often exhausting effort, yet a crucial coping strategy adopted by parents of Autistic children. Moreover, they found that parental advocacy was often described as a life-long, all-encompassing challenge, with parents needing to continually anticipate the next course of action to ensure their child receives the most appropriate and timely treatment. This mirrors the experiences of mothers in this study who not only had to advocate for their child's Autism but also for their ARFID.

Furthermore, the interviews revealed significant concerns about unequal systems and the impact on children whose parents are unable to advocate effectively. For example, Smith-Young et al. (2022), found that parents often faced significant challenges due to socioeconomic constraints and cultural differences, impacting their ability to effectively advocate for their children. The mothers in our study reflected on the challenges of confronting power differentials within the healthcare system. They described the necessity of engaging in an interpersonal dance with HCPs, balancing assertiveness with diplomacy to avoid being dismissed as overly demanding. This often required becoming comfortable with being perceived as 'that mum'—one who challenges doctors and insists on appropriate care—despite it going against social conditioning to defer to medical authority (Boshoff et al., 2019; Smith-Young et al., 2022).

Mothers also expressed concerns about the disparities in care for children whose parents might lack the resources, knowledge, or confidence to advocate effectively. The system's complexity and the need to continually challenge HCPs highlighted the critical disadvantage faced by children without strong parental advocates. This underscores the need for systemic changes to ensure all children receive appropriate care, regardless of their parents' ability to navigate the healthcare system.

6.1.10 Interventions and Treatment Approaches

The systematic literature review provided an overview of current intervention and treatment approaches for ARFID, highlighting that while there are emerging treatment protocols, there remains a significant lack of standardised guidelines. Treatments ranged from behavioural interventions to more intensive approaches such as enteral feeding for severe cases. However, the effectiveness and availability of these treatments can vary widely, leading to inconsistent care experiences for families.

Survey findings revealed that overall parental satisfaction with the availability of NHS treatment options was low, reflecting the broader challenges identified in the literature. Qualitative data from mothers' interviews also reported frustrations with the lack of tailored interventions and the variability in care quality across different regions and services. Many mothers felt that the treatments offered did not adequately address the specific needs of their children, particularly their Autism.

While some mothers shared positive experiences with specific interventions, often regarding their child's mental health or advice from private professionals, these positive outcomes were frequently overshadowed by numerous negative experiences within the NHS and ARFID care. Mothers frequently described the treatments as one-size-fits-all, lacking in personalisation and sensitivity to their child's unique needs. The theme of professional reluctance to initiate more intensive interventions, such as enteral feeding, was recurrent. One mother recounted the delays and resistance faced before her child was finally started on enteral nutrition, which ultimately proved lifesaving.

The qualitative data and systematic review both highlighted the importance of a multidisciplinary approach. For example, mothers' interviews emphasised the need for coordinated care involving Dietitians, Psychologists, and other Specialists to address the multifaceted nature of ARFID. The absence of such coordinated care often led to fragmented and ineffective treatment, further exacerbating the stress and burden on families.

6.2 Limitations and Strengths

Limitations and Strengths are presented in Table 41.

6.3 Implications and Recommendations

Implications and Recommendations are presented in Table 42.

Table 41 Study Limitations and Strengths

	Study Limitations
Sample Size	The sample size for the qualitative study was relatively small. However, it was appropriate for IPA, which focuses on in-depth exploration of individual experiences (Larkin et al., 2021).
Wide Age Range	One of the limitations of this study is the wide age range of survey participants, from 5 months to 28 years, which introduces variability in diagnostic history and ARFID symptom presentation. Older children are more likely to have accumulated multiple diagnoses over time, potentially skewing the data and complicating comparisons between age groups. Additionally, help-seeking experiences may differ over time due to the introduction of ARFID as a diagnostic label, evolving awareness, and the creation of pathways and treatments. Future research would benefit from accounting for temporal and developmental differences or focusing on a narrower age range. Within the qualitative study, the age range was smaller (8-14 years, 5-14 if including additional data about younger siblings with ARFID).
Self-Report Data	The reliance on self-report data, including diagnoses, introduces the potential for bias and inaccuracies. Additionally, there was no verification of diagnostic status reported by participants, and there was evidence of double reporting with suspected conditions and conditions awaiting assessment. This could affect the accuracy and objectivity of the data collected.

	Furthermore, despite instructions to report professionally verified diagnoses, some parental diagnoses may have been included.
Cross-Sectional Design	The cross-sectional design of the survey captures a snapshot of experiences at a single point in time. This approach does not account for changes and developments over time, which could be significant in understanding the evolving nature of ARFID diagnosis and treatment. Longitudinal studies would be beneficial to capture these dynamics and provide a more comprehensive understanding of the journey parents undergo.
Not Using Standardised Measures	The study did not use standardised measures, instead employing statements related to different aspects of the diagnostic criteria. While this approach allowed for a detailed exploration of specific aspects of ARFID symptomatology, it limits comparison with other studies. Additionally, the checklist omitted low appetite as a factor influencing food choices, which could have provided further insights into ARFID drivers.
White, Educated and Predominantly Mothers	Despite efforts to increase diverse engagement with the study, the sample is predominantly white, educated and female. Future research would benefit from exploring whether experiences differ based on these factors. Considering the key role parental advocacy played in the healthcare journey, it is expected that race, socioeconomics (Smith-Young et al., 2022), and parental gender (Docherty & Dimond, 2018) would shape parental experiences.

Study Strengths	
High Statistical Power	This study achieved high statistical power, confirmed through post-hoc power analyses using G*Power. The results indicated robust findings: • ANOVA: With a sample size of 437 participants, the study achieved a power of 0.998, far exceeding the commonly accepted threshold of 0.80. • Chi-Square: The post-hoc power analysis for the chi-square test indicated a power of 0.9997914.
Mixed-Methods Design	This mixed-methods approach allowed for a comprehensive view of the research problem, enhancing both the breadth and depth of the findings. By combining the statistical power of quantitative data with the rich, narrative power of qualitative data, the study effectively captures both the prevalence and the personal experiences of ARFID, providing a well-rounded understanding of the issues. Additionally, the triangulation of perspectives (Denzin, 2017)—gathering data from a systematic review of HCPs and interviews with mothers—provides a contextual backdrop for the reported experiences. The corroboration of insights from both HCPs and mothers, where the same stories and challenges are echoed, further strengthens the findings by confirming the consistency and reliability of the data from multiple viewpoints (Brannen, 2005).

Real-World Application	The pragmatic approach to research ensured that the study's design and methodology were closely aligned with real-world contexts and needs, enhancing the applicability and impact of the findings.
EbE Consultation	The inclusion of consultations with mothers of children with ARFID and HCPs with ARFID expertise added significant value to the study. Their insights ensured that the research was grounded in the lived experiences of those directly affected by ARFID and the reality of the healthcare system, enhancing the relevance of the findings and recommendations.

Table 42 Project findings, implications, and recommendations

Key Findings	Implications	Recommendations for Research	Recommendations for Clinical Practice
Awareness and Training of HCPs	• Significant gap in awareness and training among HCPs leads to misdiagnosis or delayed diagnosis, adversely affecting timely and appropriate care for families. • Lack of specialised knowledge results in inadequate advice and ineffective interventions, causing frustration and deterioration in child's condition.	• Investigate effective training programs for HCPs on ARFID. • Study the impact of improved training on diagnostic accuracy and patient outcomes.	• Implement continuous professional development programs for HCPs on ARFID. • Provide accessible resources and guidelines on ARFID for HCPs.

Key Findings	Implications	Recommendations for Research	Recommendations for Clinical Practice
Diagnostic Challenges and Overshadowing	• Difficulties in distinguishing ARFID from other disorders due to overlapping symptoms. • Heavy reliance on clinical judgment due to lack of validated assessment tools. • Neurodivergent children diagnosed with ARFID later than others, reflecting significant diagnostic delays. • Risk of diagnostic overshadowing where Autism is comorbid, potentially leading to under-recognition of ARFID symptoms.	• Develop validated assessment tools for ARFID. • Research the diagnostic process for neurodivergent children with ARFID to identify specific barriers and facilitators. • Investigate strategies to prevent diagnostic overshadowing in cases of comorbid Autism and ARFID.	• Improve training on differential diagnosis for ARFID. • Ensure HCPs are familiar with updated diagnostic manuals and criteria. • Clearly communicate the rationale behind diagnostic decisions, particularly when an ARFID diagnosis is not given in cases where Autism is comorbid, to address potential diagnostic overshadowing and alleviate concerns of discrimination.

Key Findings	Implications	Recommendations for Research	Recommendations for Clinical Practice
Referral Pathways and Care Coordination	• Lack of clear referral pathways and multidisciplinary collaboration. • Rejected referrals particularly for children with Autism, leading to prolonged diagnostic delays. • HCPs and families navigate the system without clear guidance.	• Evaluate the effectiveness of different referral pathways. • Study the impact of multidisciplinary teams on ARFID care outcomes.	• Establish clear and consistent referral pathways for ARFID. • Promote multidisciplinary collaboration and communication among HCPs. • Assign care-coordinator for all ARFID cases and be proactive as opposed to responsive.
Impact on the Child	• ARFID symptoms correlated with significant child distress, particularly sensory-based fluid restriction and nutritional deficiencies. • Severe physical health complications such as dehydration and dependence on enteral nutrition.	• Research interventions targeting fluid intake issues in ARFID. • Study the long-term health outcomes of children with severe nutritional deficiencies.	• Integrate fluid intake assessment into ARFID diagnostic criteria. • Adapt healthcare environments to accommodate sensory needs of children with ARFID.

Key Findings	Implications	Recommendations for Research	Recommendations for Clinical Practice
Impact on the Parents	• Direct relationship between child's eating difficulties and family's well-being. • Significant emotional and psychological strain on parents. • Feelings of isolation, guilt, frustration, and mental health challenges among mothers.	• Investigate the psychological impact of ARFID on families. • Study interventions to support parental mental health and well-being. • Research protective factors that can buffer against stress associated with ARFID care and the help-seeking journey.	• Provide psychological support services for families of children with ARFID. • Educate HCPs on the emotional and psychological impact of ARFID on families. • HCPs should assess parental wellbeing and consider if a carers assessment is necessary or referral for parent-specific support.

Key Findings	Implications	Recommendations for Research	Recommendations for Clinical Practice
Impact on HCPs	• HCPs experience frustration, helplessness, and emotional toll due to lack of training and resources. • Professional reluctance to initiate intensive interventions like enteral nutrition.	• Study the emotional and psychological impact of treating ARFID on HCPs. • Develop strategies to support HCPs in managing ARFID cases. • Research HCPs experience of enteral nutrition decision-making for ARFID.	• Offer training and resources to help HCPs better manage treating ARFID. • Encourage a supportive work environment that acknowledges the challenges of ARFID cases and reflective practice spaces. • Increase access to group supervision and clinical case consultations with ARFID experts to support dissemination of pertinent information.

Key Findings	Implications	Recommendations for Research	Recommendations for Clinical Practice
Interventions and Treatment Approaches	• Inconsistent treatment experiences and lack of standardised guidelines. • Frustration with one-size-fits-all approaches and lack of personalised care. • Need for multidisciplinary and coordinated care.	• Evaluate different treatment protocols for ARFID. • Study the impact of multidisciplinary care on treatment outcomes.	• Develop standardised treatment guidelines for ARFID, however, apply them flexibly. • Promote a personalised approach to treatment, considering the unique needs of each child and being formulation-led.
Parental Advocacy	• Continuous battle for parents to secure appropriate care. • Emotional toll of advocacy, feelings of exhaustion, frustration, and isolation. • Disparities in care for children whose parents lack resources or knowledge to advocate effectively.	• Study the impact of parental advocacy on healthcare access and outcomes.	• Provide resources and support for parents to advocate for their children in a way that is less labour intensive. • Ensure equitable access to care for all children, regardless of parental advocacy ability.

Concluding Remarks

The healthcare journey for parents of children with ARFID in England is fraught with challenges and systemic barriers. The findings illuminate the urgent need for targeted education and awareness initiatives to improve professional competence and confidence in managing ARFID throughout the healthcare system. Improving early identification of ARFID, establishing clear referral pathways, enhancing multidisciplinary collaboration, and further developing evidence-based treatments are crucial steps towards alleviating the burdens on parents and improving outcomes for children. Moreover, recognising the broader socio-political landscape and the politicisation of feeding practices is essential. While a dose of kindness is desperately needed towards parents who feel judged, shamed isolated, the review findings and corroboration by maternal accounts suggest that the same is true for HCPs, who also struggle within the same flawed system.

With the implementation of ICD-11 in England and the growing attention given to ARFID, we are poised to overcome the growing pains of recognising and treating this complex condition. The dedication and advocacy of families, alongside the committed efforts of HCPs, are paving the way for a brighter future.

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Appendix A – Language Considerations

Person-First vs. Identity-First

Disability language is personal and sensitive, with differing approaches permitted by the APA (American Psychological Association, 2020). Brown (2011) from the Autistic Self Advocacy Network wrote that Autism is *"an edifying and meaningful component of a person's identity, and it defines the ways in which an individual experiences and understands the world around him or her. It is all-pervasive"* (para 11). Autism is thus seen as integral to one's humanity, not something separate. Forbes (2020), an Autistic advocate, powerfully captures this sentiment: *"I am not a non-Autistic person first. I am an Autistic person. When others tell me I am a person first, it connotes a negative consideration of Autism. […] I am not a non-Autistic person with a side of Autism"* (lines 7, and 9). Research supports this preference. Keating et al. (2023) found a global preference for identity-first language. Similarly, Kenny et al. (2016) found a preference for identity-first language among Autistic adults, their families, and friends in the UK, though less so among professionals.

In relation to ARFID, nothing is known about language preferences. Therefore, to informally check consensus, parents from the closed Facebook group used to recruit for this project completed a short poll and a majority (83%, n = 233/280) preferred person-first language for ARFID. Thus, person first language is used, denoting that ARFID is viewed as a separate aspect of an individual's experience rather than an integral part of their identity. However, this may evolve with time, as it has with Autism.

Patient vs. Service User

There is also ongoing debate about appropriate terminology for individuals who utilise healthcare services (Keville, 2018). 'Patient' is used despite debate due to its passive connotations and roots in a biomedical approach. Costa et al. (2019) found that 'patient' was preferred among those who accessed services, recommending its use in research contexts. Alternatives like 'service user' and 'client' have faced criticism for implying agency not felt by individuals, especially within the NHS (Keville, 2018).

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Appendix B – PROSPERO Registration

Also available online:

https://www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42023447759

Systematic review

Please select one of the options below to edit your record. Either option will create a new version of the record - the existing version will remain unchanged.

A list of fields that can be edited in an update can be found here

1. * Review title. [1 change]

Give the title of the review in English

Clinicians' perspectives of perceived barriers and facilitators to diagnosis and treatment for Avoidant/Restrictive Food Intake Disorder (ARFID): A systematic review and narrative analysis

2. Original language title.

For reviews in languages other than English, give the title in the original language. This will be displayed with the English language title.

3. * Anticipated or actual start date. [1 change]

Give the date the systematic review started or is expected to start.

29/02/2024

4. * Anticipated completion date. [1 change]

Give the date by which the review is expected to be completed.

07/06/2024

5. * Stage of review at time of this submission. [1 change]

This field uses answers to initial screening questions. It cannot be edited until after registration.

Tick the boxes to show which review tasks have been started and which have been completed. Update this field each time any amendments are made to a published record.

The review has not yet started: No

Review stage Preliminary searches

Piloting of the study selection process
Formal screening of search results against eligibility criteria Data extraction

Started
Yes Yes

Yes Yes Yes Yes Yes Yes

Completed

Review stage
Risk of bias (quality) assessment

Data analysis

Provide any other relevant information about the stage of the review here.

6. * Named contact.

Started Completed Yes Yes

Yes Yes

The named contact is the guarantor for the accuracy of the information in the register record. This may be any member of the review team.

Sandra-Eve Bamigbade

Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:

Dr Bamigbade

7. * Named contact email.

Give the electronic email address of the named contact.

s.a.bamigbade@herts.ac.uk

8. Named contact address

PLEASE NOTE this information will be published in the PROSPERO record so please do not enter private information, i.e. personal home address Give the full institutional/organisational postal address for the named contact.

9. Named contact phone number.

Give the telephone number for the named contact, including international dialling code.

10. * Organisational affiliation of the review.

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University of Hertfordshire

Organisation web address:

https://www.herts.ac.uk/

11. * Review team members and their organisational affiliations.

Give the personal details and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.
NOTE: email and country now MUST be entered for each person, unless you are amending a published record.
PLEASE USE AN INSTITUTIONAL EMAIL ADDRESS IF POSSIBLE.

Dr Sandra-Eve Bamigbade. University of Hertfordshire Dr Amanda Ludlow. University of Hertfordshire

Dr Freya Cooper. Evelina London

12. * Funding sources/sponsors.

Details of the individuals, organizations, groups, companies or other legal entities who have funded or sponsored the review.

The first author is completing a doctorate in clinical psychology funded by Cambridgeshire and Peterborough NHS Foundation Trust. This review forms part of the course requirements.

Grant number(s)
State the funder, grant or award number and the date of award

13. * Conflicts of interest.

List actual or perceived conflicts of interest (financial or academic).

None

14. Collaborators.

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members. NOTE: email and country must be completed for each person, unless you are amending a published record.

15. * Review question. [1 change]

State the review question(s) clearly and precisely. It may be appropriate to break very broad questions down into a series of

related more specific questions. Questions may be framed or refined using PI(E)COS or similar where relevant.

This systematic review aims to identify and synthesise existing literature on clinicians' perspectives regarding barriers and facilitators to the diagnosis and treatment of Avoidant/Restrictive Food Intake Disorder (ARFID).

Research Questions:

What are clinicians' experiences of barriers and facilitators to diagnosis of ARFID?
What are clinicians' experiences of barriers and facilitators to the treatment of ARFID?
How do experiences differ among different types of clinicians (e.g., psychiatrists, paediatricians, psychologists)?
Do clinicians' experiences differ depending on patient characteristics such as age, gender, and co-occurring mental health conditions?
How does experience vary depending on the location of healthcare settings, and what lessons can be learned from this?

16. * Searches. [1 change]

State the sources that will be searched (e.g. Medline). Give the search dates, and any restrictions (e.g. language or publication

date). Do NOT enter the full search strategy (it may be provided as a link or attachment below.)

Databases to be Searched: PubMed, PsycARTICLES, CINAHL, Scopus, Cochrane Library. Search Terms:
("Avoidant/Restrictive Food Intake Disorder" OR ARFID OR selective eating disorder)
AND

(Clinician* OR healthcare provider* OR healthcare professional* OR therapist* OR psychiatrist* OR psychologist* OR pediatrician* OR physician*)

OR
(barrier* OR facilitator* OR challenge* OR obstacle* OR enabler* OR perspective* OR experience*) Limits and Filters: Studies published in English language and human studies

Backward and Forward Snowballing:
A manual search of references from the selected studies (backward citation searching) will be conducted to identify potentially relevant articles that might have been missed. Google Scholar will support forward citation searching.

17. URL to search strategy.

Upload a file with your search strategy, or an example of a search strategy for a specific database, (including the keywords) in pdf or word format. In doing so you are consenting to the file being made publicly accessible.

Or provide a URL or link to the strategy. Do NOT provide links to your search results.

Do not make this file publicly available until the review is complete

18. * Condition or domain being studied.

Give a short description of the disease, condition or healthcare domain being studied in your systematic review.

Avoidant Restrictive Food Intake Disorder (ARFID) was introduced as a diagnostic category in the fifth revision of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013) and subsequently added to the 11th revision of the International Classification of Diseases (ICD-11) (WHO, 2018). ARFID is classified as one of the 'Feeding and Eating Disorders' in both systems.

ARFID is characterised by an eating or feeding disturbance that manifests through limited food intake, leading to inadequate nutritional intake and significant weight loss or malnutrition. Unlike other eating disorders, such as anorexia nervosa or bulimia nervosa, ARFID is not driven by body image issues, fear of weight gain, or a desire for thinness.

Individuals with ARFID often experience avoidance or restriction of certain foods due to sensory sensitivities, aversions to specific tastes or textures, concerns about potential adverse consequences of eating (e.g., choking or vomiting), or lack of interest in eating. These limitations in food intake can result in severe nutritional deficiencies and compromised physical health.

Moreover, ARFID can impact a person's psychological well-being and social functioning, leading to distress and impairment in daily life activities. The disorder is commonly observed in children and adolescents, but it can also affect adults.

19. * Participants/population. [1 change]

Specify the participants or populations being studied in the review. The preferred format includes details of both inclusion and

exclusion criteria.

Clinicians involved in the diagnosis and treatment of Avoidant/Restrictive Food Intake Disorder (ARFID).

20. * Intervention(s), exposure(s). [1 change]

Give full and clear descriptions or definitions of the interventions or the exposures to be reviewed. The preferred format

includes details of both inclusion and exclusion criteria.

Not applicable (since this is not an intervention-focused study).

21. * Comparator(s)/control. [1 change]

Where relevant, give details of the alternatives against which the intervention/exposure will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Differences among types of clinicians (e.g., psychiatrists, psychologists, pediatricians) in their experiences of barriers and facilitators to ARFID diagnosis and treatment, differences based on patient characteristics such as age, gender, and co- occurring mental health conditions, and variation in experiences based on the location of healthcare settings.

22. * Types of study to be included. [1 change]

Give details of the study designs (e.g. RCT) that are eligible for inclusion in the review. The preferred format includes both

inclusion and exclusion criteria. If there are no restrictions on the types of study, this should be stated.

Inclusion Criteria:
Studies reporting on clinicians' perspectives of barriers and facilitators to the diagnosis and treatment of ARFID.
Primary research studies (qualitative, quantitative, or mixed methods).
Reviews, commentaries, and editorials that provide insights into clinicians' perspectives related to ARFID diagnosis and treatment, and directly address the research questions of the systematic review.
Studies involving healthcare professionals directly involved in the diagnosis and treatment of ARFID.
Studies examining clinicians' perspectives in any healthcare setting (e.g., hospitals, clinics, community health centers).

Exclusion Criteria:
Studies not focused on clinicians' perspectives.
Studies not reporting on ARFID or selective eating disorder.
Reviews, commentaries, and editorials that do not directly address the research questions of the systematic review.
Conference abstracts.

23. Context. [1 change]

Give summary details of the setting or other relevant characteristics, which help define the inclusion or exclusion criteria.

24. * Main outcome(s). [1 change]

Give the pre-specified main (most important) outcomes of the review, including details of how the outcome is defined and

measured and when these measurement are made, if these are part of the review inclusion criteria.

Clinicians' perspectives of perceived barriers and facilitators to diagnosis and treatment for ARFID, considering differences among types of clinicians, patient characteristics, and healthcare settings.

Measures of effect

25. * Additional outcome(s). [1 change]

List the pre-specified additional outcomes of the review, with a similar level of detail to that required for main outcomes. Where

there are no additional outcomes please state 'None' or 'Not applicable' as appropriate to the review

None

Measures of effect

26. * Data extraction (selection and coding). [1 change]

Describe how studies will be selected for inclusion. State what data will be extracted or obtained. State how this will be done

and recorded.

Adherence to PRISMA Guidelines:

The review will adhere to the PRISMA guidelines (Page et al., 2021) to ensure a comprehensive and rigorous analysis of the topic.

Data Screening Process:

Two independent reviewers will be involved in the data screening process. Reviewer 1 will conduct the initial screening of titles and abstracts against pre-specified criteria for all articles retrieved from the selected databases. Reviewer 2 will then independently check the data screening performed by Reviewer 1 for a randomly selected subset of included articles, approximately 10% of the total. Any uncertainties or disagreements identified during this subset check will be resolved through discussion between the two reviewers to ensure consistent and accurate inclusion of articles. In cases where disagreements persist, a third author will act as an independent moderator to make the final decision on article inclusion.

Data Extraction Process:

For further analysis and coding of the full-text articles, NVivo software will be utilised to support the narrative review. Data extraction will be conducted by one reviewer and cross-verified by another. A pilot test of the data extraction form will be performed on a subset of included articles, and necessary amendments will be made.
The data extraction form will capture key characteristics, including study design, demographic details (age, gender, diagnosis, etc.) of the study groups, primary and secondary outcomes, and the reported results.

Thematic Coding in NVivo:
In NVivo, relevant thematic codes will be developed to categorise data and facilitate analysis.

27. * Risk of bias (quality) assessment.

State which characteristics of the studies will be assessed and/or any formal risk of bias/quality assessment tools that will be used.

Quality assessment of included reviews will be undertaken independently by two reviewers. Discrepancies will be resolved by discussion or by consulting a third reviewer.

Quality will be assessed by utilising the Critical Appraisal Skills Programme (CASP) where possible.

28. * Strategy for data synthesis. [1 change]

Describe the methods you plan to use to synthesise data. This must not be generic text but should be specific to your review and describe how the proposed approach will be applied to your data.
If meta-analysis is planned, describe the models to be used, methods to explore statistical heterogeneity, and software package to be used.

For the data synthesis in this systematic review, a narrative synthesis approach will be employed to integrate findings from the included studies. This approach is well-suited for synthesising qualitative and quantitative data, allowing for the exploration of patterns, themes, and relationships across studies.

Thematic Analysis:

The data extracted from included studies will be analysed thematically to identify key themes and sub-themes related to clinicians' perspectives on barriers and facilitators to diagnosing and treating Avoidant/Restrictive Food Intake Disorder (ARFID). Themes will be identified through inductive coding, allowing for the emergence of patterns and insights directly from the data. NVivo software will be utilised to facilitate the thematic analysis process and organize coded data.

Grouping of Findings:

Synthesised findings will be grouped based on thematic similarities, allowing for the comparison of perspectives across studies. Key themes and sub-themes will be identified to represent the synthesized findings, providing a structured framework for data presentation.

Narrative Synthesis:

Synthesised findings will be presented narratively in the Results section of the systematic review.Findings will be described in detail, with supporting evidence from included studies, to provide a comprehensive overview of clinicians' perspectives on barriers and facilitators to ARFID diagnosis and treatment. The narrative synthesis will highlight commonalities, differences, and patterns observed across studies, offering insights into the complexity of the topic.

Interpretation and Discussion:
The synthesised findings will be interpreted in the Discussion section of the systematic review, addressing the research

questions and objectives. The implications of identified barriers and facilitators will be discussed in the context of clinical practice, policy, and future research directions. Any discrepancies or contradictions in the evidence will be explored, and the overall strength of the evidence will be assessed.

Quality Assessment:

The quality assessment of included studies will be integrated into the synthesis process, with considerations for the impact of study quality on the interpretation of findings. Findings from studies with higher methodological quality will be given appropriate weight in the synthesis, while limitations of studies will be acknowledged. Meta-analysis is not planned for this systematic review due to the anticipated heterogeneity in study designs, methodologies, and outcome measures across included studies. Instead, the narrative synthesis approach will be used to provide a qualitative analysis of the synthesised findings. NVivo software will be utilised for data management and thematic analysis.

29. * Analysis of subgroups or subsets. [1 change]

State any planned investigation of 'subgroups'. Be clear and specific about which type of study or participant will be included in

each group or covariate investigated. State the planned analytic approach.

Where the information is available, differences among types of clinicians (e.g., psychiatrists, psychologists, pediatricians) in their experiences of barriers and facilitators to ARFID diagnosis and treatment, differences based on patient characteristics such as age, gender, and co-occurring mental health conditions, and variation in experiences based on the location of healthcare settings will be addressed.

30. * Type and method of review.

Select the type of review, review method and health area from the lists below.

Type of review

Cost effectiveness No Diagnostic No Epidemiologic No Individual patient data (IPD) meta-analysis No Intervention No Living systematic review No Meta-analysis No Methodology No Narrative synthesis No Network meta-analysis No

Pre-clinical No Prevention No Prognostic No Prospective meta-analysis (PMA) No Review of reviews No Service delivery No Synthesis of qualitative studies No Systematic review Yes Other No

Health area of the review

Alcohol/substance misuse/abuse No Blood and immune system No Cancer No Cardiovascular No Care of the elderly No Child health No Complementary therapies No COVID-19 No Crime and justice No Dental No Digestive system No Ear, nose and throat No Education No Endocrine and metabolic disorders No Eye disorders No General interest No Genetics No

Health inequalities/health equity Yes Infections and infestations No International development No Mental health and behavioural conditions Yes Musculoskeletal No Neurological No Nursing No Obstetrics and gynaecology No Oral health No Palliative care No Perioperative care No Physiotherapy No Pregnancy and childbirth No Public health (including social determinants of health) No Rehabilitation No Respiratory disorders No Service delivery Yes Skin disorders No Social care No Surgery No Tropical Medicine No Urological No Wounds, injuries and accidents No Violence and abuse No

31. Language.

Select each language individually to add it to the list below, use the bin icon to remove any added in error.

English
There is not an English language summary

32. * Country.

Select the country in which the review is being carried out. For multi-national collaborations select all the countries involved.

England

33. Other registration details.

Name any other organisation where the systematic review title or protocol is registered (e.g. Campbell, or The Joanna Briggs Institute) together with any unique identification number assigned by them.
If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

34. Reference and/or URL for published protocol.

If the protocol for this review is published provide details (authors, title and journal details, preferably in Vancouver format)

No I do not make this file publicly available until the review is complete

35. Dissemination plans.

Do you intend to publish the review on completion?

Yes

36. Keywords. [1 change]

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords help PROSPERO users find your review (keywords do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

Avoidant/Restrictive Food Intake Disorder, ARFID, Clinicians' perspectives, Clinical care, Confidence, Diagnosis, DSM-5, ICD- 10, ICD-11, Familiarity, Guidelines, Healthcare, Treatment

37. Details of any existing review of the same topic by the same authors.

If you are registering an update of an existing review give details of the earlier versions and include a full bibliographic reference, if available.

38. * Current review status. [1 change]

Update review status when the review is completed and when it is published.

New registrations must be ongoing so this field is not editable for initial submission.

Review_Completed_not_published

39. Any additional information.

Provide any other information relevant to the registration of this review.

40. Details of final report/publication(s) or preprints if available.

Leave empty until publication details are available OR you have a link to a preprint (NOTE: this field is not editable for initial submission).
List authors, title and journal details preferably in Vancouver format.

Appendix C – Critical Appraisals

JBI Critical Appraisal Checklist for Qualitative	Magel 2021	Richmond 2020
Is there congruity between the stated philosophical perspective and the research methodology?	Unclear	Unclear
Is there congruity between the research methodology and the research question or objectives?	Unclear	Yes
Is there congruity between the research methodology and the methods used to collect data?	Unclear	Yes
Is there congruity between the research methodology and the representation and analysis of data?	Unclear	Yes
Is there congruity between the research methodology and the interpretation of results?	Unclear	Yes
Is there a statement locating the researcher culturally or theoretically?	No	No

JBI Critical Appraisal Checklist for Qualitative	Magel 2021	Richmond 2020
Is the influence of the researcher on the research, and vice- versa, addressed?	No	No
Are participants, and their voices, adequately represented?	No	Yes
Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	Yes	Yes
Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	Unclear	Yes
Overall Appraisal	Include	Seek further info

JBI Critical Appraisal Checklist for Cross-Sectional	Dinkler 2023	Coelho 2021	Harrison 2021	Seike 2016	Guss 2018	Jackson 2022	Katzman 2014
Were the criteria for inclusion in the sample clearly defined?	Yes	Yes	Yes	Yes	Yes	Yes	No
Were the study subjects and the setting described in detail?	Yes	Yes	Yes	Yes	Yes	Yes	No
Was the exposure measured in a valid and reliable way?	NA	NA	NA	NA	NA	NA	NA
Were objective, standard criteria used for measurement of the condition?	No	Yes	No	No	No	Yes	Unclear
Were confounding factors identified?	Yes	Yes	Yes	Yes	Yes	Yes	No
Were strategies to deal with confounding factors stated?	Yes	Yes	Yes	Yes	Unclear	Yes	No
Were the outcomes measured in a valid and reliable way?	Yes	Yes	Yes	Yes	Yes	Yes	Unclear

JBI Critical Appraisal Checklist for Cross-Sectional	Dinkler 2023	Coelho 2021	Harrison 2021	Seike 2016	Guss 2018	Jackson 2022	Katzman 2014
Was appropriate statistical analysis used?	Yes	Yes	Yes	Yes	Yes	Yes	Unclear
Overall Appraisal	Include	Include	Include	Include	Include	Include	Include

JBI Critical Appraisal Checklist for Diagnostic RCTs	Claudino 2019
Was true randomization used for assignment of participants to treatment groups?	Yes
Was allocation to treatment groups concealed?	Unclear
Were treatment groups similar at the baseline?	Unclear
Were participants blind to treatment assignment?	Yes
Were those delivering the treatment blind to the treatment assignment?	NA
Were treatment groups treated identically other than the intervention of interest?	Yes
Were outcome assessors blind to treatment assignment?	No
Were outcomes measured in the same way for treatment groups?	Yes
Were outcomes measured in a reliable way?	Yes
Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analysed?	Yes
Were participants analysed in the groups to which they were randomized?	Yes
Was approriate statistical analysis used?	Yes
Was the trial design appropriate and any deviations from the standard design (individual randomization, parallel groups) accounted for in the conduct and analysis of the trial?	Yes
Overall Appraisal	Include

JBI Critical Appraisal Checklist for Quasi-experimental	Raffoul 2022
Is it clear in the study what is the 'cause' and what is the 'effect' (i.e. there is no confusion about which variable comes first)?	Yes
Were the participants included in any comparisons similar?	Yes
Were the participants included in any comparisons receiving similar treatment/care, other than the exposure or intervention of interest?	Yes
Was there a control group?	Yes
Were there multiple measurements of the outcome both pre and post the intervention/exposure?	Yes
Was follow up complete and if not, were differences between groups in terms of their follow up adequately described and analyzed?	Yes
Were the outcomes of participants included in any comparisons measured in the same way?	Yes
Were outcomes measured in a reliable way?	Yes
Was appropriate statistical analysis used?	Yes
Overall Appraisal	Include

Appendix D– Qualtrics Survey

Start of Block: Introduction page

Welcome to the ARFID Pathway Study: "Charting the Course"

Thank you for considering taking part in our study. Your insights as parents/caregivers navigating the NHS for an ARFID diagnosis and treatment for your child are invaluable.

Your involvement contributes towards much-needed ARFID research, making a meaningful impact. Without participants, there is no research. If you're eligible and have the time, please consider participating so we can learn from your experiences.

Click the blue arrow below to review the participant information sheet. After this, the survey will begin.

With Gratitude,

Dr. Sandra-Eve Bamigbade

Researcher & Trainee Clinical Psychologist

Institution: University of Hertfordshire

Supervisors: Dr. Amanda Ludlow and Dr. Freya Cooper

Ethics: LMS/PGR/UH/05496

Reading this on your phone? Please note that we recommend completing this survey on a computer, laptop, or tablet for an optimal viewing experience, as some questions are formatted

for larger screens. If a larger-screened device is not available, you may continue using your mobile device.

End of Block: Introduction page

Start of Block: Participant Information Sheet

Title of study: Charting the Course: How Parents/Caregivers in England Navigate NHS Service Pathways to obtain an ARFID Diagnosis and Access to Treatment for their Children

Introduction

You are being invited to complete an online survey as part of a Doctorate in Clinical Psychology course being undertaken by Dr Sandra-Eve Bamigbade (supervised by Dr Amanda Ludlow and Dr Freya Cooper) at The School of Life and Medical Sciences, University of Hertfordshire, UK. Please read the following information carefully before deciding whether to take part. Please ask if there is anything that is not clear or if you would like more information. You are eligible to take part in this study if all of the following apply:

- Your Child has ARFID Symptoms: Your child avoids certain foods, eats a limited variety of foods, or feels upset/scared about eating. It's okay if your child is over 18, as long as you've been in touch with a healthcare professional about their ARFID symptoms before they turned 18.
- You Are the Primary Caregiver OR Equally Share Responsibility: You should be someone who is primarily or equally responsible for the medical care and well-being of the child with ARFID symptoms. This includes actions such as accessing health services on behalf

of your child, making decisions about their healthcare, and seeking professional support for your child or to support you in caring for your child.

- Use of the English Healthcare System: You have tried to get help for your child's ARFID symptoms through the English healthcare system, like the NHS-England or private healthcare.

All experiences matter; whether you found help or not, your experiences are important. Even if you talked to any kind of healthcare professional (e.g., health visitor, GP, nurse) about your child's ARFID symptoms, you're welcome to take part.

Why these conditions? We want to understand your journey in helping your child with ARFID symptoms. This is about how you've talked to healthcare professionals, made decisions, and sought support. No matter the outcome, your experiences are valuable, and your insights can make a real difference!

What if I have multiple children with ARFID symptoms?

If you have more than one child with ARFID symptoms, we're interested in your first experience getting help. You can also let us know if things were different the second time around in the additional space provided within the survey. Just keep the first child in mind

when completing the survey unless asked otherwise. This helps us see how things might have changed over time.

The Study

We want to learn from parents/caregivers about their experiences navigating the healthcare system to get support for their child's Avoidant/Restrictive Food Intake Disorder (ARFID) symptoms. This includes understanding their journey through the healthcare system to have their child assessed, diagnosed and/or treated for ARFID.

What does taking part involve?

If you agree to take part in this study, you will be asked to complete an online survey. This survey will ask about your experiences as a parent or caregiver of a child with ARFID. Your answers will help us understand how you've navigated the healthcare system and sought support for your child's ARFID. Taking part will take you approximately 30 minutes depending on how much you would like to share. You can complete the survey all at once, or may leave and return to it at any time so long as you use the same device.

Do I have to take part?

No. It is up to you to decide whether or not to take part. You are free to withdraw from the study at any time and without giving a reason. If you choose not to take part, you do not need to do anything further. If you change your mind after taking part and wish to withdraw from the study, please email s.a.bamigbade@herts.ac.uk within 2-weeks of your

participation to request your data is not analysed (please include your Participant Identification Number so we can identify your data). If you email after this point, withdrawing your data may not be possible.

Are there any benefits or risks for me if I take part?

Your input is incredibly valuable and will provide valuable insights that contribute to a better understanding of the challenges families like yours face while seeking support for your child's ARFID symptoms. By sharing your experiences, you offer essential information that can shape recommendations aimed at enhancing support for both children with ARFID symptoms and their families.

Given the current lack of established care pathways or widespread guidance for ARFID, your involvement holds particular significance. Your contributions will shed light on the experiences of parents and caregivers as they navigate the process of seeking help for their child's ARFID symptoms. These insights may pave the way for practical recommendations that offer guidance and support to others in similar situations as well as for clinical professionals. Your willingness to share your story and experiences is greatly appreciated, even though there won't be direct rewards for participating. Your input can help take small steps towards enhancing the available support for families dealing with ARFID. Your

contribution plays a crucial role in shaping the research's outcomes and potential recommendations.

Additionally, if you opt-in to the prize draw, you stand a chance of winning a £50 Love2Shop e-voucher. Two lucky winners will be randomly selected once the questionnaire is closed, likely in late Spring or early Summer 2024. An email will be sent to notify winners that will provide information on how they can claim their e-voucher. Winners will have a 2-week period to claim their prize before another winner is selected.

What are the possible disadvantages, risks or side effects of taking part?

We aim to make your participation as comfortable as possible. However, it's important to acknowledge that discussing your experiences might bring up memories or emotions that you find challenging. Especially, if you have not had positive experiences trying to access support. We want you to know that you can take breaks or pause the survey at any point if you need to, so long as you return to the survey using the same device.

Also, if you change your mind about participating, you can stop your participation at any time. Your well-being and comfort are our top priorities. If you have any concerns or

questions, please feel free to contact the researcher Sandra-Eve Bamigbade, s.a.bamigbade@herts.ac.uk.

What will happen to my data and the findings of this study?

Your privacy and confidentiality are of utmost importance to us. All information you provide will be treated with the strictest confidentiality. To maintain confidentiality, you will be asked to create an anonymity code, which will be used as the primary identifier in the research database. Your identifiable information, such as your name and contact details, will be kept separate from the research data. These details will be securely stored and accessible only by the primary researcher for the purpose of managing the study. All electronic data will be stored on the University OneDrive with strong encryption measures and will be retained for up to 5 years post the completion of the researcher's doctorate (approx. September 2029), after which it will be securely and permanently deleted. Data will be kept this long so that the researcher has a chance to go back to the raw data when working on a research paper to share these findings with the broader academic community.

If the paper is published before September 2029, your data will be deleted upon publication. If you have any further questions about the data protection plan, please

contact the researcher who will be happy to explain how your data is being kept safely and securely, s.a.bamigbade@herts.ac.uk.

The findings from this study will be reported in the thesis of the Dr Sandra-Eve Bamigbade and related publications and dissemination materials. If free-text responses from your survey are used in the write-up (as quotes), you and anyone else referred to by name (e.g., your child) will be given a pseudonym (fake name). This helps protect your identities.

Has this study received ethical approval?

This study has been approved by the University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority (SSAH ECDA). The Ethics Protocol number for this study is LMS/PGR/UH/05496.

If you would like to receive more information and for any other queries about this project you can contact me by email s.a.bamigbade@herts.ac.uk, or my Supervisor, Dr Amanda Ludlow a.ludlow@herts.ac.uk, or Dr Freya Cooper freya.cooper@gstt.nhs.uk. Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way

you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar University of Hertfordshire

College Lane,

Hatfield,

Hertfordshire,

AL10 9AB

United Kingdom

If you do not wish to participate in this survey, just close your browser.

If you are interested in taking part, please read the statements below and then click 'Yes, I consent to taking part in this study' to record your consent to participate.

- ☒ I confirm that I have read the study information. I have had the opportunity to consider the information and ask questions. Any questions have been answered satisfactorily
- ☒ I understand that my participation is voluntary, and I am free to withdraw from the study at any time during participation and within 2-weeks after participating without giving a reason
- ☒ I am 18 or over

Reading this on your phone? Please note that we recommend completing this survey on a computer, laptop, or tablet for an optimal viewing experience, as some questions are formatted for larger screens. You may wish to switch over before continuing. If a larger-screened device is not available, you may continue using your mobile device.

Consent

- ○ Yes, I consent to taking part in this study
- ○ No, I do not consent to taking part in this study

Skip To: End of Survey If Consent = No, I do not consent to taking part in this study

End of Block: Participant Information Sheet

Start of Block: Eligibility Screening Questions

Eligibility Screen 1 Are you the parent or caregiver of a child with Avoidant Restrictive Food Intake Disorder (ARFID) symptoms? Please note that you can still select 'Yes' even if your child has not been diagnosed.

- ○ Yes
- ○ No

Skip To: End of Survey If Are you the parent or caregiver of a child with Avoidant Restrictive Food Intake Disorder (ARFID)... = No

Eligibility Screen 2 Are you primarily or equally responsible for the medical care and well-being of the child with ARFID symptoms?

- ○ Yes
- ○ No

Skip To: End of Survey If Are you primarily or equally responsible for the medical care and well-being of the child with AR... = No

Eligibility Screen 3 Have you attempted to access support, advice, assessment, diagnosis, and/or treatment for your child's ARFID symptoms through the English healthcare system while they were under the age of 18 years?

- ○ Yes
- ○ No

Skip To: End of Survey If Have you attempted to access support, advice, assessment, diagnosis, and/or treatment for your ch... = No

End of Block: Eligibility Screening Questions

Start of Block: About Your Child and Their Diagnostic & Developmental History

This survey will take approximately 30-45 minutes to complete. You can take breaks if needed and return to the survey at any time, so long as you return from the same device. We recommend completing this survey on a computer, laptop, or tablet for an optimal viewing experience, as some questions are formatted for larger screens. If a larger-screened device is not available, you may continue using your mobile device.

Page Break

In this section, you will find a series of questions about your child, including their diagnoses and developmental history. Some questions might seem unrelated to your child's eating behaviours, however, all items have been carefully selected based on the latest ARFID research.

As of today, how old is your child in years and months?

_____

What is your child's gender?

- ○ Male
- ○ Female
- ○ Non-binary
- ○ Trans male
- ○ Trans female
- ○ Other _____
- ○ Prefer not to say

Has your child been diagnosed as neurodivergent? (i.e., diagnosed with a neurodevelopmental condition such as Autism, ADHD, Dyslexia)

- ○ Yes, diagnosed
- ○ No, but suspected
- ○ No, they are neurotypical
- ○ Prefer not to say

Page Break

Display This Question:

If Has your child been diagnosed as neurodivergent? (i.e., diagnosed with a neurodevelopmental condi... = Yes, diagnosed

Or Has your child been diagnosed as neurodivergent? (i.e., diagnosed with a neurodevelopmental condi... = No, but suspected

Please indicate whether your child has received a confirmed diagnosis or is suspected of having each condition listed.

For diagnosed conditions, select 'yes' in the first column, then you can select 'N/A' for the last two columns as these do not apply.

If your child does not have a diagnosis nor are not suspected to have the condition, please select 'No' for the first column, then 'N/A' for the last two columns as these do not apply.

If a condition is suspected, please select 'no' for the first column (as not diagnosed), then specify who suspects the condition and if your child is awaiting assessment ('yes' or 'no').

Where text boxes are available, please specify the condition your child has or is suspected to have.

Professionals include teachers as well as healthcare professionals such as doctors, nurses and psychologists.

Please note that depending on your screen size, you may need to scroll right to see all of the options.

	Suspected by who?				Awaiting assessment?			Diagnosed?	
	N/A	Family	Professional(s)	Family & Professional(s)	N/A	Yes	No	Yes	No
Autism Spectrum Disorder (ASD)(including what was once known as Asperger's syndrome)	○	○	○	○	○	○	○	○	○
Attention-Deficit Hyperactivity Disorder (ADHD)	○	○	○	○	○	○	○	○	○
Down Syndrome	○	○	○	○	○	○	○	○	○
Dyscalculia (difficulty with math)	○	○	○	○	○	○	○	○	○
Dysgraphia (difficulty with writing)	○	○	○	○	○	○	○	○	○

	Suspected by who?				Awaiting assessment?			Diagnosed?	
	N/A	Family	Professional(s)	Family & Professional(s)	N/A	Yes	No	Yes	No
Dyslexia(difficulty with reading)	○	○	○	○	○	○	○	○	○
Dyspraxia (difficulty with coordination)	○	○	○	○	○	○	○	○	○
Intellectual Disability/Global Developmental Delay	○	○	○	○	○	○	○	○	○
Mental Health Conditions (like bipolar disorder, obsessive-compulsive disorder, and more)	○	○	○	○	○	○	○	○	○
Prader-Willi Syndrome	○	○	○	○	○	○	○	○	○

	Suspected by who?				Awaiting assessment?			Diagnosed?	
	N/A	Family	Professional(s)	Family & Professional(s)	N/A	Yes	No	Yes	No
Sensory Processing Difficulties	○	○	○	○	○	○	○	○	○
Tourette Syndrome/Movement Disorder	○	○	○	○	○	○	○	○	○
Williams Syndrome	○	○	○	○	○	○	○	○	○
Other	○	○	○	○	○	○	○	○	○

Display This Question:

If Has your child been diagnosed as neurodivergent? (i.e., diagnosed with a neurodevelopmental condi... = Yes, diagnosed

Order of Dx Was your child diagnosed as neurodivergent before or after their ARFID assessment?

- ○ Diagnosed before
- ○ Diagnosed after

Page Break

Does your child have or experience any of the following conditions? Please select ALL that apply.

	No	Suspected	Awaiting diagnosis	Diagnosed
Allergies (e.g., cows milk protein, pollen, nuts)	○	○	○	○
Anxiety	○	○	○	○
Asthma	○	○	○	○
Conditions that affect chewing and swallowing (e.g., Dysphagia)	○	○	○	○
Constipation	○	○	○	○
Depression	○	○	○	○
Diabetes	○	○	○	○
Eczema	○	○	○	○
Eosinophilic esophagitis (Eoe)	○	○	○	○

GI or digestive issues (e.g., GERD, Coeliac, IBS/IBD)	○	○	○	○
OCD (Obsessive-Compulsive Disorder)	○	○	○	○
Sensory Processing Difficulties	○	○	○	○

Does your child have any of the following feeding or eating diagnoses? Please select ALL that apply.

	No	Suspected	Awaiting Assessment	Diagnosed
Anorexia	○	○	○	○
Binge Eating Disorder	○	○	○	○
Bulimia	○	○	○	○
Eating Disorder Not Otherwise Specified (EDNOS)	○	○	○	○
Other Specified Feeding or Eating Disorder (OSFED)	○	○	○	○
Pica	○	○	○	○
Rumination Syndrome	○	○	○	○

Page Break

Did you experience any challenges with your child's early feeding pattern? (e.g., feeding and weaning difficulties)

- ○ Yes
- ○ No

Display This Question:

If Did you experience any challenges with your child's early feeding pattern? (e.g., feeding and wea... = Yes

Please use this space to provide information about any challenges with your child's early feeding pattern.

_____

_____

_____

_____

_____

Does your child have any other diagnosis not already captured? (e.g., physical health condition, genetic disorder)

- ○ Yes _____
- ○ No

Was your child born premature (before 37 weeks)?

- ○ Yes
- ○ No
- ○ Prefer not to say

End of Block: About Your Child and Their Diagnostic & Developmental History

---

Start of Block: About your child's ARFID

Based on your observations, please indicate which aspects of the ARFID diagnostic criteria apply to your child. Please select ALL that apply.

☐ My child avoids or restricts certain foods or food groups based on how they look, taste, smell or the texture

☐ My child avoids or restricts certain foods or food groups based on worries about choking or being sick

☐ 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)

☐ 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)

☐ My child's limited diet has led to significant weight loss or failure to gain weight

☐ My child's limited diet has led to significant nutritional deficiency (i.e., deficiencies that result in noticeable symptoms)

☐ My child's limited diet has led to needing to have NG tube or PEG

☐ My child's limited diet has led to needing to take prescribed prescribed vitamins due to deficiencies (this does not include general multivitamins taken without medical advice)

☐ My child's limited diet has led to needing to take prescribed nutritional supplement drinks such as Ensure, Pediasure and Fortini

☐ My child's difficulties with eating impacts on their life and wellbeing

☐ My child's difficulties with eating impacts on our family life and wellbeing

☐ None of the above

☐ Other _____

Based on your observations, is your child dissatisfied with their body shape and/or weight?

Please note that this refers to dissatisfaction with the way one's body looks, whether that be to do with being underweight, overweight or concerns around body shape.

- ○ Yes
- ○ No
- ○ Unsure

Display This Question:

If Based on your observations, is your child dissatisfied with their body shape and/or weight? Pleas... != No

Could you please share more details about your child's feelings of dissatisfaction with their body? Additionally, feel free to elaborate on the significance or impact of these feelings.

_____

_____

_____

_____

_____

Based on your best understanding, is your child's eating behaviour explainable by other factors? (e.g., intolerances, allergies, eating disorders such as anorexia or other medical conditions?)

- ○ Yes
- ○ No
- ○ Unsure

Display This Question:

If Based on your best understanding, is your child's eating behaviour explainable by other factors?... != No

Please provide further information as to what you believe may be influencing your child's eating behaviour

_____

_____

_____

_____

_____

Page Break

This section asks questions about the first contact made with professionals about your child's ARFID symptoms. Please provide as much information as possible to help us understand your experiences.

At roughly what age did you notice your child's ARFID symptoms?

- ○ From birth
- ○ Birth- 6 months
- ○ 6 months- 12 months
- ○ 12 months- 18 months
- ○ 18 months- 24 months
- ○ 2- 3 years
- ○ 3- 4 years
- ○ 5 + years
- ○ Unsure

What did you first notice?

_____

_____

_____

Which professional did you first raise your concerns with?

Some people might have accessed support through CAMHS, but for this question we are interested in the first professional you spoke to i.e., who referred you to CAMHS.

- ○ Allergist/Immunologist
- ○ Clinical Psychologist
- ○ Dietitian
- ○ Gastroenterologist
- ○ GP (General Practitioner)
- ○ Health Visitor
- ○ Lactation Consultant
- ○ Occupational Therapist
- ○ Paediatrician
- ○ Psychiatrist
- ○ Speech and Language Therapist
- ○ Other (e.g., teacher) _____

When did you initially raise this concern? Please note that we ask this question as ARFID was officially introduced as a diagnosis into the American diagnostic manual (DSM-5) in 2013 and into the International manual (ICD-11) in 2018.

- ○ Before 2013
- ○ Between 2013 and 2018
- ○ After 2018
- ○ Can't remember

What concerns did you raise with the professional? What was the outcome?

_____

_____

_____

_____

_____

Page Break

Has your child been assessed for their ARFID symptoms?

- ○ Yes
- ○ No

Page Break

Display This Question:

If Has your child been assessed for their ARFID symptoms? = Yes

This section asks questions about your experience of assessments. Please provide as much information as possible to help us understand your experiences.

Display This Question:

If Has your child been assessed for their ARFID symptoms? = Yes

At what approximate age was your child first assessed? Please provide the age in years and months if possible (e.g., 8 years and 3 months).

_____

Display This Question:

If Has your child been assessed for their ARFID symptoms? = Yes

Has your child been assessed for their eating behaviours by more than one service/professional?

- ○ No, only assessed by one service/professional
- ○ Yes, assessed by multiple services/professionals

Display This Question:

If Has your child been assessed for their eating behaviours by more than one service/professional? = Yes, assessed by multiple services/professionals

Which services conducted the assessments? (e.g., Birmingham Feeding Clinic, Complex Feeding Clinic at Evelina, Feeding and Eating Disorder Service at Great Ormond Street Hospital)

Kindly list all services in chronological order. Start from the first service to provide an assessment and finish with the most recent. Additionally, please provide reasons for multiple assessments, such as referrals, relocation, second opinion, opting for private assessments, or transitioning between private and NHS assessments.

_____

_____

_____

_____

_____

Display This Question:

If Has your child been assessed for their eating behaviours by more than one service/professional? = No, only assessed by one service/professional

What service conducted the assessment? (e.g., Birmingham Feeding Clinic, Complex Feeding Clinic at Evelina, Feeding and Eating Disorder Service at Great Ormond Street Hospital)

_____

_____

_____

_____

_____

Display This Question:

If Has your child been assessed for their ARFID symptoms? = Yes

What county did you live in during the time of assessment?

_____

Display This Question:

If Has your child been assessed for their ARFID symptoms? = Yes

Can you provide information about the assessment process, including how professionals assessed your child's eating behaviours and how you felt about the experience overall. For

example, was you given a screening measure/questionnaire, assessed by a single professional or a multidisciplinary team.

_____

_____

_____

_____

_____

Display This Question:

If Has your child been assessed for their ARFID symptoms? = No

Please outline any reasons why your child has yet to have an assessment.

_____

_____

_____

_____

_____

Page Break

Display This Question:

If Has your child been assessed for their ARFID symptoms? = Yes

Has your child been diagnosed with ARFID?

- ○ Yes
- ○ No

Page Break

Display This Question:

If Has your child been assessed for their ARFID symptoms? = Yes

This section asks questions about your experience of getting a diagnosis. Please provide as much information as possible to help us understand your experiences.

Display This Question:

If Has your child been diagnosed with ARFID? = Yes

Who provided the diagnosis? (e.g., Birmingham Feeding Clinic, Complex Feeding Clinic at Evelina, Feeding and Eating Disorders Service at Great Ormond Street Hospital)

_____

Display This Question:

If Has your child been diagnosed with ARFID? = Yes

What county did you live in at the time of diagnosis?

_____

Display This Question:

If Has your child been diagnosed with ARFID? = Yes

At what approximate age was your child diagnosed? Please provide the age in years and months if possible (e.g., 8 years and 3 months).

_____

Display This Question:

If Has your child been diagnosed with ARFID? = Yes

Can you provide information about the experience of getting a diagnosis and its impact on you and your child? (i.e., what difference, if any, did it make to your lives?)

_____

_____

_____

_____

_____

Display This Question:

If Has your child been diagnosed with ARFID? = No

If your child underwent an assessment but was not diagnosed with ARFID, please share the reasons provided by the assessing team for not giving a diagnosis. Include information on the factors they considered, specifically those identified as reasons for not being eligible for a diagnosis or not meeting the diagnostic criteria (e.g., your child's dietary range, weight, nutritional health, or the presence of another explanation for their eating

Note: If you are unaware of the reason why your child was not given a diagnosis, please write 'reason not communicated'.

_____

_____

_____

_____

_____

Display This Question:

If Has your child been diagnosed with ARFID? = No

Did the assessor/assessing team provide you or your child with any of the following after they informed you that your child was not eligible for an ARFID diagnosis?

Please select ALL that apply and provide details where possible.

☐ Signposted to resources or educational materials about eating behaviours (if recalled, please list resources)

_____

☐ Referred to another relevant healthcare professional, specialist or service (please specify whom you were referred to)

_____

☐ Given guidance on managing specific challenges related to eating behaviours at home or in school

☐ Given recommendations for alternative interventions or therapies (please specify) _____

☐ Given information on local support groups (e.g., BEAT groups) or community resources for individuals with eating behaviour challenges (please specify)

_____

☐ Given follow-up appointment(s) or scheduled reviews to monitor your child's progress

☐ None of the above

☐ Other _____

Display This Question:

If Has your child been assessed for their ARFID symptoms? = Yes

Has your child received any other diagnoses (besides ARFID) for their eating behaviours?

○ Yes

○ No

Page Break

Display This Question:

If Has your child received any other diagnoses (besides ARFID) for their eating behaviours? = Yes

What diagnoses where they given for their eating behaviour (besides ARFID) and by who?

_____

_____

_____

_____

_____

Display This Question:

If Has your child received any other diagnoses (besides ARFID) for their eating behaviours? = Yes

What was the impact of this diagnosis? (for example, if you believe your child was misdiagnosed, please use this space to provide information about the impact of this misdiagnosis).

_____

_____

_____

_____

_____

Page Break

Display This Question:

If Has your child been assessed for their ARFID symptoms? = Yes

This section asks questions about your experience of treatment for ARFID. Please provide as much information as possible to help us understand your experiences.

Page Break

Display This Question:

If Has your child been assessed for their ARFID symptoms? = Yes

Have you or your child participated in any interventions for ARFID?

Note: This includes formal treatments and participation in support groups.

Select 'Yes' if you've received any ARFID-specific help.

Select 'No' if you've only used self-help, social media (e.g., Facebook groups) or received advice from friends and family.

- ○ Yes
- ○ No

Display This Question:

If Have you or your child participated in any interventions for ARFID? Note: This includes formal t... = Yes

At what approximate age was your child when they or you were first given access to treatment for their ARFID?

This includes indirect interventions (e.g., parent-led interventions). Please provide the age in years and months if possible (e.g., 8 years and 3 months).

_____

Display This Question:

If Have you or your child participated in any interventions for ARFID? Note: This includes formal t... = Yes

Please share what treatment(s) you and your child have been offered (even if declined) or completed. For completed treatments, please let us know the outcome.

Please provide as much detail as possible so we may attempt to identify the type of treatment provided.

_____

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Display This Question:

If Have you or your child participated in any interventions for ARFID? Note: This includes formal t... = Yes

If you received treatment, assistance, or support from any voluntary or community organisations (including registered charities like BEAT) please share details about the organisation(s). Include their names, what support they provided, and the outcome of the support.

If not applicable, please type 'N/A'

_____

_____

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_____

Display This Question:

If Have you or your child participated in any interventions for ARFID? Note: This includes formal t... = Yes

If you accessed professional support for ARFID privately, can you please detail what support you accessed, with who (i.e., name of service/professional), and the outcome. Please also include what factors or considerations led you to make the decision to seek support privately?

If not applicable, please type 'N/A'

_____

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_____

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_____

Display This Question:

If Have you or your child participated in any interventions for ARFID? Note: This includes formal t... = No

If treatment was offered but declined, can you please explain what led you to make this decision?

If not applicable, please type 'N/A'

_____

_____

_____

_____

_____

Display This Question:

If Have you or your child participated in any interventions for ARFID? Note: This includes formal t... = Yes

On a scale from 0 to 10, how satisfied are you with the available treatment options for ARFID?

	Extremely dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Extremely satisfied	Not Applicable
	0 1	2 3 4	5	6 7 8	9 10	
Satisfaction with NHS treatment options						
Satisfaction with Private treatment options						
Satisfaction with Third Sector (e.g., BEAT) treatment options						

Display This Question:

If Have you or your child participated in any interventions for ARFID? Note: This includes formal t... = Yes

Please use this space to explain your satisfaction ratings and what improvements you would like to see in treatment availability. Your written responses are valuable in helping us understand your experiences.

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Page Break

Display This Question:

If Have you or your child participated in any interventions for ARFID? Note: This includes formal t... = No

If you and/or your child have not been offered treatment, please share the reasons provided by the assessing team, professional or service for this decision.

For example, some reasons might include your child's contentment with their current diet, lack of motivation for change, not meeting the diagnostic criteria for ARFID, not meeting the service threshold, or meeting nutritional needs without intervention. Based on what was communicated to you, if at all, why was your child and/or you not offered treatment?

If not applicable, please type 'N/A'

_____

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_____

_____

Please share information about informal support you have received concerning your child's ARFID symptoms, including peer support networks, Facebook groups, social media platforms, and resources.

Describe your experiences with these sources of support (i.e, what has been helpful/unhelpful).

_____

_____

_____

_____

_____

If you have more than one child with ARFID symptoms, please use this space to explain how further attempts for assessment, diagnosis and treatment for your other child(ren) differed from your first experience. If you have only one child with ARFID symptoms or have not pursued an assessment for the other child(ren), please type 'N/A'

_____

_____

_____

_____

_____

Page Break

On a scale from 0 to 10, how satisfied are you with the overall process of navigating the NHS for the following...

	Extremely dissatisfied	Somewhat dissatisfied	Neither satisfied nor dissatisfied	Somewhat satisfied	Extremely satisfied	Not Applicable
	0 1	2 3 4	5	6 7 8	9 10	
Obtaining an assessment for your child's ARFID symptoms						
Obtaining an ARFID diagnosis for your child						
Obtaining ARFID treatment						

Please use this space to explain your satisfaction ratings and what improvements you would like to see within the NHS for ARFID care

_____

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_____

In looking back at your journey, can you identify any factors that helped or hindered obtaining a diagnosis for your child and accessing treatment?

_____

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_____

Knowing what you know now, is there anything you would have done differently? If so, please explain why.

_____

_____

_____

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_____

What advice would you give to a parent looking to navigate the healthcare system due to concerns about their child's eating behaviours? (i.e., a parent seeking assessment, diagnosis, and/or treatment for ARFID?)

_____

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Page Break

By sharing your experiences, you have offered essential information that can shape recommendations aimed at enhancing support for both children with ARFID symptoms and their families.

If there is anything else that you feel we should know about your experiences that have not been captured yet, please do use this space below.

_____

_____

_____

_____

_____

End of Block: About your child's ARFID

Start of Block: About you and your household

Thank you for all your responses so far. You're almost done. This section asks contextual questions about you and your household.

What is your relationship with the child with ARFID symptoms?

- ○ Mother
- ○ Father
- ○ Step-mother
- ○ Step-father
- ○ Grandmother
- ○ Grandfather
- ○ Aunt
- ○ Uncle
- ○ Legal Guardian
- ○ Other _____

How old are you? If you prefer, you can enter your specific age (e.g., 35) or name a range that best represents your age (e.g., mid 30s).

_____

Which region of England are you based? (e.g., South East of England, West of England)

_____

What ethnicity do you identify with most? Please select the option that best applies.

- ○ Arab or Middle Eastern: This category can encompass individuals from countries in the Arab world and the broader Middle East region.
- ○ Asian: This category includes Indian, Pakistani, Bangladeshi, Chinese, and other Asian backgrounds.
- ○ Black: This category includes Black African, Black Caribbean, and other Black backgrounds.
- ○ Mixed/Multiple Ethnic Backgrounds: This category includes people of mixed ethnic backgrounds, such as White and Black Caribbean, White and Black African, White and Asian, and others.
- ○ White: This category includes various White ethnic groups, such as White British, White Irish, White European, and other White backgrounds.
- ○ Prefer not to say
- ○ Other _____

What is the highest level of formal schooling you have completed?

- ○ No formal schooling
- ○ Left school before age 16
- ○ Left school between ages of 16 and 18
- ○ Further secondary education (ages 16-19)
- ○ Vocational/trade school
- ○ Professional qualification without a degree
- ○ Undergraduate Degree
- ○ Master's Degree
- ○ Doctorate
- ○ Other _____
- ○ Prefer not to say

What is your current occupation status? Please select ALL that apply.

- [ ] Employed, Full-time
- [ ] Employed, Part-time
- [ ] Employed, zero-hour contract
- [ ] Self-Employed
- [ ] Unemployed and actively seeking work
- [ ] Unemployed and not actively seeking work
- [ ] Student, Full-time
- [ ] Student, Part-time
- [ ] Unpaid family carer (e.g., stay at home parent, homemaker, carer for relative), Full-time
- [ ] Unpaid family carer (e.g., stay at home parent, homemaker, carer for relative), Part-time
- [ ] Unpaid employment (e.g., intern, volunteer)
- [ ] Retired

☐ Unable to work due to disability or health condition

☐ Other _____

☐ Prefer not to say

End of Block: About you and your household

Start of Block: Code & Consent

Just a few logistical questions...

We request that you create an anonymity code for this study. This code allows you: (1)To be identified anonymously, (2) To provide any further information to the study,(3) To opt out.

Your code should have: 2 letters and up to 4 numbers

For example: If your initials are UH and your postcode is AL10 9AB, your code could be UH109.

Please ensure your code does not reveal your identity but can be remembered easily. Only you and the primary researcher knows your code. If you have forgotten your code, please contact Sandra-Eve at s.a.bamigbade@herts.ac.uk

---

What is your anonymity code?

_____

Would you like to be entered into the £50 prize draw? (there will be 2 lucky winners!)

- ○ Yes
- ○ No

Would you be interested in taking part in an online interview about your experiences? (another chance to enter a prize draw)

- ○ Yes
- ○ No

Would you like to be contacted with the outcome of the study? (likely end of 2024)

- ○ Yes
- ○ No

Display This Question:

If Would you like to be contacted with the outcome of the study? (likely end of 2024) = Yes

Or Would you like to be entered into the £50 prize draw? (there will be 2 lucky winners!) = Yes

Or Would you be interested in taking part in an online interview about your experiences? (another ch... = Yes

*

What is your email address?

_____

Display This Question:

If Would you like to be entered into the £50 prize draw? (there will be 2 lucky winners!) = Yes

And Would you like to be contacted with the outcome of the study? (likely end of 2024) = Yes

And Would you be interested in taking part in an online interview about your experiences? (another ch... = Yes

To maintain confidentiality, email addresses will be stored separately to your survey responses.

End of Block: Code & Consent

Thank you for your participation in this study.

If any part of your participation has raised difficult issues for you or concerns, you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend.

Just as a final reminder, your personal details will be kept confidential, and all data will be anonymised. Please feel free to contact the researcher, Sandra-Eve Bamigbade (s.a.bamigbade@herts.ac.uk) if you have any questions, including questions about how your data will be handled. You may also request the request your data be withdrawn from the study if you change your mind about taking part. Please make sure this is within 2 weeks of participating (before data is anonymised).

Resources that might be helpful:

Be Body Positive

https://bebodypositive.org.uk/

Designed as an early intervention, Be Body Positive promotes building a positive relationship with food and your bodies. The content is designed by a team of experts and tested by young people. They provide the support and guidance which can help people to overcome challenges around eating, body image and self-care. They have free resources for parents/carers as well as youth workers, teachers and health professionals; there is something new to learn for everyone.

Be Body Positive has an ARFID module to help manage anxiety around food, understand hunger and how best to support young people with ARFID as well as pick or fussy eaters.

Support Organisations

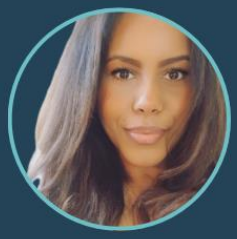
https://www.arfidawarenessuk.org

https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/types/arfid/

Post 1, part 1


SURVEY ABOUT YOUR CHILD'S ARFID-CARE JOURNEY
We're recruiting!!
UH ETHICS: XXXXXXXXXXXXXXXXXX
CHANCE TO WIN PRIZE DRAW
YOU ARE ELIGIBLE IF ...
You are the parent/caregiver of a child with symptoms of ARFID
You have primary or equal medical responsibility for the child with ARFID symptoms
You have sought or are seeking support through the UK healthcare system for the child with ARFID symptoms
Click HERE for more info

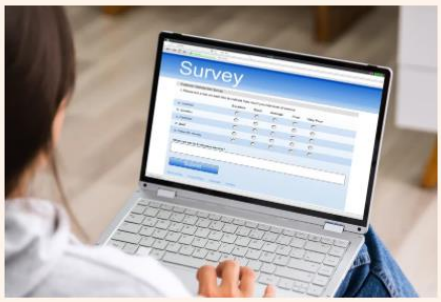
Post 1, part 2



Research by Dr Sandra-Eve Bamigbade

@arfid_research

ONLINE SURVEY

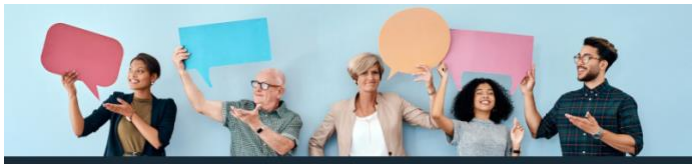


Parents/caregivers, your experience matters! Share your journey navigating the healthcare system for your child's ARFID symptoms - whether seeking assessment, diagnosis, or treatment. Your insights will shape recommendations for better support. Take our 30-minute survey now to have your say!

MORE TO SAY?

After the survey, opt-in for a follow-up interview to share more of your story. Only 15 spots are available, so sign up now for a chance to contribute to a richer understanding of your journey

Post 2 (attempt to recruit more fathers)



HAVE YOUR SAY!!

WE WANT TO LEARN ABOUT YOUR CHILD'S AVOIDANT RESTRICTIVE FOOD INTAKE DISORDER (ARFID) CARE JOURNEY

University of Hertfordshire UH

Research by
Dr Sandra-Eve
Bamigbade

@arfid_research

UH ETHICS: LMS/PGR/UH/05496

YOU ARE ELIGIBLE IF ...

- You are the parent/caregiver of a child with symptoms of ARFID
- You have primary or equal medical responsibility for the child with ARFID symptoms
- You have sought or are seeking support through the English healthcare system for the child with ARFID symptoms

ONLINE SURVEY

Parents/caregivers, your experience matters! Share your journey navigating the healthcare system for your child's ARFID symptoms - whether seeking assessment, diagnosis, or treatment. Your insights will shape recommendations for better support. Take our 30-45-minute survey now to make a difference!

Appendix F – Participant info sheet for IPA study and consent form

Participant Information Sheet

1 Title of study

Charting the Course: How Parents/Caregivers in England Navigate NHSE Service Pathways to obtain an ARFID Diagnosis and Access to Treatment for their Children

2 Introduction

Thank you for completing our survey and expressing interest in phase-2 of the study. We appreciate an opportunity to learn more about your experiences and ask follow-up questions based on your survey responses. You are being invited to take part in a study. Before you decide whether to do so, it is important that you understand the study that is being undertaken and what your involvement will include. Please take the time to read the following information carefully and discuss it with others if you wish. Do not hesitate to ask us anything that is not clear or for any further information you would like to help you make your decision. Please do take your time to decide whether or not you wish to take part. The University's regulation, UPR RE01, 'Studies Involving the Use of Human Participants' can be accessed via this link:

https://www.herts.ac.uk/about-us/governance/university-policies-and-regulations-uprs/uprs

(after accessing this website, scroll down to Letter S where you will find the regulation)

Thank you for reading this.

3 What is the purpose of this study?

We are conducting a follow-up interview study to gain deeper insights into the experiences and challenges parents and caregivers face while navigating the healthcare system to seek support for their child's Avoidant/Restrictive Food Intake Disorder (ARFID) symptoms. Our aim is to deeply understand your journey through the healthcare system – from the initial assessment, diagnosis, to treatment. This includes experiences that have not resulted in gaining a diagnosis or being offered treatment.

Your participation in the initial survey provided valuable information, but we recognise that your experiences are unique. Through in-depth interviews, we hope to delve deeper into your stories, emotions, and decisions, enabling us to capture the complexity of your experiences in greater detail. By sharing your story, you contribute significantly to advancing our understanding of ARFID and enhancing support systems for affected families.

4 Do I have to take part?

It is completely up to you whether or not you decide to take part in this study. Agreeing to join the study does not mean that you have to complete it. You are free to withdraw at any stage without giving a reason.

5 Are there any age or other restrictions that may prevent me from participating?

As a follow-up study, we are only interviewing people who took part in our online survey. The following eligibility criteria applied for the survey:

1. **Your Child has ARFID Symptoms:** Your child avoids certain foods, eats a limited variety of foods, or feels upset/scared about eating. It's okay if your child is over 18, as long as you've been in touch with a healthcare professional about their ARFID symptoms before they turned 18.

2. **You Are the Primary Caregiver OR Equally Share Responsibility:** You should be someone who is primarily or equally responsible for the medical care and well-being of the child with ARFID symptoms. This includes actions such as accessing health services on behalf of your child, making decisions about their healthcare, and seeking professional support for your child or to support you in caring for your child.

3. **Use of the UK Healthcare System**: You have tried to get help for your child's ARFID symptoms through the UK healthcare system, like the NHS or private healthcare. All experiences matter; whether you found help or not, your experiences are important. Even if you talked to any kind of healthcare professional about your child's ARFID symptoms, you're welcome to take part.

Why these conditions?

We want to understand your journey in helping your child with ARFID. This is about how you've talked to healthcare professionals, made decisions, and sought support. No matter the outcome, your experiences are valuable, and your insights can make a real difference!

6 How long will my part in the study take?

If you would like to take part in the follow-up interview, this will take up to 60 minutes, depending on how much you would like to share. To make interviews more convenient and accessible, they will be held via MS Teams.

7 What will happen to me if I take part?

Once you indicate that you would like to be interviewed, you will be contacted by the researcher to schedule a 60 minute MS Teams call. You will also be given access to the broad interview questions in advance, allowing you to familiarise yourself with the topics that will be discussed.

Before the interview, the researcher will review your survey responses so the interview may delve deeper into specific aspects of your experiences. This will help us explore your journey and allow you the opportunity to elaborate on any points you feel are important.

During the interview, please feel free to share your thoughts openly and honestly. Your perspectives are crucial in shaping our understanding of ARFID and informing future support initiatives. Rest assured that your confidentiality and privacy will be maintained throughout the interview process and beyond.

If you have any questions or need help understanding any of the questions, please email the researcher Sandra-Eve Bamigbade, at s.a.bamigbade@herts.ac.uk.

8 What are the possible disadvantages, risks or side effects of taking part?

We want to acknowledge that discussing your experiences, particularly related to seeking support for your child's ARFID symptoms, can stir challenging emotions or memories. It's important to note that while the interviewer is a trainee clinical psychologist, they are not your psychologist. The interview will be conducted strictly for research purposes, and no therapeutic interventions will be provided.

However, we recognise that many participants find talking about their experiences to be therapeutic in itself. Sharing your story can be empowering and cathartic, and it may provide a sense of relief or validation. While the interview is not a therapeutic session, the process of discussing your experiences openly may offer you a chance to reflect and gain insights.

As mentioned earlier, your participation is entirely voluntary, and you have the right to withdraw from the interview at any time. There will be no repercussions for deciding not to participate or for discontinuing your involvement.

If, at any point, you feel uncomfortable or distressed, please feel free to let the interviewer know. Your well-being and comfort are our top priorities, and we are here to support you throughout the research process.

If you have any concerns, questions, or if you need further clarification, please do not hesitate to contact the researcher, Sandra-Eve Bamigbade, at s.a.bamigbade@herts.ac.uk. We appreciate your participation and trust in our study.

9 What are the possible benefits of taking part?

Your participation in this study is immensely valuable. By sharing your experiences, you are instrumental in providing insights into the challenges faced by families navigating the complexities of ARFID support. Your unique perspective enriches our understanding and contributes significantly to shaping recommendations aimed at improving the support systems for both children with ARFID and their families.

Given the current absence of established care pathways and widespread guidance for ARFID, your input is key. Your contributions clarify the journey of parents and caregivers seeking help for their child's ARFID, paving the way for practical recommendations. These insights not only benefit others in similar situations but also provide valuable guidance to clinical professionals working in this field.

We deeply appreciate your willingness to share your story, even though direct rewards for participation are not provided. Your contribution is fundamental to shaping the outcomes of this research and the potential recommendations that may arise.

Additionally, if you choose to participate in the prize draw, you have the opportunity to win a £60 e-voucher (provided as two £30 e-vouchers should you wish to share one with your child with ARFID). Two winners will be randomly selected once the interviews have ended (before May 2024). If you are selected as a winner, you will receive an email notification with instructions on how to claim your e-voucher. Winners will have a 2-week period to claim their prize before another winner is selected. Please also note that the vouchers need to be used by June 2024.

10 How will my taking part in this study be kept confidential?

Ensuring your privacy and confidentiality is our top priority. All information you provide will be treated with the strictest confidence. To protect your identity, both you and anyone mentioned by name will be assigned pseudonyms (fake names) in transcripts and publications. Additionally, specific details that could potentially reveal your identity will be carefully adjusted.

Your identifiable information, including your name and contact details, will be kept separate from the research data. These details will be securely stored and accessible only to the primary researcher for the purpose of managing the study.

During interviews, recordings will be made via MS Teams. To prevent data loss, a backup audio recording will be stored on One Drive. This backup will be deleted immediately once the researcher confirms there are no issues with the main recording. The main recording will be used solely for transcription purposes and will be deleted once the transcripts have been verified. Access to your recording will be restricted to the primary researcher, and in some cases an assigned transcriber.

If you have any further inquiries about our data protection procedures, please feel free to contact the researcher. Sandra-Eve Bamigbade can explain in detail how your data is being protected: s.a.bamigbade@herts.ac.uk .

If you have any further questions about the data protection plan, please contact the researcher who will be happy to explain how your data is being kept safely and securely, s.a.bamigbade@herts.ac.uk.

11 What will happen to the data collected within this study?

- All electronic data will be saved on the University's One Drive in a password protected folder (different password to the laptop or university account). Only the researcher will have access to the One Drive folder with all research files and the supervisory team (Dr Amanda Ludlow and Dr Freya Cooper) will have access to the anonymised dataset(s);
-

- The data collected will be stored electronically on the University's One Drive for 5 years post the completion of the doctorate (approx. September 2029), after which time it will be destroyed under secure conditions;

- The data will be anonymised prior to storage.

12 Will the data be required for use in further studies?

No, your data will not be used within further studies.

13 Who has reviewed this study?

This study has been reviewed by: The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

The UH protocol number is LMS/PGR/UH/05496

14 Factors that might put others at risk

Please note that if, during the study, any medical conditions or non-medical circumstances such as unlawful activity become apparent that might or had put others at risk, the University may refer the matter to the appropriate authorities and, under such circumstances, you will be withdrawn from the study.

15 Who can I contact if I have any questions?

If you would like further information or would like to discuss any details personally, please get in touch with me, by email: s.a.bamigbade@herts.ac.uk.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar

University of Hertfordshire

College Lane

Hatfield

Herts

AL10 9AB

Thank you very much for reading this information and considering taking part in this study.

Consent Form

UNIVERSITY OF HERTFORDSHIRE

ETHICS COMMITTEE FOR STUDIES INVOLVING THE USE OF HUMAN PARTICIPANTS

('ETHICS COMMITTEE')

FORM EC3

CONSENT FORM FOR STUDIES INVOLVING HUMAN PARTICIPANTS

I, the undersigned *[please give your name here*, *in BLOCK CAPITALS]*

……..…

of *[please give contact details here, sufficient to enable the investigator to get in touch with you ,e.g., email address]*

…..……

hereby freely agree to take part in the study entitled Charting the Course: How Parents/Caregivers in England Navigate NHSE Service Pathways to obtain an ARFID Diagnosis and Access to Treatment for their Children

……..

(UH Protocol number LMS/PGR/UH/05496)

1 I confirm that I have been given a Participant Information Sheet (a copy of which is attached to this form) giving particulars of the study, including its aim(s), methods and design, the names and contact details of key people and, as appropriate, the risks and potential benefits, how the information collected will be stored and for how long, and any plans for follow-up studies that might involve further approaches to participants. I have also been informed of how my personal information on this form will be stored and for how long. I have been given details of my involvement in the study. I have been told that in the

event of any significant change to the aim(s) or design of the study I will be informed, and asked to renew my consent to participate in it.

2 I have been assured that I may withdraw from the study at any time without disadvantage or having to give a reason.

3 In giving my consent to participate in this study, I understand that video recording will take place and I have been informed of how this recording will be used (only for transcription purposes).

4 I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

5 I understand that if there is any revelation of unlawful activity or any indication of non-medical circumstances that would or has put others at risk, the University may refer the matter to the appropriate authorities.

Signature of participant……..…Date……

Signature of (principal)

investigator……Date……

Name of (principal) investigator *Dr Sandra-Eve Bamigbade*

Appendix G – Interview debrief

Thank you for your participation in this study.

If any part of your participation has raised difficult issues for you or concerns, you may wish to contact appropriate professional services such as your GP, therapist, counsellor, family member or friend.

Just as a final reminder, your personal details will be kept confidential and all data will be anonymised. Please feel free to contact the researcher, Sandra-Eve Bamigbade (s.a.bamigbade@herts.ac.uk) if you have any questions, including questions about how your data will be handled. You may also request the request your data be withdrawn from the study if you change your mind about taking part. Please make sure this is within 2-weeks of participating (before data is anonymised).

Resources that might be helpful:

Be Body Positive
https://bebodypositive.org.uk/

Designed as an early intervention, Be Body Positive promotes building a positive relationship with food and your bodies. The content is designed by a team of experts and tested by young people. They provide the support and guidance you need to overcome challenges around eating, body image and self-care. They have resources for parents/carers as well as youth workers, teachers and health professionals, there is something new to learn for everyone.

Be Body Positive have an ARFID module to help manage anxiety around food, understand hunger and how best to support young people with ARFID as well as pick or fussy eaters.

Support Organisations
https://www.arfidawarenessuk.org
https://www.beateatingdisorders.org.uk/get-information-and-support/about-eating-disorders/types/arfid/

BEAT Helplines:
England Helpline: 0808 801 0677 | help@beateatingdisorders.org.uk
Scotland Helpline: 0808 801 0432 | Scotlandhelp@beateatingdisorders.org.uk
Wales Helpline: 0808 801 0433 | Waleshelp@beateatingdisorders.org.uk
Northern Ireland Helpline: 0808 801 0434 | NIhelp@beateatingdisorders.org.uk

Appendix H – Figures for Chapter 4

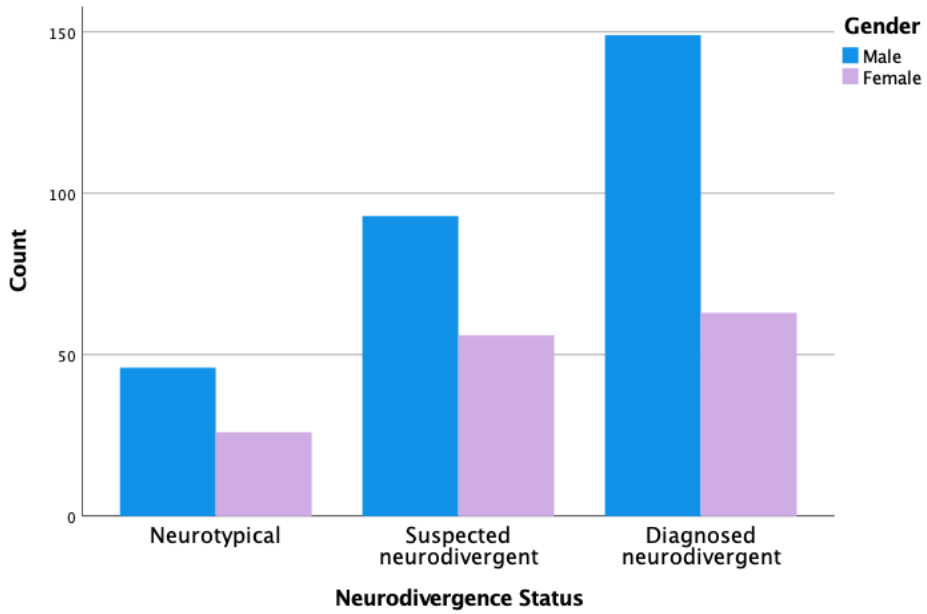


Figure 5 Bar Chart of Gender Differences in Neurodivergence Status (Table 14)

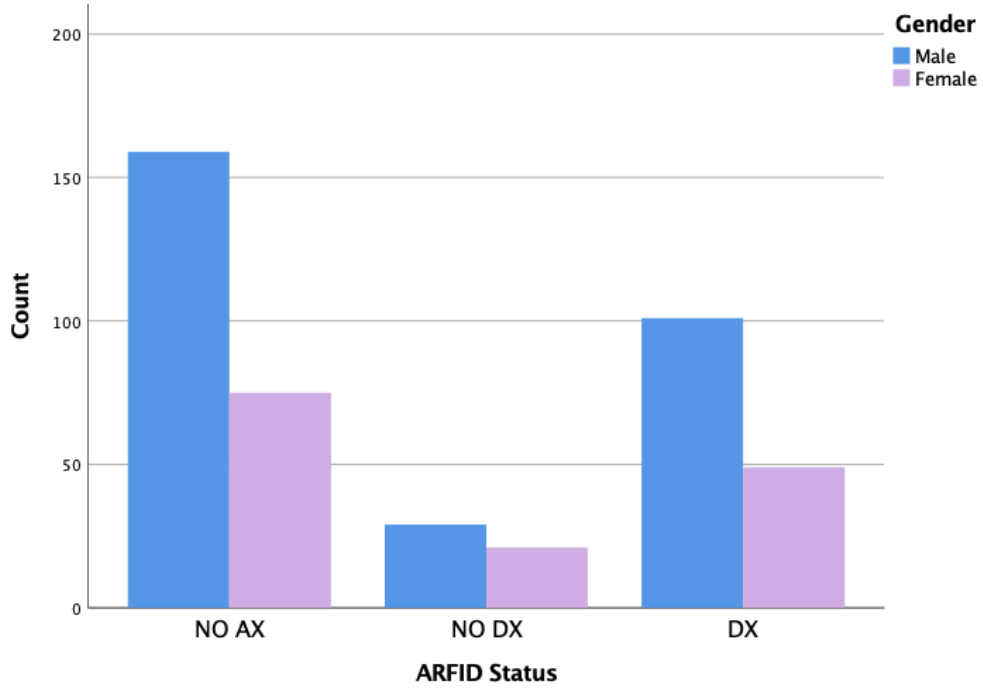


Figure 6 Bar Chart of Gender Differences in ARFID Status (Table 15)

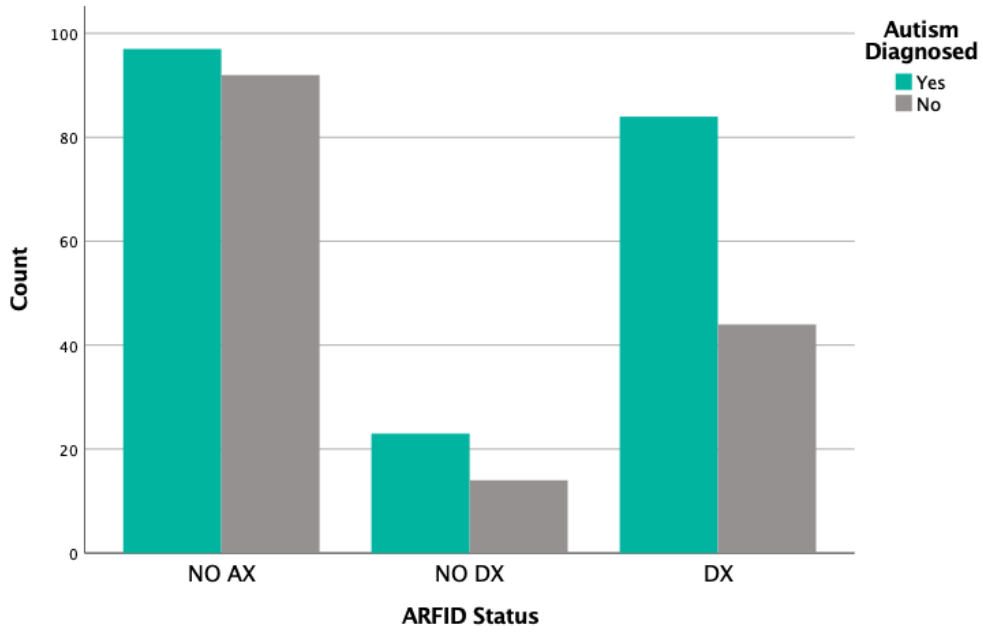


Figure 7 Bar Chart of Autism Diagnosis by ARFID Diagnosis Status (Table 19)

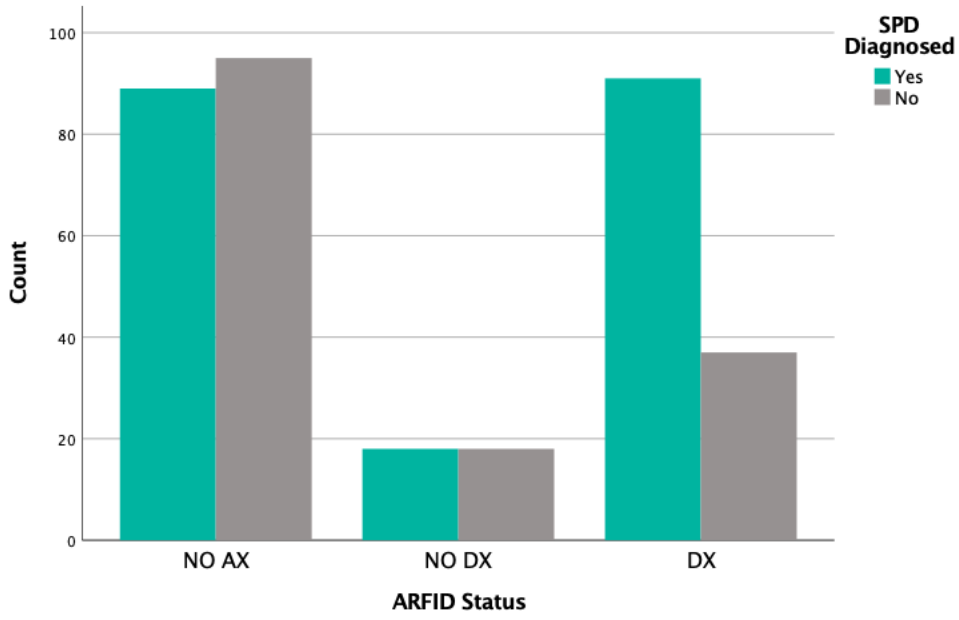


Figure 8 Bar Chart of SPD diagnosis by ARFID status (Table 20)

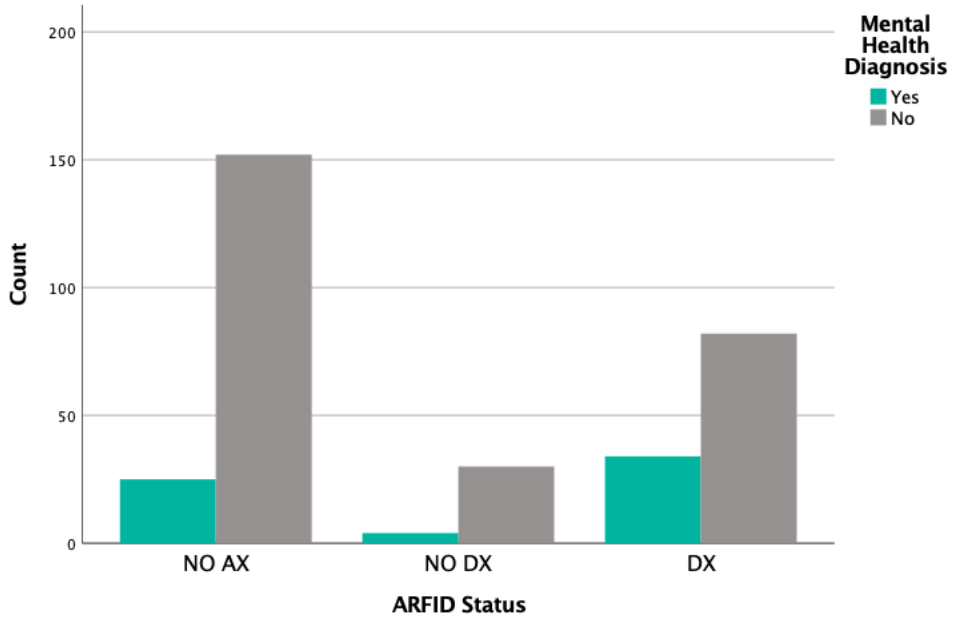


Figure 9 Bar Chart of Mental Health Diagnoses by ARFID status (Table 21)

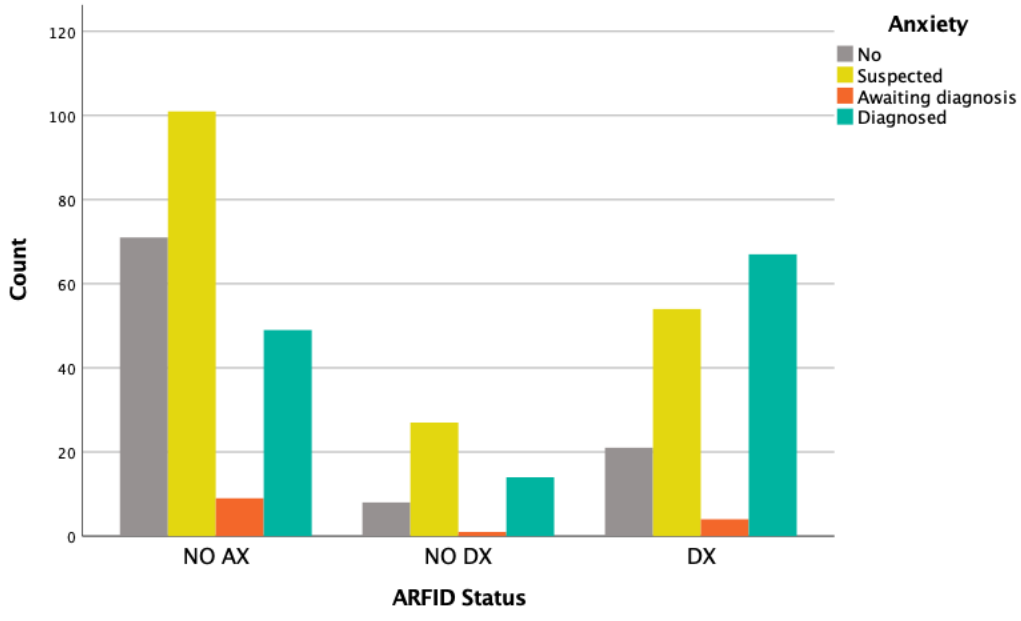


Figure 10 Bar Chart of Anxiety diagnosis by ARFID diagnosis (Table 22)

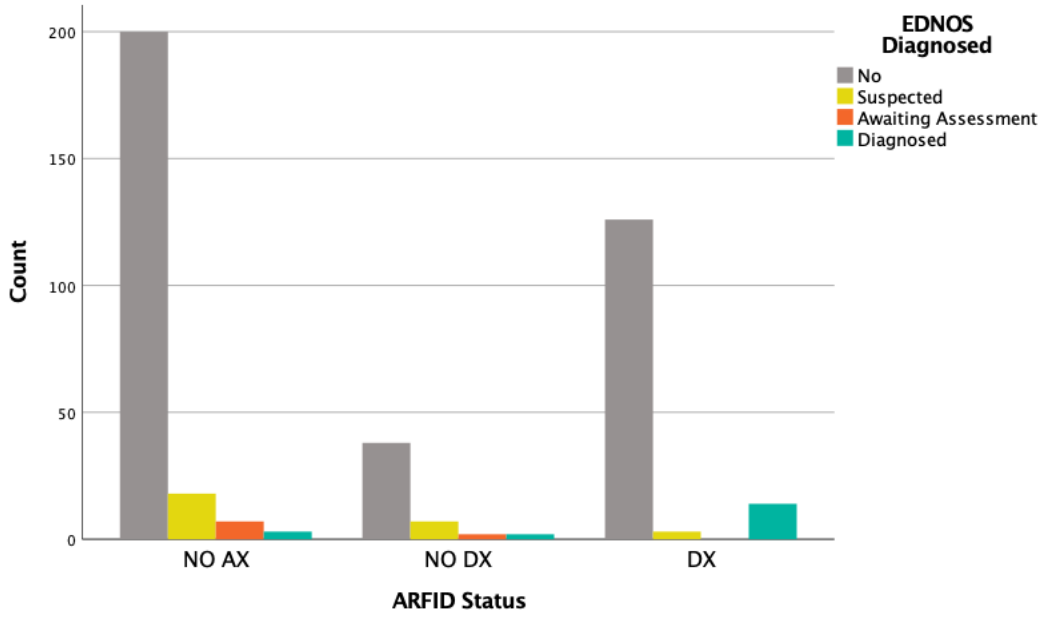


Figure 11 Bar Chart of EDNOS diagnosis by ARFID diagnosis (Table 23)

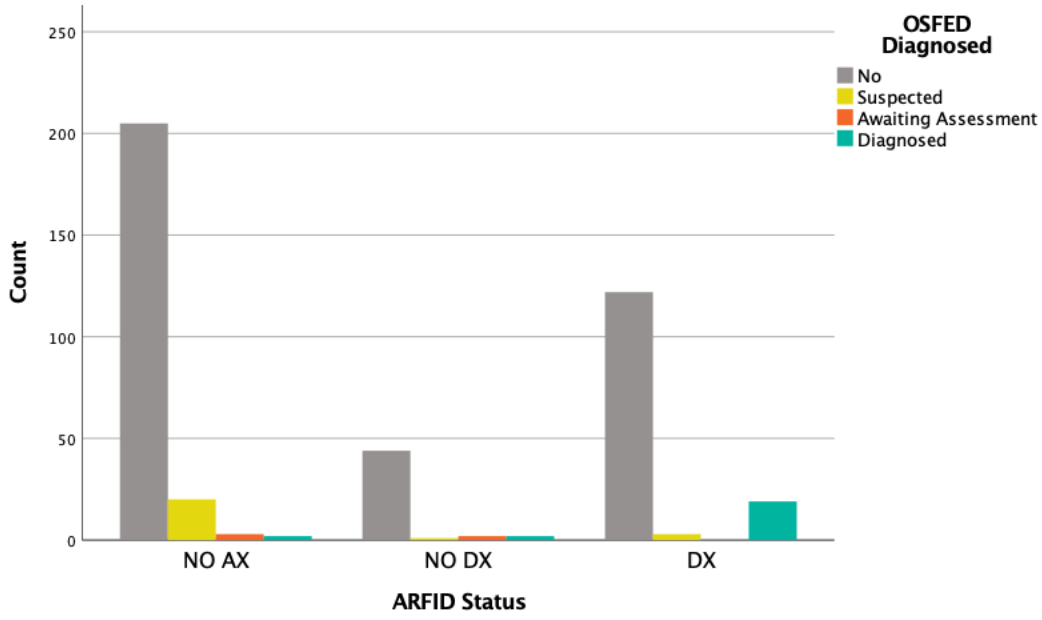


Figure 12 Bar Chart of OSFED diagnosis by ARFID diagnosis (Table 24)

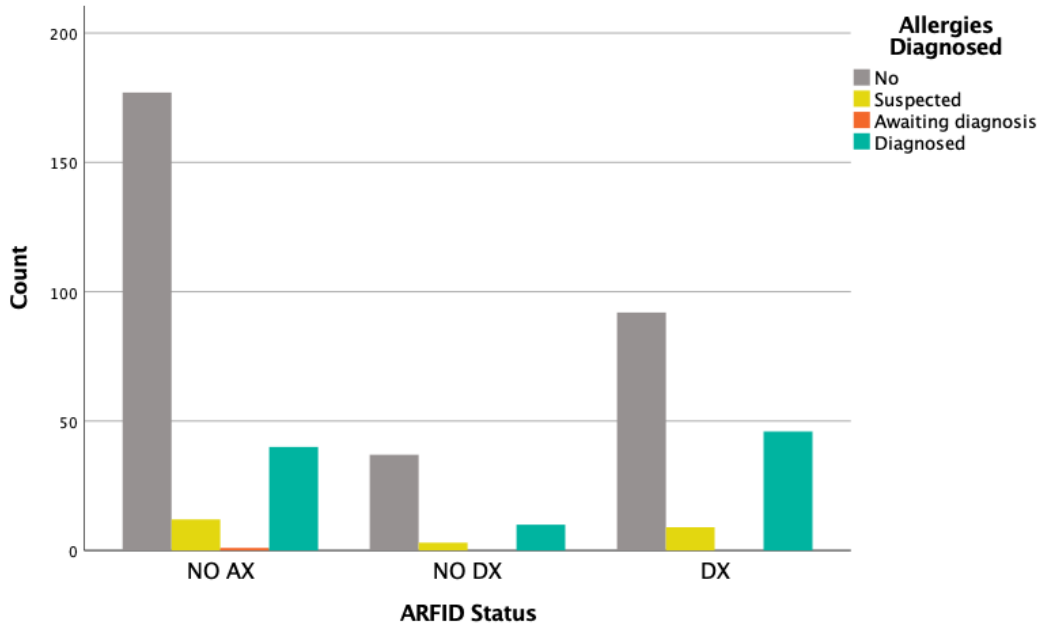


Figure 13 Bar Chart of Allergy diagnosis by ARFID diagnosis (Table 25)

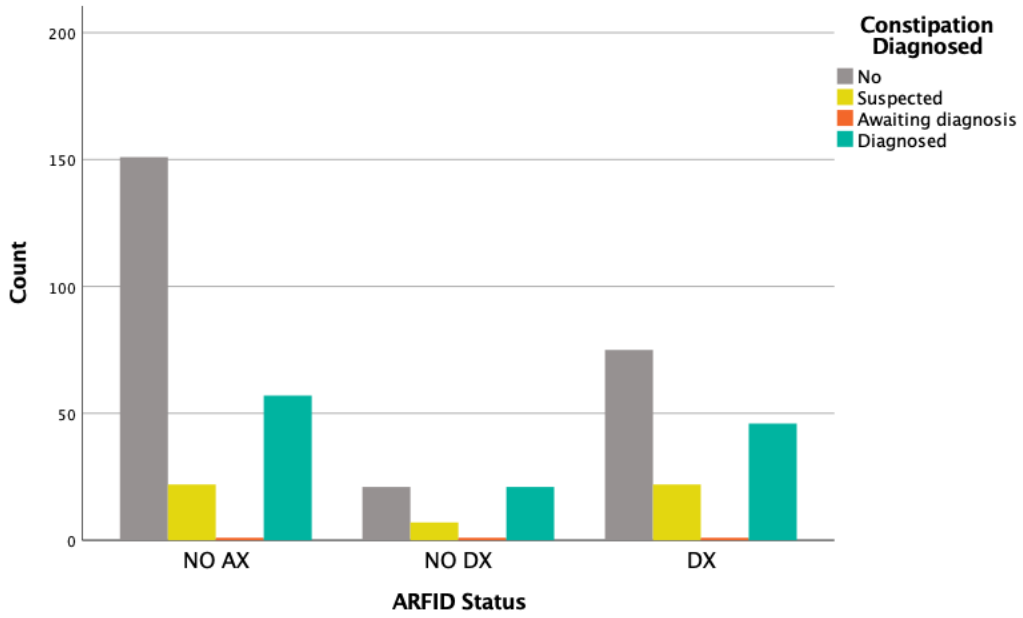


Figure 14 Bar Chart of Constipation diagnosis by ARFID diagnosis (Table 26)